

The Community

American Health Information Community

**November 12, 2008
8:30 a.m. - 1:45 p.m.**



**Department of Health and Human
Services**

Hubert H. Humphrey Building
200 Independence Avenue, SW, Room 800
Washington, DC 20201

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200 Independence Avenue, S.W.

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- 8:30 a.m.** **CALL TO ORDER** – *Secretary Leavitt*
- 8:35 a.m.** **Introductory Comments** – *Secretary Leavitt*
- 9:00 a.m.** **Comments** – *Kerry Weems, Vice-Chair and
Acting Administrator, Centers for Medicare & Medicaid Services*
- 9:15 a.m.** **Comments** – *Robert M. Kolodner
National Coordinator for Health Information Technology*
- 9:20 a.m.** **AHIC Successor Update**
– *John Tooker, American College of Physicians*
- ONC Recommendations on Transitioning Workgroup Activities**
– *Robert M. Kolodner, National Coordinator*
- 10:00 a.m.** **Update on Healthcare Information Technology Standards Panel**
– *John Halamka, Healthcare Information Technology Standards Panel*
- Update on Certification Commission for Healthcare Information Technology**
– *Mark Leavitt, Certification Commission for Healthcare Information Technology*
- 10:30 a.m.** **Panel Presentation on Adoption:**
- Electronic Health Records Workgroup**
– *Karen Bell, Office of the National Coordinator*
– *Jonathan Perlin, HCA, Inc.*
- Progress in the Hospital Sector**
– *Ashish Kumar Jha, Partners HealthCare System*
– *Catherine DesRoches, Partners HealthCare System*
- Chronic Care Workgroup**
– *Brian DeVore, Intel Corporation*
- Secure Messaging**
– *Mohan Nair, The Regence Group*
- Consumer Empowerment Workgroup**
– *Nancy Davenport-Ennis, Patient Advocate Foundation*
- 11:45 a.m.** **BREAK**

- 12:15 p.m. Quality Workgroup**
– *Carolyn Clancy, Agency for Healthcare Research & Quality, Co-Chair*
– *Richard Stephens, The Boeing Company, Co-Chair*
- 12:45 p.m. Personalized Healthcare Workgroup**
– *Douglas Henley, American Academy of Family Physicians, Co-Chair*
- 1:00 p.m. Clinical Decision Support Ad Hoc Committee**
– *Charles Friedman, Deputy National Coordinator*
- 1:15 p.m. Closing Comments**
– *Secretary Leavitt*
- 1:30 p.m. Public Comment**
- 1:45 p.m. ADJOURN**

Meeting Report

American Health Information Community September 23, 2008

The American Health Information Community (the Community), a federally chartered commission formed to help advance President Bush's call for most Americans to have electronic health records (EHRs) within ten years, held its 24th meeting on September 23, 2008, at the Hubert H. Humphrey Building's Great Hall, 200 Independence Avenue SW, Washington, DC 20201.

The purpose of the meeting was to bring together Community members to continue discussion of steps toward ways to achieve its mission of providing input and recommendations to the Department of Health and Human Services (HHS) on how to make health records digital and interoperable, and assure that the privacy and security of those records are protected in a smooth, market-led way. The meeting focused on: (1) a presentation from the Population Health/Clinical Care Connections (PH/CCC) Workgroup, (2) the introduction of Department of Veterans Affairs Secretary James Peak, (3) a discussion of the AHIC successor entity, (4) a presentation on the Nationwide Health Information Network (NHIN), (5) recommendations from the Confidentiality, Privacy, and Security (CPS) Workgroup, and (6) a presentation on the health information technology (HIT) strategic plan.

HHS Secretary Michael O. Leavitt chairs the Community. The remaining 16 members, selected by Secretary Leavitt, are key leaders in the public and private sectors who represent stakeholder interests in advancing the mission of the Community and who have strong peer support. Members serve two-year terms.

A summary of the discussion and events of that meeting follow.

Call to Order

Joining Secretary Leavitt around the table were:

Secretary James Peake, Department of Veterans Affairs

Stephen Jones, Principal Deputy Assistant Secretary of Defense for Health Affairs, Department of Defense (Dr. Jones represented S. Ward Casscells, Assistant Secretary for Health Affairs, Department of Defense)

Brian DeVore, Industry Affairs Manager for Intel's Digital Health Group (Mr. DeVore represented Craig Barrett, PhD, Chairman of the Board, Intel)

Nancy Davenport-Ennis, founder of both the National Patient Advocate Foundation and the Patient Advocate Foundation

Linda Dillman, Executive Vice President, Risk Management, Insurance and Benefits Administration, Wal-Mart

Cita Furlani, Director of the Information Technology Laboratory, National Institute of Standards and Technology's Information Technology Laboratory, Department of Commerce

John Glaser, Vice President and CIO, Partners HealthCare

Dan Green, Deputy Associate Director, Office of Personnel Management (Mr. Green represented Linda Springer, Director of the Office of Personnel Management)

Linda Fischetti, Acting Chief Health Informatics Officer, Department of Veterans Affairs (Ms. Fischetti represented Gail Graham, Director of Health Data at the Department of Veterans Affairs, Veterans Health Administration)

Kevin Hutchinson, At-Large AHIC member, President and CEO, Prematics

Charles N. (Chip) Kahn III, President of the American Federation of Hospitals (Mr. Kahn was also represented by Samantha Burch, Director of Health Care Policy and Research for the American Federation of Hospitals)

Robert Kolodner, MD, National Coordinator for Health Information Technology

Leslie Lenert, NCPHI Director, Centers for Disease Control and Prevention (Mr. Lenert represented Julie Gerberding, MD, Director of The Centers for Disease Control and Prevention)

Scott Serota, President and CEO, Blue Cross Blue Shield Association (Mr. Serota was also represented by Laura Wooster, Senior Policy Consultant at Blue Cross Blue Shield Association)

Kerry Weems, Acting Administrator, Centers for Medicare and Medicaid Services, and Vice-Chair, AHIC

Introductory Comments

Secretary Leavitt acknowledged that this was the second-to-last meeting of AHIC as it currently exists. The first time the Community met, it was clear that sufficient universal standards were lacking to support broad health information exchange (HIE). Since that first meeting, AHIC has established the infrastructure and the process for the establishment of standards. It has now prioritized 13 use cases, and the organization continues to accelerate the development of those cases. Secretary Leavitt has officially recognized 52 interoperability standards that have been harmonized and recommended to AHIC. By the end of January 2009, he expects that he will have recognized an additional 60 standards. The Certification Commission for Health Information Technology (CCHIT) has passed its second anniversary as the officially recognized certification body. To date, it has certified about 75 percent of the outpatient EHR products that are being used by doctors today, and has certified more than one-third of the vendors with computerized physician order entry products that are used in inpatient settings. Trial implementations of the new NHIN also have been launched and demonstrated on a fairly broad scale. These are major accomplishments, from both a technical and a sociological perspective.

The Secretary commented that it is easy, when talking about data standards, reimbursement, and other technical details, to forget that this work is about more than just standards and platforms. This work affects people's lives. Individuals are affected every day by additional expense and by unnecessary medical errors. Countless hours are lost and immeasurable frustration results when people lack access to

appropriate information. The progress being made by AHIC is already beginning to change this scenario. Secretary Leavitt also acknowledged that the nature of standards is that they always change. Technologies will continue to evolve; the standards that exist today simply will not be adequate for the future. That is why it is critical to have in place a process that will continue to refine and improve these standards. The Secretary reported that substantial progress continues to be made regarding the development of AHIC's successor organization (referred to as A2).

Mr. Weems announced that Medicare has been running a personal health records (PHRs) program in South Carolina; this program will expand to include the Department of Defense (DoD) and TRICARE. A Memorandum of Understanding has been signed with DoD and with TRICARE to expand that demonstration project for PHRs. They will begin with active medications from TRICARE that will be brought into the PHR, and will expand to other data from there.

Approval of July 29, 2008, Meeting Minutes

Minutes from the July 29, 2008, Community meeting were distributed, reviewed by Community members, and approved unanimously with no changes.

Population Health and Clinical Care Connections Transition Report

Dr. John Lumpkin of the Robert Wood Johnson Foundation and Co-Chair of the PH/CCC Workgroup reminded the Community that the Workgroup's initial charge was to address the issue of biosurveillance (i.e., how to move data from the clinical care setting into the public health system for monitoring, and particularly to look for outbreaks of disease and potential acts of terrorism). As the group began its efforts, through the leadership of AHIC, it became clear that the scope of this Workgroup was too small. AHIC asked the PH/CCC Workgroup to expand its scope and explore how the clinical care and the population health system can work together to achieve two important goals: (1) improve the quality of clinical care, and (2) improve the health of the public. To accomplish these goals, the definition of population health needed to be clarified.

The PH/CCC Workgroup developed a construct to guide their work that begins by examining the issue of public health surveillance and response. Dr. Lumpkin used an outbreak of salmonella in milk in Illinois as an example of how the construct might be applied. First, the outbreak was detected in the clinical setting. It was reported to the public health system, which began an investigation. The investigation determined that the source was milk, and worked to determine how to stop that outbreak from occurring. At the same time, communication went to the clinical setting to warn clinicians that their patients may be at risk, and to look for particular symptoms that they might not normally look for.

The PH/CCC Workgroup also felt that there were other components to the population health approach. Dr. Lumpkin cited the model developed by Ed Wagner called The Chronic Care Model. This model has been engaged in defining how to look beyond just the clinical care systems, to the other components that are required to achieve good clinical outcomes, such as decisional support and clinical information systems. The focus is also on how the system is designed, whether or not patients know how to manage their own care, and what is happening in the communities—all of these are important for good outcomes. The most important is the interaction between the informed, active patient and the prepared, proactive practice team. Within that context is the interplay between PHRs that help develop and inform the activated patient, and the EHRs, which help the practice team to be prepared and proactive.

Dr. Lumpkin used what he called perhaps the most serious epidemic that this nation faces—childhood obesity—to further illustrate the construct of health status and disease monitoring. Clinicians begin to identify the fact that more and more children are developing type 2 diabetes, to the point that it is no longer called adult onset diabetes. This is part of the disease health status and disease-monitoring domain within population health. In terms of population-based research, experts look at data both in the clinical setting and the population health arena, and begin to understand that there is a connection between childhood obesity and type 2 diabetes. Then, it is determined that certain actions need to be taken. Health communications are a very important component (and another important area of the construct).

The PH/CCC Workgroup identified a set of challenges facing these efforts. In response to such challenges, the following actions are needed:

- Modernize population health infrastructure at the local, state, and federal levels.
- Support and organize infrastructure, policies, and internal capacity for epidemiologic, economic analyses, and health services research.
- Allow funding by program function, to support building a common informatics capacity.
- Articulate and communicate the value to clinical care for including public health as an integral partner in HIT.
- Efficiently deliver health education messages based on community-level data to patients in the community.
- Develop flexible information systems that can be certified using functional, security, and interoperability criteria to support public health activities.

Dr. Lumpkin noted that challenges in moving towards these goals will include the following: (1) finding community-level data sources to support population-based clinical care, (2) manual data collection methods hamper health status and disease monitoring efforts, and (3) inadequate integration between population-based registries and EHRs.

In working towards overcoming these challenges, the Workgroup (and others) has made a number of accomplishments. The Biosurveillance Use Case was developed as a result of prioritizing biosurveillance as an AHIC breakthrough area. The minimum dataset for biosurveillance has been defined and standards have been harmonized by the Healthcare Information Technology Standards Panel (HITSP). In addition, two population health use cases have been advanced: (1) Public Health Case Reporting, and (2) Immunizations and Response Management. Dr. Lumpkin reported that standards harmonization for these use cases is on track for December 2008. General Lab Orders has been identified as an extension to the Electronic Health Record (EHR) Lab Reporting use case and is slated for 2009; and Consumer Adverse Events Reporting has been identified as a 2009 extension/gap.

The Centers for Disease Control and Prevention (CDC) released a solicitation (Accelerating Public Health Situational Awareness Through Health Information Exchange), which was awarded in the spring of 2008 and is expected to address a number of the PH/CCC recommendations accepted by the Community in March 2007. Additionally, the CDC and the Council of State and Territorial Epidemiologists have created a process to define a common list of nationally-notifiable conditions to be reported by all levels of public health. Dr. Lumpkin reported that the most notable contribution of the PH/CCC Workgroup has been to build bridges between public health and clinical care, and recognize where synergy between the

two groups improves health outcome at the point of care, and improves the health of the population.

Dr. Lumpkin presented the PH/CCC Workgroup's recommendations and suggestions for future activities for AHIC 2.0:

- Develop a business case for data/information exchange between public health and clinical care.
- Evaluate population health domains to determine future priorities for use case development (e.g., maternal and child health, population-based research, population-based clinical care).
- Conduct gap analysis between data elements needed to support population health and data elements that are currently available in EHRs.
- Ensure HITSP harmonization of standards, followed by CCHIT certification criteria development for population health use cases.
- Develop certification criteria for EHRs and state or regional health information exchanges to support sending laboratory test orders to, and receiving result reports from, public health laboratories (include veterinary and environmental data), unambiguous linking of laboratory data to clinical and public health records, define infrastructure and architecture for unambiguous unique identification of medical service providers in association with the Nationwide Health Information Network (NHIN).
- Develop clear and consistent communications that clarify the scope and authority of the Health Insurance Portability and Accountability Act (HIPAA), especially regarding exceptions for public health research.
- Provide health promotion and health education materials to patients, clinical care, and public health through EHRs, PHRs, Web sites and other associated pathways.
- Establish and manage an authoritative Web site to share recognized standards and implementation guidelines.
- Include a collaborative space for the sharing of standards and implementation guides that are under development.
- Evaluate current measures that can be used to assess population health. Use a defined and endorsed iterative process.
- Support efforts to enhance informatics training in public health practice (professionals who will become informaticians/scientists; those who will not be informaticians, but would like to increase their understanding of public health informatics; continuing education in informatics for existing public health practitioners).

Dr. Lenert, Workgroup Co-Chair, affirmed that summarizing and exchanging data coming out of clinical care records is an activity that requires continued focus. The view is that population health is something that belongs to the community, and that one day there will be a scientific practice of population health research at the community level.

Discussion Highlights

“I’d like to suggest [that Mr. Weems] talk for a moment about the Sentinel project over at the partnership with CMS and FDA. I think that’s an interesting expression of the way this can and is beginning to work.”—Secretary Leavitt

“We are now able to construct a whole profile of a Medicare beneficiary using their experience in part A, in part B, and also importantly, their experience with part D drugs. So, pharmacology is an extremely important part of the record; we’re able to construct at least in a claims basis, the clinical experience of a Medicare beneficiary. At the same time, linking that data with the data from the Food and Drug Administration, we’re able to begin to detect adverse drug events, other types of things that we might be seeing in a population, just through that simple linkage in a fairly substantial dataset. This is something that we’ve just begun, but we expect to achieve huge rewards as we get more and more data.”
—Mr. Weems

“Mr. Secretary, I would just like to emphasize how important it would be to extend this type of activity to the entire population, and to be able to regionalize it and to be able to plan effectively based on the types of analyses that could be conducted inside the Sentinel databases.”—Dr. Lenert

“Once we have the ambiguity that is currently existing around the use of Medicare data...I can see a day when information from many different sources could, in a de-identified, highly protected way, be used to identify and blend on not just a national basis, but in our chartered value exchanges. Having access to that, seeing it regionally, and then rolling up for large population studies...we’ll begin to tease out the potential of these long before they manifest themselves in serious large scale population events.”
—Secretary Leavitt

“You had mentioned this certification criteria for EHRs to get lab results from public health labs and things like that, as well as local information exchanges and things. Do you see that as different than what we’re doing right now in certification for EHRs, for lab results to be delivered into those EHR systems? Is there a different standard, a different approach, or just a certification process of those information exchanges and those labs?”—Mr. Hutchinson

“Public health laboratories tend to be [at] a little bit lower technology [level] than the national laboratory vendors. They tend to lack the same levels of IT support. It’s going to be a little bit more difficult haul for those activities. We do have active projects we support in the CDC for that area—that is, with the Public Health Laboratories Association—something called the flip project, where we’re working on public laboratory data exchange. The technology level of the public labs is the real challenge.”—Dr. Lenert

“One of the other challenges [facing] public health laboratory data and public health data...involves information that may come from veterinary and environmental resources. And so we have to make sure that the ability to exchange data is robust enough than just what normally happens in a clinical lab.”
—Dr. Lumpkin

“As we move into A2...if you had to recommend, of the series of priority activities, the proverbial top three, where would you focus or have the successor focus, initially?”—Dr. Glaser

“Maternal and child health certainly would be our top priority for use case. I think that the next would be to continue to focus on the harmonization of the standards, and then the use of CCHIT certification as a way to begin to build the linkage for the implementation of the use cases.”—Dr. Lumpkin

“The most important thing would be to certify or develop the criteria to certify electronic records for population health reporting, and then for two-way messaging from public health. I’m going to take a slightly different tact and say that the process of getting information from public health, or about population health back into clinical care, at the point of care, is probably one of the key drivers we have. The value case depends on public health being able to get information back in at the point of care with the patient and the clinician.”—Dr. Lenert

“The business case elements that we have looked at have been automating mandatory reporting of notifiable conditions and diseases so that the less effort is spent in that activity with communication to public health, automating the process of investigation of records so that the cost per case of tracking down elements was reduced. [In terms of the] two-way communication between public health and the clinical care, so that when there is a public health alert or a disease that’s been noted in an area, clinicians can behave differently.”—Dr. Lenert

“In 2000, when I was state health director in Illinois, we had a case in a small town in Illinois of a patient who had invasive group A strep, so-called flesh-eating bacteria. Over the next three months, there were another 11 cases, all which resulted in deaths...before they had the first report to the public system, again, because reporting wasn’t automated...The cost to the health care system, and not to mention the lives that were lost, were staggering...If this system worked, we would have identified that much earlier. The investigation would have been there. The recommendations on treatment would have occurred at the point of care. And tremendous savings, both in terms of lives and disability, as well as cost, would have been [realized].”—Dr. Lumpkin

Additional Discussion Highlights

Following the comments above, Community members engaged in additional discussions, the highlights of which appear in the following paragraphs:

“We are in a process right now with Booz Allen to sort of step back and take a look at what’s been accomplished and what options we think we have, or would suggest to policymakers, for the next go-round of policy making...We’re hoping sometime late October/early November to have a paper done that does this sort of an assessment of where we are, and then give some options about where we should go next. So...sometime probably in early November that we’ll come out with a paper and hopefully will be helpful to the process.”—Mr. Kahn

“I can give you some updates relative to the American Academic of Family Physicians and our membership, in terms of the adoption of electronic health record technology...We do a survey of our members every year...and I’m happy to report, at least for our members, that 47 percent have adopted electronic health record technology as of about a month ago. Another 25 percent say that they’re going to write the check to implement an EHR within the next 18 months. Even the recalcitrant group seems to be moving a bit, based upon a market that is producing more innovative products, that are focused on small and medium sized practices, focused on the importance of interoperability, and connecting with practice management systems, and dealing with issues of cost.”—Dr. Henley

“We are very excited in working with CMS about the upcoming e-prescribing conference, and pushing that technology to our members as an interim step to improve patient care and the quality of that care over time. Now, what we also know and are concerned about relative to the 47 percent who have adopted EHR technology, is that the chaos that creates, the challenge that creates within a practice, doesn’t allow them to immediately turn on all the switches in terms of, how do you really get to the implementation of electronic registries and quality improvement processes within the practice? So rather than focusing so much on adoption and implementation, which we have been about the last five years, we are now

focusing on concentrating with those who have adopted the technology, to turn on the switches, so that again, in a very real way, in a very functional way, they can improve the quality of care for patients with chronic disease.”—Dr. Henley

“We have open enrollment coming up for part D...I know many of us sit with family members, make sure they’re in the right prescription drug plan. Just part of that discussion, we need to start asking, so does the physician you go to, do they e-prescribe? Let me tell you about e-prescribing. We need to make open enrollment part of the e-prescribing adoption process. Also as part of open enrollment, this is a time when people can make choices about Medicare Advantage plan. Many of the Medicare Advantage plans offer personal health records or have electronic health records as part of their business, so we’d ask folks to take a look at that. So open enrollment presents a number of opportunities to advance electronic health records.”—Mr. Weems

“Within the Department of Veterans Affairs, as most know, we have a fully deployed electronic health system, which we’ve had for quite a while. We use it in all of our clinical practices through our business practices, in running the healthcare operations, as well as to glean intelligence so that we can measure our quality, and then go back and very specifically adjust areas that need to be improved. So we tend to engage with the larger industry around us, both the early adopters to share our experiences and share our stories, and then also those who have been using electronic health record systems for quite a while.”
—Ms. Fischetti

“The one common theme that we find from both the early adopters and the people who are seven, ten years post adoption, is the need to make these systems smarter. And the opportunity is now with the standardization of medical terminologies of how we represent data to continue to improve clinical decision support, as well as the other ways that we can make the systems smarter, improving the quality and safety and efficacy of the healthcare we provide.”—Ms. Fischetti

“Dossia is a not-for-profit that was founded by a group of employers, and the idea is to be the data store that allows us to share data among applications, among insurers, among providers, and the data belongs to the individual. Our open enrollment started on Saturday, and as part of open enrollment, this year Wal-Mart is offering personal health records to all of our associates. We have about 1.1 million people on our health plan that will have access to that. It is a WebMD front end, so we’re using WebMD tools, but it’s powered by Dossia. And our associates and their families will be able to have access to their claims information and their prescription history as part of it, so they don’t have to key everything in...We’ve spent a lot of time with our marketing folks, trying to understand the right way to communicate it to our associates and their family so they’ll understand what it is and why they’ll want that. And so we’ve had a very strong communications program. We’re very hopeful that first of all, most of them will sign up, will choose to do it. And then the next year our challenge will be to help them understand how to use it effectively.”—Ms. Dillman

Introduction of Secretary Peake

Secretary Leavitt introduced to the table Secretary of the Department of Veterans Affairs James Peake. Secretaries Leavitt and Peake will both serve as the federal representatives to A2 [the AHIC Successor organization]. Secretary Leavitt expressed enthusiasm that Secretary Peake has accepted the position, and described Secretary Peake as someone who has had a number of distinguished careers. He has been a physician, a decorated lieutenant general in the U.S. Army, and now, once again a public servant in his capacity as the Secretary of Veterans Affairs.

The VA is a very big player in electronic medical records, Secretary Leavitt said. Annually, it spends about \$40 billion purchasing and providing health care for more than 5.5 million veterans. The VA has also advanced in the integration of EHRs.

Secretary Peake acknowledged that the day of this meeting was a celebration of two impressive milestones: (1) the announcement of the A2 board, and (2) the NHIN demonstration. He said he is pleased that the VA has been an active participant in AHIC from its inception, and that the VA feels a compelling need to be a part of this work. About 40 percent of veterans seek care from both the VA and the private sector, as well as experiencing the transition from DOD to VA care. Secretary Peake indicated that he wants to ensure continuity of care among active duty military treatment facilities, VA facilities, Indian Health Service clinics, and non-federal treatment facilities for both inpatient and ambulatory care.

AHIC Successor: Update on Status and Activities

Dr. Glaser expressed thanks to the Brookings and LMI team members, and also to the AHIC successor (A2) Interim Executive Director Laura Miller, who has been providing leadership support on the staff side as the core activities necessary to get the successor in place continue. A2 was incorporated on July 17, 2008, and obtained funding from HHS on August 29, 2008. Work continues to get the accountants and lawyers in place, to create the bylaws, and to complete a wide variety of fundamental tasks that are necessary for any organization to exist and to be in a position to carry on its activities.

Dr. Glaser explained that A2's Board of Directors will be comprised of 13 at-large members, plus two consumer and two federal government representatives. Year one includes seats for the three incorporators. Board members will serve terms of 1, 2, and 3 years. In addition, Board members will: (1) fulfill fiduciary responsibilities, (2) ensure the organization has resources to fulfill its mission, (3) attend a minimum of four to six Board meetings per year, (4) implement Board actions, (5) provide thought leadership on industry trends and developments, and (6) participate in and/or chair periodic advisory committee meetings.

Dr. Glaser described the Board nominating process. A Nominating and Governance Committee nominated candidates. Individual candidates were judged on four criteria: (1) Board experience, (2) ability to work by structured consensus, (3) thought leadership, and (4) strategic experience. The candidate pool was evaluated as a whole and selected to ensure diversity in stakeholder groups, expertise, geography, gender, race, and ethnicity. A2 incorporators then selected the final slate of 15 Board members.

The first A2 Board meeting is scheduled for November 13, 2008. At that meeting, Board members will discuss the near and intermediate term direction of the organization. The agenda will include discussions on bylaws, the A2 committee structure, staff and budget, value cases and prioritization approach, and strategic and business plans. Dr. Glaser noted that the A2 bylaws will be available for public comment, and the specifics for reviewing these will be announced shortly. Dr. Glaser then discussed value cases briefly to orient the Community to the modifications that will be made to the current use case process. He noted that a value case describes an aspect of health care where: (1) specific, identifiable harmonization standards can be identified; (2) use of a standardized approach can clearly increase quality and/or reduce costs of care for patients; and (3) if the value case were completed, there is clear reason to believe that HIT adoption would increase.

Dr. Glaser explained that value case proposals must have stakeholder proponents; stakeholders willing to provide resources to facilitate value case development; and assessments of interoperability value, costs to

adopt, and measures of impact. Overall, value cases must fit and advance a national interoperability contextual framework.

In the coming months, the AHIC Successor will collaborate with HITSP, CCHIT, and NHIN to craft strategies for the implementation of the value case prioritization process, increased standards adoption, and NHIN governance.

Finally, the AHIC Successor will complete an integrated membership and communications plan and begin soliciting members in late fall. A2 member organizations will have the opportunity to:

- Set priorities as well as identify and quantify opportunities for standards adoption.
- Provide expertise on policies related to an interoperable, standards-based electronic health care system.
- Support the implementation of standards through market-driven approaches.
- Provide and share technical resources.

The Board will develop a tiered membership dues structure that differentiates between non-profit and for-profit organizations. It is anticipated that there will be a total of approximately 120-160 members representing large organizations, small organizations, providers, health plans, those in the public health arena, vendors, and others. The business community will be included in the membership of the organization. Dr. Perlin then introduced the new A2 Board, as follows:

Laura Adams, President and Chief Executive Officer, Rhode Island Quality Institute
Simon Cohen, MD, MPH, Associate Director for Health Information Policy, Kaiser Permanente
Janet Corrigan, PhD, MBA, President and Chief Executive Officer, National Quality Forum
Arthur Davidson, MD, MSPH, Director of Public Health Informatics and Preparedness, Denver Public Health
Linda Dillman, Executive Vice President, Wal-Mart Stores, Incorporated
Lori Evans, MPH, Deputy Commissioner, New York State Department of Health
Steven Findley, Health Care Analyst and Managing Editor, *Consumer Reports* Best Buy Drugs, Consumer's Union
Thomas Fritz, MA, MPA, Chief Executive Officer, Inland Northwest Health Services
John Glaser, Vice President and Chief Information Officer, Partner's Healthcare System Incorporated
C. Martin Harris, MD, MBA, Chief Information Officer and Chairman, Cleveland Clinic
Kevin Hutchinson, President and Chief Executive Officer, Prematics
Charles Kennedy, MD, MBA, Vice President, Health Information Technology, Wellpoint, Incorporated
Michael Lardiere, MSW, Director of Health Information Technology, Association of Community Health Centers
Jonathan B. Perlin, MD, Medical Officer and President of Clinical Services, Hospital Corporation of America
Steven Rubert, PhD, Senior Research Fellow, Eli Lilly & Company
Lisa Simpson, MB, BCH, MPA, Professor and Director, Child Policy Research Center, University of Cincinnati and Cincinnati Children's Hospital Medical Center
Paul Tang, MD, MS, Chief Medical Information Officer, Palo Alto Medical Foundation
Dr. John Tooker, MD, MBA, Executive Vice President, Chief Executive Officer, American College of Physicians

Discussion Highlights

“This is a fragile moment in the pathway for health IT and the vision I think we have as a community and as a country for interoperable health records. The passing of this baton is an important moment, and one that I feel confident, given the nature and the quality of people that have accepted this role, will be done effectively.”—Secretary Leavitt

“I appreciate those of you who have accepted this responsibility. It’s a big one for the nation. And clearly, we do have a dog in the fight, and absolutely look forward to participating with the strength of our agencies behind us.”—Secretary Peake

“As we make this transition and accelerate our progress, it will be vitally important in my mind that Congress recognize the importance of the work that has been done and that will be done, and that any legislation that is written support this effort, and enable it, and that will be a very important part as we move into the next administration.”—Secretary Leavitt

“I think one of the concerns we had initially when we transitioned this group was that CMS was not part of the makeup of the Board. Are there legal reasons why you can’t?”—Dr. Henley

“Yes, there are legal reasons as to the actual role that members of the federal government can play on this, so we’ve structured it in a way that there will be federal representatives that will be able to represent that interest. But let me also recognize that in order for any standard to be effective, the marketplace has to adopt it. And given the fact that the federal government, between the VA, the Department of Defense, Indian Health Service and CMS represents 38 to 40 percent of the market, having us as enthusiastic supporters and participants is a critical part. And by our reflection today, we intend to do just that.”
—Secretary Leavitt

Nationwide Health Information Network Presentation (NHIN), Part 1

Dr. Kolodner introduced a demonstration of the NHIN, explaining that over the past few years, the feasibility of the NHIN was confirmed, and in the past year, contracts and grants were awarded to share interoperable electronic health information via the NHIN, under the leadership of Dr. John Loonsk. A total of 19 participating organizations were organized into workgroups, and agreements on HITSP standards have been reached. The workgroups have determined whether any additional enhancements to those standards were necessary, and what additional technical specifications were needed to enable the secure, reliable exchange of health information among networks. In addition, the contents of a common trust agreement have been developed to ensure the seamless secure exchange of health data.

Dr. Kolodner thanked Dr. Loonsk for his pioneering work with the NHIN. Dr. Loonsk has asked that he be replaced as the lead for this effort, and Dr. Kolodner has named Ginger Price as his choice to continue the work. He thanked Secretary Peake and Dr. Kussman for allowing Ms. Price to serve as the Office of the National Coordinator lead for the NHIN. Ms. Price was instrumental in the conceptualizing, designing, developing, managing, and delivering VA’s My HealthVet Program, used by 650,000 veterans nationwide.

Dr. Kolodner explained that the NHIN trial implementations would show that by working together, a nationwide health information highway can be developed that will support both better health care for individuals and better health for communities. This demonstration, and the one that will follow in December, are the first implementations of the nationally accepted and recognized HIT standards across a

network of networks, Dr. Kolodner explained. By using standards and the agreements that have been tested and agreed upon by a diverse group of networks, an infrastructure is developing that will be a springboard to advances in both the health information exchange capabilities and broad use of those capabilities.

Ms. Price then began the presentation of the culmination of work on a core set of capabilities for the NHIN. These capabilities include looking up a patient and transmitting a patient summary record nationwide, honoring consumer preferences, and doing so safely and securely. Before beginning the demonstrations, Ms. Price reviewed the basics of the NHIN. The Network is being built on the Internet to provide a safe and secure way for health-related organizations to interconnect, bridging various technologies, approaches and geographies. Some of the defining characteristics of the NHIN include: (1) it is a network of networks; (2) it has no national data store or centralized systems, and it has no national patient identifier; (3) it consists of standards, implementation guidelines, and specific testing abilities to measure conformance—together, these represent a type of shared “dial tone” that allows diverse organizations using different architectures and technologies to exchange health information safely and securely; and (4) the NHIN technology is being built to permit various policy options and will continue to adapt as those policies evolve.

Ms. Price emphasized that a key component that cannot be overstated is the work of the NHIN Cooperative on specifications and trust agreements. This diverse group of experts has come together and self organized into a collective that addresses complex issues. They have come to consensus, not only on standards, but also on the implementation of those standards. Ms. Price assured the group that the demonstrations being shown involve real technology. The demonstrations are live, with data moving in real time among the networks. The presentation was shown on two screens: on the left screen were PowerPoint slides, on the right screen were the home systems of the various presenting organizations from across the country, returning information in real time. The applications were on the laptops in the Community’s meeting room, but when a query was made during the demonstration, data were being returned from New York, New Mexico, West Virginia, Delaware, North Carolina, the VA, DoD, and the Social Security Administration (SSA). Ms. Price noted that there were no personally identifiable patient data; all demonstration participants were using test data and test patients, but the technology used is real.

The demonstrations were organized into three parts: (1) how the NHIN will support the patient; (2) how the NHIN will support the consumers, including a discussion on the work of the Cooperative and a demonstration of how a consumer would express their preference and how the networks would honor that preference; and (3) how the NHIN can be applied to support a person’s health outside of the traditional care setting.

The first demonstration showed an exchange related to emergency care. The lead demonstrator was Indiana University (Indiana Health Information Exchange); the responding exchanges were HealthBridge (Cincinnati, OH); HealthLINC (Bloomington, IN); Community Health Information Collaborative (Duluth, MN); Cleveland Clinic (Cleveland, OH); New York eHealth Collaborative; Long Island Patient Information Exchange (Long Island, NY); New York Clinical Information Exchange (New York, NY); and Wright State University (Dayton, OH). In this scenario, a Cincinnati resident travels to Indianapolis, experiences chest pain, and is taken to a local hospital for emergency care. The local Indianapolis hospital determines that the patient is from Cincinnati and uses the NHIN to retrieve records from Cincinnati and other NHIN participants. Patient data from other provider organizations participating in the NHIN play a critical role in the patient’s care.

The next demonstration dealt with transfer of care. The lead demonstrator was Lovelace Clinic Foundation (New Mexico Health Information Collaborative); the responding exchange was Long Beach Network for Health. This scenario involved Mr. Oscar Pena, a fictitious patient who lives in

Albuquerque, NM, and receives ongoing primary care locally, and who decides to temporarily stay with family in Long Beach, CA. While in Long Beach, Mr. Pena is hospitalized—his care involved tests, a procedure, and medication changes. The discharging physician advised Mr. Pena to arrange follow-up care within 2 weeks so that laboratory tests and medication monitoring could be accomplished. In a subsequent related episode, Mr. Pena must visit an urgent care facility in New Mexico that requires further information regarding his previous hospital visit.

At this point Secretary Leavitt acknowledged Congressman Dave Weldon from Florida, who joined the meeting. Congressman Weldon is a physician, and plays an important role in the House Appropriations Committee on Labor, Health and Human Services, and Education. Secretary Leavitt noted that Congressman Weldon was attending today because of his interest in HIT and his subcommittee's jurisdiction, and of course, his interest as a physician.

The final component of the patient care demonstration showed a wounded warrior scenario, with transfer of information among the lead demonstrator, the VA, and the following additional participants: DoD, Kaiser Permanente, CareSpark (Kingsport, TN), MedVirginia (Richmond, VA), and NCHICA (Research Triangle Park, NC). This setting follows the care of a soldier (Gunnery Sergeant William Ozzie) injured in Iraq. Patient records for Sergeant Ozzie are transferred between federal and private-sector agencies to provide coordinated care to the wounded veteran. Panelists from each of the organizations participating in the demonstration remarked on the importance of the NHIN to their communities of patients and their ability to make the best and most informed patient care decisions.

Following the demonstrations was a panel discussion among the leadership of the NHIN Cooperative Workgroups. Ms. Price began by describing the progress of the Workgroups, which she characterized as key to the success of the NHIN. The Workgroups developed data and technical specifications, formulated testing tools and the ability to verify that the systems worked, and most importantly, built a common trust agreement for participation in the NHIN and a working model for privacy, security, and respecting the rights of consumers.

Ms. Lisa Carnahan from the National Institute of Standards and Technology (NIST) first gave some background about the Workgroups. She said there are 200 active participants across 19 participating organizations. They are each equally represented on each Workgroup, and each organization carries equal weight so there is no undue influence from any one organization. Many of those 200 participants devote a significant amount of their time, not just a few hours here and there, Ms. Carnahan explained. The subject matter expertise comes from the NHIN Cooperative itself as well as from experts at HITSP, CCHIT, and NIST. The Office of the National Coordinator plays a supportive role in the collaborative process as well, facilitating much of the cross-communication with the Workgroups and helping to keep them focused. The NHIN Cooperative takes the HITSP interoperable specifications and applies them to the network communication to test and vet them. They also, through the Data Use and Reciprocal Support Agreement (DURSA), are tackling those questions of consumer consent, privacy and legal issues, and policy issues.

Ms. Carnahan then introduced two members of the NHIN Core Content Workgroup, Dr. Gil Kuperman and Dr. Jeffrey Blair. Dr. Blair explained that the objective of the Core Content Workgroup was to specify the data content requirements, so the patient information can flow from one NHIE network to another NHIE network, in such a way that the physician that receives this information can interpret it with the same clinical meaning as the physician who originally entered the data. The only way that this can be done is if the content specifies the standard data types and standard terminologies.

Dr. Kuperman explained that the final product of the Core Content Workgroup was, therefore, the specification for the summary patient record. The guiding vision for the specification is: what data

would a physician need to care for a patient if they had no other information about this patient? The specification is based on HL-7 and other standards from HITSP, the continuity of care record, and the emergency responder use case. The specification that was created is being used to exchange clinical data among the organizations all across the country, and was used in this meeting's NHIN demonstrations.

Although it was relatively straightforward for the NHIEs to implement the specification, Dr. Kuperman commented that their experience indicates that provider organizations are going to need better tools to help them convert terminologies in their current, proprietary systems. Also, while the HITSP constructs were able to meet the needs of this use case quite well, the content standards are going to need to continue to evolve to meet the more diverse use cases that will present themselves in the future.

Ms. Carnahan then introduced Mr. Martin Renwick and Mr. Dave Riley, Co-Chairs of the Technical and Security Core Services Workgroup. Mr. Riley said that their charter has been to create a core set of services to move information around on the NHIN. To do so, they have taken all of the input from the Core Content Workgroup and DURSA, plus all the input from the AHIC use cases. He noted that although there are only seven use cases approved right now, those seven use cases translate into 38 constructs from HITSP, which, in turn, identify another 100 standards that are named by those constructs that have to be digested and abstracted.

Mr. Renwick explained that they have implemented subject discovery, document query, document retrieve, the audit log query, the consumer preference profile, message platform, and the authorization framework. He acknowledged that although a significant amount has been accomplished, some work remains to be done before taking the NHIN live. Before December (i.e., when the next public demonstrations occur), they intend to define and implement three more standards services: (1) the health information event messaging service, (2) the NHIE service registry, and (3) the pseudonymization service. The Workgroup believes that with this work completed, they will be ready for NHIE-to-NHIE exchange of health information to become operational.

Ms. Carnahan then introduced her Co-Chair on the Testing Workgroup, Mr. Benson Chang. Mr. Chang explained that the Testing Workgroup works with the Core Content Workgroup and the Technical and Security Workgroup to understand whether or not the specifications that have been written are truly usable by people creating systems. Included in these efforts is making sure that the specifications meet the functional requirements of the NHIN. The Testing Workgroup also ensures that there is a baseline set of test materials, as well as standard, reusable test tools that can be extended to other organizations wishing to join the NHIN in the future.

Ms. Carnahan then introduced Mr. Steve Gravely and Mr. Holt Anderson, Co-Chairs of the DURSA Workgroup. Mr. Gravely acknowledged that none of what is being demonstrated today could have happened without the work of the technical experts, nor could it have happened without a legal framework. The DURSA Workgroup was tasked with creating a legal framework that would support the demonstration of the testing that was seen today, as well as the prospect of exchanging live data in the near future. In many cases, laws from state-to-state are contradictory and in conflict, at least in the context of interoperability across the United States. None of them, at present, were designed with a functioning NHIN in mind. Therefore, it is a challenge in terms of trying to create a legal framework within that existing body of law. Once the framework was constructed, the DURSA Workgroup's mission turned to memorializing that into a multiparty user agreement that would accommodate not just the 15 NHIE participants that are at the table now, but as many future participants as could be imagined in all shapes and sizes.

DURSA consists of two distinct agreements. One is for the test data that have been developed for the purposes of this meeting's demonstration as well as subsequent demonstrations. The other is a live

production-ready document that would support full implementation with live data. In terms of accomplishments to date, Mr. Gravely noted that a test data DURSA has been completed. The agreement has been signed by all the participants exchanging data during this demonstration. At the same, the Workgroup has been working on the live data, production-ready DURSA. Much consensus has been developed around many complex issues involving the exchange of live data. A preliminary draft of a live data, production-ready DURSA has been shared with the Office of the National Coordinator, and the Workgroup looks forward to receiving comments back from the Office. Mr. Gravely said the Workgroup is committed to completing the live data production DURSA by the end of 2008.

Discussion Highlights

“Let’s assume I want to have a personal health record, and I’m interested in having that information populate my personal health record. What are the steps that those who are producing personal health records need to go through in order to access this information and populate my record without me having to put it in? I recognize there are probably a bunch of legal things that we’re going to have to get into in the next iteration, but aside from that, let’s talk about the technical aspects of this first, and then maybe the legal.”—Secretary Leavitt

“The specifications that we’ve put in place for this demonstration project would be sufficient to technically represent the data in the personal health record. So [in terms of] representing the data, I think we’ve done sufficient work.”—Mr. Chang

“What we’ve done with the agreement is to assume that personal health records can occupy the status of an NHIN participant. So our agreement talks about participants without prejudging what those participants look like. We know who 15 of them are right now, but without having a comprehensive understanding of what PHRs even necessarily mean right now, because that is evolving so rapidly, we chose to say, ‘Sure, PHRs can be participants in the NHIN.’ They will be expected to execute the document. And in order to be granted admission to the NHIN, they will have to agree to meet whatever standards are established, both technical and probably organizational and in governance standards.”
—Mr. Gravely

“With PHRs, one of the huge issues is how do we validate that an organization presenting itself for admission actually represents the people that it says it represents? And that’s a little different than provider, patient-provider relationships...What is important is that we anticipate, and have built into our document structure, an equal status for PHRs as participants, recognizing that there needs to be a panoply of operational infrastructure built around that. And I don’t, by that, suggest federal regulation of PHRs. I’m simply saying that there needs to be some organizational structure built around PHRs so they can participate within the NHIN.”—Mr. Gravely

“At the end of the day, we have this content issue that is obviously one of the highest priority items, the lurking item that could be the potential downfall of being able to share this information in an intelligent manner. So we touched on it a little bit, but I’d just like to get a little deeper kind of sense of what are the major barriers in this happening, and where do we see other collaborators coming to the table, whether it be academia or others that can help move this forward through medical schools and creating some common use on the terminology?”—Mr. Hutchinson

“This is a major challenge, but it’s also a major opportunity for us, because one of the things that we were so pleased about in New Mexico was seeing that the construct for the nationwide health information network was to be able to support clinically specific terminologies. Clearly, most of the health care providers today are using legacy and proprietary code sets. And in order to make our demonstration

work, we had to do translations of those legacy and proprietary code sets into the standardized terminologies.”—Dr. Blair

“The benefits of standardized terminologies is with electronic health records, with electronic prescribing, as well as with the NHIN, but the NHIN enables and facilitates these because it can support these...So the ability of the NHIN to be able to communicate using standardized terminologies is something that we’ll be able to have dramatic improvements in the quality of care, patient safety, and ultimately lowering costs.”—Dr. Blair

“I think that many of the standards are moderately mature and that maturity needs to be increased, whether it’s medications or lab results or radiology results. So that work needs to keep on happening. And then similarly, the situation where there are legacy systems in place that have proprietary terminologies, we need tools. And there are tools, but they’re complex, so more of those need to be made easier to use, to convert what’s in place today into the standard sets, even as those are improving.”
—Mr. Chang

“As the base of systems that are in place are retired and new ones are put in, obviously those should be encouraged strongly to be standards-based. But that’s going to take a long time, to replace that broad set of assets. So activities in those three areas, I think, will move us there, realizing that it’s kind of long and asymptotic to where you’d really like to be.”—Mr. Chang

“For each use case that AHIC has developed, HITSP has created this package of standards to support those use cases...HITSP calls them constructs. And that was the beginning of what we used to be able to determine what we could do. In this case, the emergency responder use case was the AHIC developed use case we used. The HITSP construct for that was the one to support the summary patient record.”
—Mr. Blair

“HITSP really has kind of pulled together all of the different standard development organizations; however, many of the standard organizations in terms of terminologies are professional associations like the American Medical Association that’s developed CPT codes, like the group that has developed SNOMED codes. The National Library of Medicine has developed clinically specific medication terminologies, Rx Norm, which is very valuable. And the federal government has funded the development of laboratory results data, which is clinically specific, called LOINC, Logical Observation Identifier Names and Codes. Those are the ones we really want to drive towards in the future, because those will really give us the greatest benefits.”—Mr. Blair

“I would just add that many of these are organized under HL-7, and some of the work is happening there as well.”—Dr. Kuperman

Nationwide Health Information Network Presentation (NHIN), Part 2

Following the comments above, Ms. Price then presented the next part of the demonstration, which addressed the ability to support the consumer. The demonstration illustrated the capability to choose to participate or not to participate in the NHIN network exchange of a consumer’s health information. The NHIN will be a flexible framework that will permit various policy options—the demonstration barely scratches the surface of capabilities in terms of consumer preferences. The Cooperative participants are also working on additional capabilities that will be tested in November and demonstrated in December at the NHIN Forum.

The presentations in this setting focused on the capabilities that support the consumer's ability to designate their interest in participating in health information exchanges based upon law and policy. Policies within health information exchanges vary, with consumers initially electing to participate or not participate. This presentation showed how the consumer's preference for participation is managed and applied for data exchange.

Ms. Price introduced Michael Matthews, CEO of MedVirginia, a private health information exchange serving the central Virginia region. The co-lead presenter of this scenario is CareSpark of Kingsport, Tennessee. Dr. Matthews described the scenario, as follows. A consumer, Anna Rooney, receives care at a provider participating in the MedVirginia exchange. During this visit, Ms. Rooney elects to not share her private health information from MedVirginia with the NHIN. In a subsequent care episode while visiting a provider participating in the CareSpark exchange of Tennessee, Ms. Rooney provides CareSpark permission to retrieve her MedVirginia data through the NHIN. The presentation demonstrated how Ms. Rooney's decision to not participate in the NHIN is applied when another organization requests it.

Ms. Price then introduced Sally Milam from the West Virginia Health Information Network, who led the next part of the demonstration, depicting the ability for a consumer to opt in to information exchange. The co-lead presenter of this scenario was the Delaware Health Information Network, represented by Ms. Gina Perez. In this presentation, although the consumer received treatment at several West Virginia Health Information Network facilities over the past few years, the consumer previously elected to not participate in sharing his personal health information with the exchange. Due to a recent promotion, the consumer is relocating to Dover, DE, and is in the process of identifying a new physician, registered with the Delaware Health Information Network electing to share his personal health information. Additionally, the consumer's new physician encouraged him to update his previous election to opt out of the West Virginia exchange and to make this information available to the Delaware exchange.

For the final demonstration, Ms. Price introduced Mr. David Foster, Executive Counselor to Mr. Michael Astrue, Commissioner of the Social Security Administration (SSA). Mr. Foster acknowledged that the perspective at the SSA is different from that of HHS and other agencies, because they are not medical providers. However, they depend heavily on the medical community to serve 2.5 million people who apply for disability benefits each year, a number that continues to increase. To make a determination of disability, the SSA must access a patient's medical record, and the present system is cumbersome and inefficient. He said they spend more than \$6 billion each year in administrative costs—not program costs—to run their disability program. So they are taking steps to address this workload by maximizing their use of technology.

Mr. Foster then introduced Ms. Debby Somers, SSA's Program Manager for HIT, who walked the audience through the demonstration; additional demonstration participants included MedVirginia (Richmond, VA), and NCHICA (Research Triangle Park, NC). For the SSA, the disability decision is based on how a particular condition affects the claimant's ability to perform work. The SSA must obtain evidence for people applying for disability (diagnosis, procedures, laboratory findings, etc.) that is sufficient to demonstrate their inability to work for at least 1 year or that their condition is expected to result in death. The demonstration showed how the SSA obtains the health care consumer's authorization to gather their information, and the value to the SSA of enhancing their business process and added value to the consumer in speeding up the claims process.

Mr. Holt Anderson emphasized how this is important to North Carolina. The outstanding claims or the number of claims that North Carolina received in federal fiscal year 2007 was more than 133,000. The average number of days to the initial SSA determination is currently 82 or 83. And the average amount of payout per individual in the state of North Carolina is about \$9,000 a year. That is \$1.2 billion sitting in

potential benefits that individuals and their families are not receiving, Mr. Anderson commented, noting also that not all of those will get approved. Accelerating this determination process not only assists those families and those individuals, but it assists the providers who are holding accounts receivable, waiting on those determinations to be made.

Discussion Highlights

“I would like to essentially close this session with this observation: sometimes the pathway to great accomplishment is marked by events. In fact, almost always it’s marked by events. I believe what we have had today is an event. We have had complex organizations bring together, in one place, a demonstration of the capacity to do something quite basic.”—Secretary Leavitt

Confidentiality, Privacy and Security Workgroup Recommendations

Jodi Daniel, Office of the National Coordinator, discussed the work of the CPS Workgroup, acknowledging the leadership of Co-Chairs Deven McGraw and Kirk Nahra (who was represented at this meeting by Jill Dennis). Ms. Daniel reminded the Community that the Workgroup’s broad charge was to make recommendations to the AHIC regarding the protection of personal health information to secure trust, and support appropriate interoperable electronic health information exchange. The Workgroup’s specific charge was to make actionable confidentiality, privacy, and security recommendations to the AHIC 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 electronic health record-related breakthroughs.

The Workgroup developed a number of recommendations, largely trying to bring everybody up to the same bar and pushing for electronic health information exchange participant compliance with common privacy and security policies, and not just those entities that are covered under HIPAA. The CPS Workgroup also had a set of recommendations aimed toward recognizing that individuals should continue to exercise their individual rights by working directly with those whom they have a direct relationship with, since most consumers do not have direct relationships with health information exchanges at this point. These recommendations also clarified the importance of health information exchanges posting their notice of privacy practices on their respective Web sites so that consumers who are interested in that can understand how the exchanges may use and disclose information.

The CPS Workgroup will not transition into A2. Workgroup members have drafted a final recommendation letter that shares some of the knowledge that they have gained over the past two years, identifies issues that are still open, discusses what some of the significant challenges were, and sets a road map for future work that needs to be done.

Ms. McGraw and Ms. Dennis reviewed the Workgroup’s recommendations, as follows:

Policies Regarding Network Access

- **Recommendation 1.0:** The CPS Workgroup recommends that HHS work with other stakeholders to create a set of guidelines for protecting the confidentiality, privacy and security of information that is collected by, or shared through, an electronic health information exchange network. Such guidelines should cover who can access information in a network and for what purposes. This effort may require revisions to, or clarifications of, the HIPAA Privacy and Security Rules. HHS should give particular consideration to those areas where there are “differences” in the way that information is

accessed, used, and disclosed in an electronic health information exchange environment as compared to what occurs absent the presence of electronic exchange.

- **Recommendation 1.1:** The CPS Workgroup recommends that the guidelines developed by HHS pursuant to Recommendation 1 (and any revisions to the HIPAA Privacy and Security Rules) address how “minimum necessary” would apply to the access, use, and disclosure of personal health information in or through a network. While the rules may not need to be revised for this context, there is sufficient confusion and concern about how the minimum necessary rule would apply in this exchange environment that, at a minimum, HHS should provide additional guidance on this issue.
- **Recommendation 1.2:** The CPS Workgroup recommends that the guidelines developed by HHS pursuant to Recommendation 1 (and any revisions to the HIPAA Privacy and Security Rules) address the potential uses and disclosures of personal health information for research purposes.
- **Recommendation 1.3:** The CPS Workgroup recommends that HHS work with other stakeholders to continue to monitor whether there are any new confidentiality, privacy, or security issues related to the use or disclosure of personal health information through an electronic health information exchange network for public health.

Policies Regarding a Network’s Own Activities

- **Recommendation 2.0:** As part of its effort to create a set of guidelines for protecting the confidentiality, privacy, and security of information maintained by or shared through an electronic health information exchange network pursuant to Recommendation 1, the CPS Workgroup recommends that HHS also work with stakeholders to consider the appropriate uses and disclosures of personal health information by and from the network itself (i.e., whether and to what extent the network will be able to act independently in the use and disclosure of personal health information for its own purposes).

De-Identification

- **Recommendation 3.0:** HHS should conduct an analysis of whether the current HIPAA Privacy Rule de-identification standard provides sufficient protection against re-identification and consider revising the HIPAA Privacy Rule, as appropriate.

Consistent Rules for Personal Health Information

- **Recommendation 4.0:** The CPS Workgroup recommends that as HHS develops policies, guidelines, or requirements for safeguarding personal health information exchanged in a networked environment, network participants should not be required to treat personal health information differently depending on its source.

Roles, Rights, and Responsibilities of Consumers

- **Recommendation 5.0:** The CPS Workgroup recommends that policies, guidelines, or requirements developed by HHS with respect to electronic health information exchange networks specifically address the role of consumers and their caregivers (health care providers, family members, and other authorized individuals). These policies, guidelines or requirements should determine the degree to which consumers should be permitted to control the use or disclosure of their personal health information by an electronic health information exchange network.

- **Recommendation 5.1:** The CPS Workgroup recommends that HHS consider appropriate requirements for electronic health information exchange networks and their participants to safeguard personal health information in a way that supports the choices afforded to consumers through Recommendation 5.
- **Recommendation 5.2:** The CPS Workgroup recommends that when consumers are provided the opportunity to choose whether or not to share certain personal health information, that such a choice be accompanied by appropriate consumer education.

Safeguarding Information in a Personal Health Record

- **Recommendation 6.0:** The CPS Workgroup recommends that HHS work with other Federal agencies, such as the Federal Trade Commission, and stakeholders in the public and private sectors to create a set of guidelines, policies, or requirements for safeguarding personal health information within a personalized health record (PHR). These policies, guidelines, or requirements should support the right of consumers to control how information is used or disclosed from their PHR.
- **Recommendation 6.1:** HHS should consider whether the HIPAA Privacy and Security Rules should be revised or clarified, as appropriate, to provide for the privacy and security of PHRs maintained by a covered entity or their business associates.

The Community unanimously agreed to submit the letter with these recommendations and the Community's observations to the Secretary for further consideration.

Discussion Highlights

“Are there rules...if I opt out in one of those, that you're recommending a requirement that any other exchange that may have that information so that as a consumer, I'm not having to go find all the various different six or seven different exchanges that may get access to the source information, whether it be EMR systems, or hospital records, or lab records, or other things?”—Mr. Hutchinson

“We don't actually get so specific about opt-in versus opt-out...We could not reach consensus, in part because we wanted to take as a threshold matter, what are you opting into or opting out of? You have to have a complete understanding of what that exchange is doing with your data before you can really make that meaningful choice. And so it really varied, and our sense was, to the extent that they're only doing exchange for treatment purposes, do we really need to provide national policy that says opt-in or opt-out versus allowing the state and local variation that exists today?”—Ms. McGraw

“The practical reality is that patients can also change their mind over time. It needs to be easy for that to happen...You may have a patient who wants to opt in to all relevant health information exchange, except for their psychiatric condition. You can have those mixes, even within a single patient themselves. So it does have implications for how you design the system and adds another layer of complication that needs to be dealt with.”—Ms. Dennis

“It strikes me that in a number of instances here, you've noted that some of the circumstances weren't contemplated when HIPAA was put together, when our regulations were promulgated. Certainly that's always going to be the case with any regulatory construct. And your recommendations point to HHS as an entity to at least work with stakeholders, or in some cases I think you contemplate promulgating rules, at least guidelines. To stay nimble, would you consider it adequate if another entity were to come up with model standards, model guidelines?”—Mr. Weems

“Our recommendations are directed at HHS, first of all, in part because we don’t really have any authority to recommend to anybody other than you what we think ought to be done going forward. Having said that, I think that if the Committee decides to endorse them and send them on to the Secretary, there might be a way for you to do that and to encourage it to be open to other members of the public dealing with these issues.”—Ms. McGraw

“NIST has the mandate under FISMA [Federal Information Security Management Act] to establish standards and guidelines that are mandatory for all the civilian agencies...My suggestion for Recommendation 1 is that the stakeholders work with other stakeholders to identify and create a set of guidelines where they can pick up the FISMA standards and guidelines that are already mandated...which are designed specifically to protect the confidentiality, privacy and security of information networks. So I just wanted to ask if that change could be made to the first recommendation.”—Ms. Furlani

“I don’t know that we would have any objection to that.”—Ms. McGraw

“I didn’t notice any recommendation in your text today about non-medical uses of information in any kind of privacy guidance. Was that not something that you felt was inside the scope of where you were?”—Mr. Roob

“If a woman, 85-year-old woman is in a nursing home and she’s suffering from dementia, the person who was her authorized representative in that nursing home is no longer at that nursing home, right? And so when she comes back up in an automated environment for reauthorization, she doesn’t have an authorized representative. She’s demented. It is a real problem, and it is a problem when you go to an automated environment, because in the past, we simply disregarded it. We looked at that information in a paper-based environment...In the future, we can’t afford to benignly neglect it prospectively...For the disabled, for the mentally ill and for the elderly, the issue of authorized representative is a bigger problem on privacy than I would have anticipated.”—Mr. Roob

“For Recommendation 6.1, it only refers to PHRs that are maintained by a covered entity or business associate...did the Workgroup consider any type of recommendation that would apply a uniform standard to all PHRs, regardless?”—Ms. Wooster

“We did, and actually one of our earlier recommendations in the series got at the broader question of entities that are not covered entities under the rule, but are participants in the health information exchange network, the national network, and that extending equivalent like HIPAA obligations to those organizations as well. So this really builds on that prior recommendation.”—Ms. Dennis

Health IT Strategic Plan

Dr. Kolodner introduced a discussion about the Health IT Strategic Plan by reminding the Community that at the June AHIC meeting, he announced the release of the Health IT Strategic Plan, a collaborative effort across federal agencies. A briefing on this topic was scheduled for the previous AHIC meeting, but was postponed until this meeting because of time constraints. Dr. Kolodner introduced Dr. Charles Friedman, the Deputy National Coordinator for Health IT, who helped to coordinate with a variety of agencies on this project.

Dr. Kolodner briefly discussed the motivators of the Strategic Plan, which include the following: providing clarity, guidance, and a way to measure progress; the fact that many have asked for the plan; Presidential Executive Order 13330; U.S. Congress; observations from the Institute of Medicine; the

natural obsolescence of the Strategic Framework; the need for collaboration across the federal government; and the overall need for clarity and guidance. Dr. Kolodner also touched on the following characteristics of the plan: (1) collaborative (across the government, with seven Departments/Agencies outside HHS); integrative (one infrastructure serves the needs of two goals); complete (eight objectives that improve quality and efficiency of health care and population health); and disciplined (how projects of multiple agencies work in pursuit of shared goals).

Dr. Kolodner then showed a slide illustrating the types of collaborations, initiatives, and constructs that were involved in creating the Strategic Plan. They included the following:

- Colleagues at HHS.
- Others who are active in something related to health care and health within the federal government.
- A Health IT Policy Council that allowed us to cut across the various agencies in the federal government, comparing and coordinating policies.
- Federal health architecture (presented as part of the federal role in the NHIN) at a technical level.
- Colleagues at the state level, and a number of initiatives put into place with HISPIC and the State Alliance.
- A number of constructs that allowed there to be coordination, whether that is the AHIC itself, the AHIC 2.0, or HITSP.

Dr. Friedman then presented the goals of the plan, as follows:

- **Goal One: Enable Patient-Focused Health Care.** Enable the transformation to higher-quality, more cost-efficient, patient-focused health care through electronic health information access and use by care providers, and by patients and their designees.
- **Goal Two: Improve Population Health.** Enable the appropriate, authorized, and timely access and use of electronic health information to benefit public health, biomedical research, quality improvement, and emergency preparedness.

Dr. Friedman then presented a matrix that exposes the basic structure of the plan, with a series of objectives addressing the four themes of the national health IT agenda: (1) privacy and security, (2) interoperability, (3) adoption, and (4) collaborative governance. The eight objectives of the plan then exist at the intersection of one of the themes and one of the goals, as follows:

Summary of Health IT Strategic Goals and Objectives: 2008-2012

	Privacy and Security	Interoperability	Adoption	Collaborative Governance
Goal 1. Patient-focused Health Care	Objective 1.1: Facilitate electronic exchange, access, and use of electronic health information, while protecting the privacy and security of patients' health information.	Objective 1.2: Enable the movement of electronic health information to support patients' health and care needs.	Objective 1.3: Promote nationwide deployment of electronic health records (EHRs) and personal health records (PHRs) and other consumer health IT tools.	Objective 1.4: Establish mechanisms for multi-stakeholder priority-setting and decision-making
Goal 2. Population Health	Objective 2.1: Advance privacy and security policies, principles, procedures, and protections for information access in population health.	Objective 2.2: Enable exchange of health information to support population-oriented uses.	Objective 2.3: Promote nationwide adoption of technologies to improve population and individual health.	Objective 2.4: Establish coordinated organizational processes supporting information use for population health.

Like many strategic plans, this has a hierarchical structure. Under the goals are objectives, and under each objective is a set of strategies, which delineate in a more specific way the kinds of things that will have to be done to realize the outcome associated with each objective. He showed for illustrative purposes Objective 1.3 related to adoption of health IT for healthcare, as follows:

- **Objective 1.3 – Adoption:** Promote the nationwide adoption of interoperable electronic health records (EHRs) by providers, and the adoption of personal health records (PHRs) and other consumer health IT tools by consumers and their designees.
 - Strategy 1.3.1: Remove business barriers and disincentives for provider and delivery system adoption of EHRs.
 - Strategy 1.3.2: Increase the likelihood of efficient and effective EHR purchase and implementation.
 - Strategy 1.3.3: Increase the value of EHRs through interoperability, clinical decision support, and other technical advances.
 - Strategy 1.3.4: Promote certified health IT products as critical components and standards of clinical care.
 - Strategy 1.3.5: Develop the workforce for health IT product development and use.
 - Strategy 1.3.6: Identify key PHR functions and features that will allow individuals to link their health information to a wide variety of market-driven personal health tools that they and their designees find valuable in managing their health and care.
 - Strategy 1.3.7: Design methods to promote the use of PHRs and other consumer health IT tools by consumers and their designees.
 - Strategy 1.3.8: Minimize liability risks and clarify misperceptions of liability risks for providers using health IT, while preserving or enhancing patient protections.
 - Strategy 1.3.9: Remove technical, financial, workflow, and other barriers to diagnosing, treating, and communicating with patients outside the boundaries of traditional health care settings.

In addition, each of the strategies has a milestone associated with it, continuing the hierarchy. For example:

- **Strategies for Objective 1.3 - Adoption:** Promote the nationwide adoption of interoperable electronic health records (EHRs) by providers, and the adoption of personal health records (PHRs) and other consumer health IT tools by consumers and their designees.
 - Strategy 1.3.7: Design methods to promote the use of PHRs and other consumer health IT tools by consumers and their designees.
 - Milestone 1.3.7: By 2010, creation of a plan that can guide efforts directed at developing and marketing personal health information tools.

Dr. Friedman pointed out that the plan includes an index to the current federal activities that support each objective. Finally, Dr. Friedman offered an example from another one of the plan's appendices. This appendix is a table that cross-references all of the federal activities currently under way against the one or more of the plan's objectives.

Centers for Medicare & Medicaid Services (CMS)

CMS: Beneficiary Information Services

One of CMS' priorities, as indicated in its most recent Strategic Plan, is to empower beneficiaries to make more informed decisions about their health and health care. To support this priority, CMS has implemented an online Medicare account management tool for beneficiaries, the Medicare Beneficiary Portal, and has begun to explore the use of personal health records for beneficiaries.

CMS: EHR Adoption Demonstration

CMS is implementing a new demonstration project in which up to 1,200 small to medium sized primary care practices in up to 12 different locations will be eligible to receive additional Medicare payments for using EHRs to coordinate and provide care to Medicare beneficiaries and achieve certain clinical quality measures will be eligible to earn up to several thousand dollars per year in incentive payments. By design, the demonstration will be budget neutral by requiring that the associated costs be offset by savings resulting from more efficient healthcare delivery.

CMS: E-Prescribing Efforts

The Medicare Prescriptions Drug, Improvement, and Modernization Act of 2003 (MMA), (Pub.L.No. 108-173) directed the Secretary to promulgate uniform standards for the electronic transmission of prescription and certain other information for covered Part D drugs prescribed for Medicare Part D eligible individuals. CMS adopted a set of foundation standards for e-prescribing under Medicare Part D, worked in collaboration with AHRQ to pilot test additional e-prescribing standards, published a required report to Congress on the results of that pilot and issued a final rule that will require the use of the successfully tested standards and the National Provider Identifier in e-prescribing Part D covered drugs for Part D eligible individuals under specified circumstances.

To close the presentation, Dr. Friedman returned the discussion to the beginning of this meeting and the day's agenda, the contents of which dovetail into this plan. During the presentation from the PH/CCC Workgroup, several issues were addressed that fall directly into the domain of Objective 2.3. Then, there was a discussion about AHIC 2, which falls in line with the theme of collaborative governments, Objectives 1.4 and 2.4. Then, there was a presentation and demonstration of the NHIN, which falls squarely with the interoperability objectives, 1.1 and 2.1. Finally, the Community heard recommendations presented relating to confidentiality, privacy and security, obviously aligning with Objectives 1.1, and particularly given some of the comments that were made, Objective 2.1, which brings together confidentiality and privacy considerations in relation to population health.

Discussion Highlights

“There is yet another level to the hierarchy to the plan that I didn’t mention, and that is a set of action steps that are detailed under each strategy and, in fact, there was a larger number of action steps that we identified than are actually listed in the plan itself. In the process of generating these action steps, the most important of which are detailed in the plan, we...revisited what worked and what didn’t work...We are going to, based on the strategic plan, develop an operational plan which will take the strategic directions that are outlined in the plan and make them very much action-oriented in a way that is interdependent on each other.”—Dr. Friedman

“The inclusion of MITA here...the management information systems that are coming online for Medicaid will be very helpful in promoting this effort. You might also look at including a PHR in that MITA architecture down the line. We have begun playing around with a PHR. I think Florida is playing around with a PHR, in terms of that MITA technology...I think you could relatively easily bolt that on to your MITA piece.”—Mr. Roob

“The strategic plan has to be dynamic. It has to be live and refreshed, because it does change...We need to be learning from what we’re doing. We need to be able to reevaluate. I think one of the important things is that as we move forward, this is really meant to be a policy-neutral framework that these are our goals, that are reasonable ones, regardless of one’s particular political party...The overall general structure of the framework was intended to be something that could continue forward, and hopefully be less subject to some of the periodic changes that we know we undergo from time to time in the government.”—Dr. Kolodner

“How do we transition this plan into the new organization? And do they accept that as their outcomes and goals?”—Dr. Jones

“We will be participating as federal entities within A2 in helping to move forward, particularly in the area of the interoperability and the overall governance of the process and the networking...A strategic plan to help interact with the nation, as A2 moves forward, will continue to be needed and be updated. A lot of the activities may be carried out within that construct rather than within the federal government, but I think that’s where we look at the particular elements, and a lot of that governance column may be things that we look to, to take the ones that are appropriately non-governmental and work with A2 to move forward.”—Dr. Kolodner

“The real power of the federal government is as a purchaser, and the reason we established A2 is because we did not want it to be limited in its speed and agility by what often is a quite constraining process. We want it to pick up speed. We want the velocity to accelerate. The federal government will be a big, bold participant. We’ll be a big dues payer at several levels. We will be a profound implementer. This strategic plan will constitute an overall construct of the direction we’re headed. And I think that A2 very clearly will be guided by what we have done, but will not be constrained by what can be bureaucratic slow processes.”—Secretary Leavitt

“I just want to thank all of you for the remarkable tenacity that you have shown through this process, and to celebrate the success, at least for today, of demonstrating the NHIN and its basic form, and having a strategic plan that’s in place, and having a process now launched that is now in its own orbit.”
—Secretary Leavitt

Public Comment

Speaker Number 1—Lee Jones, HITSP Program Manager, congratulated the Secretary, the Office of the National Coordinator, and the Community on the successful NHIN demonstrations. He described HITSP's work as enabling many of the activities that occurred during these demonstrations. He also acknowledged and congratulated the almost 500 organizations that are members of HITSP and represent tens of thousands of volunteer hours.

Speaker Number 2—Carol Bickford of the American Nurses Association congratulated the newly appointed AHIC 2.0 Board members and expressed disappointment that clinicians are not represented on the Board. She also emphasized that the American Nurses Association, acting on behalf of nurses across the country, will continue to be strong participants in supporting initiatives to move forward on AHIC 2.

Closing Remarks

Before adjourning the 24th meeting of the AHIC, Dr. Kolodner thanked the Community members, speakers, and participants for their attendance and participation.

American Health Information Community Successor, Inc.

Current Status and Activities

John Tooker, MD, MBA, FACP
Interim Chair, AHIC Successor, Inc.

November 12, 2008

1

AHIC Successor, Inc.



Agenda

- Current Status of Transition
 - Current Status Overview
 - November 13 Board of Directors Agenda
- Value Case Prioritization Process
 - Nationwide Priorities
 - Nationwide Prioritization Process Overview
 - Interoperability Specification Process

2

AHIC Successor, Inc.



Current Status Overview

- AHIC Successor, Inc. basic operational infrastructure is in place and recruitment of permanent CEO underway
- Plans and procedures drafted
 - Bylaws
 - Proposed charters for Executive, Nominations, Finance, and Membership and Communications Committees
 - Strategic and Business Plan
 - Prioritization Process
 - Communications Plan
 - Membership Dues Structure
- Board of Directors nominated and selected and Federal Liaisons identified

3

AHIC Successor, Inc.



Upcoming Board of Directors Agenda

- Public Session (10:00 – 11:00)
 - Secretary Leavitt Remarks
 - National Coordinator Remarks
- Planning Session (11:00 – 4:00)
 - Introduction of Board Members
 - Strategic Planning Presentation and Discussion
 - Framework to Conduct Board Meetings
 - Bylaws Presentation and Discussion
 - Proposed Board Operating Committee Structure
 - Operations Report
- Public Summary (4:00 – 4:30)

4

AHIC Successor, Inc.



Nationwide Priorities

- AHIC has prioritized Use Cases for 2009
- AHIC Successor, Inc. is establishing a new prioritization process for 2010 and beyond
 - The new process will likely employ a “Value Case”

Value Case

- Value Case is a document that describes an aspect of healthcare where:
 - specific, identifiable harmonization standards can be identified;
 - use of a standardized approach can clearly increase quality and/or reduce costs of care for patients; and
 - if the value case were completed, there is clear reason to believe that health IT adoption would increase

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AHIC Successor, Inc.



Nationwide Prioritization Process Overview

- The Value Case is designed to ensure an open and transparent stakeholder driven approach
 - Bottom up approach solicits Value Cases from all stakeholders and promotes ownership
 - Successor intends to build source of funding support for value cases whose stakeholders lack sufficient resources
 - The Value Case will be evaluated against business criteria
 - All stakeholders will be informed throughout the process – from Value Case submission to acceptance and recognition
 - Committee membership will enable stakeholder participation and promote ownership of the results

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AHIC Successor, Inc.



Interoperability Specification Process

- Gradual transition of the prioritization process will occur over 2009 to respect Federal procurement requirements
- The new prioritization process will continue to feed the harmonization of standards
- Initial steps at January 8 Board meeting
 - Report on the status of the 2007 HITSP priority work items scheduled for Recognition by HHS
 - HITSP will present the 2008 priority work items that will be conveyed to HHS for Acceptance
 - HITSP will acknowledge receipt of the 2009 priorities
 - AHIC, Inc. will announce the beginning of the process of gathering Value Cases for 2010

Thank you

- The work of the AHIC Successor Planning Groups was essential
 - Leaders from across the healthcare industry volunteered time and talent to develop the AHIC Successor governance, membership, sustainability, and transition models
- Your commitment to participating in the AHIC Successor stakeholders forums is key to continued progress
 - Membership campaign and committee roles will begin soon

CONTACT INFORMATION

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American Health Information Community

Opportunities to Carry Forward AHIC Workgroup Activities

Robert M. Kolodner, MD
National Coordinator for Health Information Technology

November 12, 2008

Identified Activities for Future Action by the AHIC Successor, Inc. and Others

- The opportunities reflect unfinished or additional activities of the seven AHIC workgroups and ad hoc CDS planning group based on their “broad charges.”
- ONC is conveying to the successor:
 1. A list of important activities for the initial year of the AHIC Successor, Inc.’s operations.
 2. A complete list of activities, including those best taken on by other entities (including the Federal Government or a FACA body).
 3. Suggestions for approaching the activities.

Proposals are intended for use in conjunction with other key artifacts

- Other important artifacts have been produced that the AHIC Successor, Inc. should take into consideration as it makes decisions regarding transition of workgroup activities.
 - Past AHIC Workgroup recommendations
 - AHIC Workgroup Closing Reports
 - AHIC Successor Transition Planning Group Recommendations
 - ONC Strategic Plan
- ONC's proposals do not supersede any of these important artifacts.
- Instead, they are intended to assist the organization in making decisions going forward.

3

ONC's approach to developing proposals for the AHIC Successor, Inc.

- Focused on activities and opportunities to be moved forward, not workgroups *per se*.
- Looked for synergies among the recommended activities from existing workgroups.
- Looked for opportunities to carry over the "intellectual capital," energy, and engagement of current workgroup participants.

4

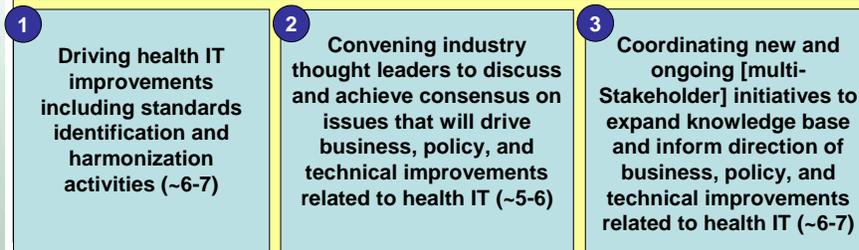
1. Activities proposed for the initial year of the Successor's operations

The list of activities....

- Describes time critical activities that ONC suggests the organization take on within its first year
- Is deemed in line with the current understanding of the AHIC Successor's purpose and scope
- Encompasses ongoing or additional work related to the AHIC workgroups' broad charges that present opportunities for the Successor
- Focuses on synergies and consolidates overlap from among the workgroups' activities

1. Activities proposed for the initial year of the AHIC Successor's operations

17 activities identified as opportunities for ASI during Year 1 focus on...



- Involvement of multiple disciplines and stakeholder groups will ensure transition activities are tackled comprehensively
- Some issues may require collection of testimony, research, and/or significant deliberations in order to achieve consensus

1. Activities proposed for the initial year of the AHIC Successor's operations

1

Driving health IT improvements including standards identification and harmonization activities

- Examples...
 - Identify technical standards and develop technology that can provide for consumer-controlled privacy at increasingly granular levels.
 - Address technical issues associated with e-prescribing.

1. Activities proposed for the initial year of the AHIC Successor's operations

2

Convening industry thought leaders to discuss and achieve consensus on issues that will drive business, policy, and technical improvements related to health IT

- Examples
 - Articulate strategic positioning of adoption of EHRs within context of greater infrastructure.
 - Drive development of standardized ... principles for patient and provider record-matching.

1. Activities proposed for the initial year of the AHIC Successor's operations

3

Coordinating new and ongoing [multi-Stakeholder] initiatives to expand knowledge base and inform direction of business, policy, and technical improvements related to health IT

- Examples
 - Conduct gap analysis between data elements needed to support priority domain areas for population health and data elements that are currently available through EHRs.
 - Develop and implement a model for a standard Clinical Decision Support Knowledge Repository that can collect, organize, and distribute clinical knowledge and CDS interventions, including information regarding associated IT standards and technical capabilities.

2. Complete list of activities, including those best taken on by other entities

- 50 activities were identified to carry forward after the current AHIC workgroups end their operations.
- Four key types of future homes were identified for current AHIC Workgroup activities where work needs to continue:
 - AHIC Successor, Inc.
 - Federal Government
 - Federal Advisory Committee
 - Other (including state and local governments, academic institutions, public-private collaboratives, associations, etc.)

3. Suggestions for approaching the activities

- The AHIC Successor will need to determine how to incorporate the activities into its operations.
- Options for the AHIC Successor to approach the suggested activities within the first three months include:
 - Establish one interim committee
 - Establish selected initial working committees

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3. Suggestions for approaching the activities *(continued)*

- Establish one ad hoc committee to facilitate the BOD's decisions regarding the organizational model and committee structures.
 - This committee might examine and prioritize recommendations from all sources and recommend a committee structure appropriate for the prioritized work.
- Proceed immediately to set up initial committees modeled after examples.
 - Prior AHIC workgroups.
 - HITSP consumer, provider, population "perspectives" (to which the research perspective might be added).
- For any of these or other approaches:
 - Cross-cutting committees, such as one focused on confidentiality, privacy and security, would be useful.
 - The effort could be facilitated by including individuals who have been working in the areas being transitioned to the AHIC Successor, and could include people from both the public and private sectors.

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Department of Health & Human Services
Office of the National Coordinator for
Health Information Technology

**AHIC Workgroup Transition Proposals
for the AHIC Successor, Inc.**

October 31, 2008

1. Introduction

This document presents the recommendations of the Department of Health and Human Services (HHS) Office of the National Coordinator for Health Information Technology (ONC) for transitioning work from the existing American Health Information Community (AHIC) workgroups to the new AHIC Successor, Inc. More specifically, it presents:

- A prioritized list of transition activities for the AHIC Successor, Inc. to take on in its initial year of operations;
- A complete list of transition activities that should be advanced in the future by the AHIC Successor, Inc. organization and/or other entities;
- Approaches for operationalizing transition to the AHIC Successor, Inc. along with a set of notional committee options for the organization to use to continue advancing transition activities.

ONC's recommendations reflect input from multiple sources, including the work of the seven AHIC workgroups, the Clinical Decision Support ad hoc planning group currently functioning at the behest of the existing AHIC and which was established in early 2008, and ONC staff. The recommendations address activities identified by the workgroups as necessary for realizing the goal of a national health information infrastructure that supports more cost effective and higher quality care delivery and which improves the health of our nation. They are consistent with the deliberations of the AHIC Successor Transition Planning Group, but provide a greater level of detail and specificity regarding needed actions. These recommendations are intended to be used in conjunction with the closing reports developed by each of the AHIC workgroups, which provide additional context and detail regarding each workgroup's accomplishments and recommendations for the future. ONC's recommendations also take into account the current purpose and scope of the AHIC Successor as described at the June 29, 2008 AHIC meeting.

AHIC Successor Purpose and Scope Statement

The AHIC Successor will be an independent, sustainable public-private enterprise that brings together the best of the public, non-profit and private sectors into a trusted, purpose-driven organization for the creation and use of a secure interoperable nationwide health information system. Its vision is to realize interoperability that engages individuals, providers, institutions and other stakeholders in a patient-centered learning healthcare system that supports continuously improving healthcare quality, safety, efficiency and accessibility. The AHIC Successor's primary purpose is, through achievement of its vision, to improve and maintain the health and well-being of all individuals and communities in the United States.

1. Accelerate the adoption of interoperable health IT by ensuring the availability of harmonized, coordinated, up-to-date standards and rigorous conformance testing through certification.
2. Prioritize stakeholder requirements for health IT interoperability.
3. Advance health information policies and technical approaches that promote the AHIC Successor's vision and purpose and protect confidentiality, privacy, and security, consistent with the policies established by HHS and applicable federal and state laws.
4. Oversee and facilitate the Nationwide Health Information Network (NHIN – a network-of-networks).

ONC's recommendations do not address activities related to current AHIC-driven use case development process. Both the 2008 and 2009 use cases will be completed and conveyed to HITSP for standards identification and harmonization according to the current process. The role that the AHIC Successor, Inc. and ONC will play in this process for 2008 and 2009 is being determined through a separate process.

The remainder of the document is organized as follows:

- Section 2: AHIC Workgroup Priority Areas for the AHIC Successor, Inc.
- Section 3: Complete List of Transition Activities Suggested for Transition to AHIC Successor, Inc. and/or Other Entities
- Section 4: Approaches for Operationalizing Transition

2. AHIC Workgroup Priority Areas for the AHIC Successor, Inc.

Each of the AHIC Workgroups established a specific and broad charge to guide their work efforts. Each of the workgroups has completed their specific charge and advanced recommendations to the AHIC to fulfill their broad charges.

AHIC Workgroups	AHIC Workgroup Specific Charges	AHIC Workgroup Broad Charges
Chronic Care	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.	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.
Confidentiality, Privacy, and Security	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 electronic health record related breakthroughs.	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.
Consumer Empowerment	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.	Make recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.
Electronic Health Records	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 are deployed for clinical care by authorized parties.	Make recommendations to the Community on ways to achieve widespread adoption of certified EHRs, minimizing gaps in adoption among providers.
Personalized Healthcare	Make recommendations to the American Health Information Community to consider means to establish standards for reporting and incorporation of common medical genetic/genomic tests and family health history data into electronic health records, and provide incentives for adoption across the country including federal government agencies.	Make recommendations to the American Health Information Community for a process to foster a broad, community-based approach to establish a common pathway based on common data standards to facilitate the incorporation of interoperable, clinically useful genetic/genomic information and analytical tools into electronic health records to support clinical decision-making for the clinician and consumer.
Population Health	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 healthcare delivery and public health systems can be transmitted in standardized and anonymized format to authorized public health agencies within 24 hours.	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.
Quality	Make recommendations to the American Health Information Community that specify how certified health information technology should capture, aggregate and report data for a core set of ambulatory and inpatient quality measures.	Make recommendations to the American Health Information Community so that health IT can provide the data needed for the development of quality measures that are useful to patients and others in the healthcare 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 health IT.

The priorities described in this section encompass ongoing or additional work related to the workgroups’ broad charges that ONC has identified should continue after the current AHIC charter ends. Each of these priorities was deemed in line with the current understanding of the AHIC Successor’s purpose and scope. In addition, they describe time critical activities that ONC recommends the organization take on within its first year. A full list of unprioritized activities identified for transition to the AHIC Successor, Inc. as well as other entities is included in Section 3. Rather than focusing on transitioning each workgroups’ activities, ONC took the approach of looking for synergies among recommended activities from the existing workgroups, eliminating any overlap that may exist, and focusing instead on opportunities to carry over the “intellectual capital,” energy, and engagement of current workgroup participants regardless of each activity’s original workgroup affiliation. Accordingly, the table below includes a mapping of each priority to the topic areas to which it is relevant.

Priorities for Year 1 of AHIC Successor, Inc. Operations		Related Topic Areas						
		Chronic Care	Confidentiality, Privacy & Security	Consumer Empowerment	Electronic Health Record	Quality	Personalized Healthcare	Population Health
1	Develop plan for NHIN oversight and facilitation, including governance and development of organizational policies related to CPS.	X	X	X	X	X	X	X
2	Adhere to existing and new government regulations and policies to protect consumers and identify what technical solutions, best practices and operational policies are needed to support and comply with these consumer protections.	X	X	X	X	X	X	X
3	Establish coordination mechanisms among HITSP, CCHIT, and HHS, including coordination on technical and policy issues related to confidentiality, privacy and security (CPS).	X	X	X	X	X	X	X
4	Drive development of guidelines to standardize record de-identification and state of the art technologies for data and record anonymization.	X	X	X	X	X	X	X
5	Identify technical standards and promote development of technology that can provide for consumer-controlled privacy at increasingly granular levels.	X	X	X	X		X	X
6	Articulate strategic positioning of adoption of EHRs within context of greater infrastructure.	X	X	X	X	X	X	X
7	Drive comprehensive EHR adoption in small physician offices, hospitals, and additional healthcare settings by identifying means to improve the value of adoption and by improving usability.	X			X	X		X
8	Address technical issues associated with e-prescribing.		X		X			
9	Support achievement of consensus around specific terminologies, their standardization, coding, and uniform implementation in products (i.e., SNOMED).	X			X	X		X
10	Drive identification and harmonization of standards for data elements in EHRs to enable quality measurement and improvement and health information exchange across providers and institutions. Gap analyses should be conducted for data elements that are currently available through EHRs and should take into account multiple reporting needs.	X	X	X	X	X	X	X
11	Drive development of standardized approaches and principles for patient and provider record-matching.	X	X	X	X	X	X	X
12	Promote capabilities to support longitudinal data collection, including genetic/genomic data and sentinel events, with sufficient patient privacy protections in order to support clinical practice, quality improvement, research, and personalized healthcare.	X	X		X	X	X	X
13	Prioritize interoperability standards for pharmacogenomics and e-prescribing that support pharmacogenomics lab test results and/or interpretation messaging at the point of prescribing and dispensing.		X		X		X	
14	Determine priority domain areas for population health and prioritize value case development for those domains while taking into account other relevant domain areas that may overlap with those that are prioritized.		X	X	X		X	X

15	Conduct gap analysis between data elements needed to support priority domain areas for population health and data elements that are currently available through EHRs.		X		X			X
16	Prioritize interoperability standards for telehealth, in its broadest definition, which includes any type of remote and virtual care supported by remote devices and tele-communication.	X	X	X	X	X	X	X
17	Develop and implement a model for a standard Clinical Decision Support Knowledge Repository that can collect, organize, and distribute clinical knowledge and CDS interventions, including information regarding associated IT standards and technical capabilities.	X			X	X	X	X

3. Complete List of AHIC Activities Suggested for Transition to AHIC Successor, Inc. and/or Other Entities

As with the list of priorities identified for transition to the AHIC Successor, Inc. in its first year of operations (Section 2), the full list of transition activities included in this section encompasses ongoing or additional activities related to the broad charges of the workgroups that should continue after the current AHIC charter ends. It also focuses on opportunities to carry over the “intellectual capital,” energy, and engagement of current workgroup participants regardless of original workgroup affiliation.

This full list is intended to help the AHIC Successor, Inc. make decisions regarding future activities beyond their initial year of operations. ONC recognizes that not all of the activities identified for transition are appropriate for the organization to take on. However, ONC is also of the opinion that these are important activities of which the organization should be aware, and thus activities assigned to other homes are also included in the full list below. Four “types” of organizations, including the AHIC Successor, Inc., were identified that could carry on the identified activities and serve as home for these activities in the future. The four homes include:

1. Any organization that is responsible for developing a framework and priorities for national interoperability must take into account the full spectrum of related activities, extending from decisions about basic terminologies and coding (e.g., uniform implementation of SNOMED, when to adopt ICD-10 or 11) to governance of a nationwide health information network. The **AHIC Successor, Inc.** will be the decision-making and oversight body that will guide and coordinate activities in the public and private sectors.
2. It is also clear that a **Federal Advisory Committee**, existing or new, may need to formally address the policy and governmental issues that are out of scope for the AHIC Successor, Inc.
3. There will also continue to be the need for the **Federal Government** to maintain inherently governmental functions such as ensuring consumer protections, to coordinate with the AHIC Successor, Inc. in all aspects of its efforts to advance interoperability, and to work with and, as appropriate, act on recommendations from relevant Federal Advisory Committee(s).
4. Finally, **Other Organizations** that are playing existing roles in the activities described or who are logical drivers for these activities in the future must also remain engaged.

Each activity has been assigned to a home or multiple homes if deemed appropriate. Activities that have been assigned to multiple homes denote activities where ONC thought that more than one player needed to be engaged. In these cases, the activities’ homes are categorized as either having equal level of dependence, in which case a ① is marked for each home, or as having one home that is a primary home and one which is a secondary home, in which case a ① and ② are marked respectively.

Finally, similar to the mechanism used in Section 2, the topic areas relevant to each of the transition activities are also identified.

Description of Actions Needed (<i>Other Owners</i>)		Potential Organization Types / Homes for AHIC Workgroup Gaps or Future Activities				Related Topic Areas						
		AHIC Successor, Inc.	Federal Advisory Committee	Federal Government	Other Organizations	Chronic Care	Confidentiality, Privacy & Security	Consumer Empowerment	Electronic Health Record	Quality	Personalized Healthcare	Population Health
1*	Adhere to existing and new government regulations and policies to protect consumers and identify what technical solutions, best practices and operational policies are needed to support and comply with these consumer protections.	①				X	X	X	X	X	X	X
2*	Establish coordination mechanisms among HITSP, CCHIT, and HHS, including coordination on technical and policy issues related to confidentiality, privacy and security (CPS).	①				X	X	X	X	X	X	X
3*	Drive development of guidelines to standardize record de-identification and state of the art technologies for data and record anonymization.	①				X	X	X	X	X	X	X
4	Establish a Federal framework for privacy and security with respect to electronic health information exchange, including principles, preferred policies, protection, and penalties for non-compliance.			①		X	X	X	X	X	X	X
5*	Identify technical standards and promote development of technology that can provide for consumer-controlled privacy at increasingly granular levels.	①				X	X	X	X		X	X
6	Provide oversight over new application development to ensure that consumer protections are in place.	①				X	X	X	X			X
7	Ensure that technical capabilities to maintain consumer anonymity are built into products and the health information exchange process, including those that provide data for secondary use. Technical capabilities that are developed will need to adhere to government regulations and policies to protect consumers.	①	②				X	X		X		X
8	Develop an ongoing certification process to assure that privacy, security and interoperability are incorporated into certified PHRs. Certification of interoperability should assure that information can flow from EHR to PHR and PHR to EHR.	①					X	X	X		X	X
9	Establish a mechanism to ensure that products clearly state their privacy and security policies.	①		②			X	X	X		X	
10	Educate Consumers on the benefits and risks of using PHRs, EHRs, and other personal health applications, compliant with Section 508. (Consumer Advocacy Groups)			②	①		X	X	X		X	
11	Assess the needs of the consumer for personally controlled HIT applications/records.		②	①	①	X	X	X	X		X	
12*	Support achievement of consensus around specific terminologies, their standardization, coding, and uniform implementation in products (i.e. SNOMED).	①				X			X	X		X
13*	Articulate strategic positioning of adoption of EHRs within context of greater infrastructure.	①		②		X	X	X	X	X	X	X
14*	Drive comprehensive EHR adoption in small physician offices, hospitals, and additional healthcare settings by identifying means to improve the value of adoption and by improving usability.	①	①			X			X	X		X
15*	Address technical issues associated with e-prescribing.	①					X		X			
16	Develop support networks for adopters of interoperable HIT.	①		①					X			
17	Address business case issues related to EHR and HIT adoption and use.	①	①	①					X			X
18	Conduct cost/quality benefit analyses for EHR adoption.			①					X			
19	Align best practices in provider workflow with EHR usability and functionality.			①					X			
20*	Drive identification and harmonization of standards for data elements in EHRs to enable quality measurement and improvement and health information exchange across providers and institutions. Gap analyses should be conducted for	①				X	X	X	X	X	X	X

Description of Actions Needed (<i>Other Owners</i>)		Potential Organization Types / Homes for AHIC Workgroup Gaps or Future Activities				Related Topic Areas						
		AHIC Successor, Inc.	Federal Advisory Committee	Federal Government	Other Organizations	Chronic Care	Confidentiality, Privacy & Security	Consumer Empowerment	Electronic Health Record	Quality	Personalized Healthcare	Population Health
	data elements that are currently available through EHRs and should take into account multiple reporting needs.											
21*	Drive development of standardized principles and approaches for patient and provider record-matching.	①		②		X	X	X	X	X	X	X
22	Clarify the definition, role and business model for data stewardship; evaluate the utility of a nationwide certification process for data stewards and their oversight over data aggregation and analysis; move beyond the identification of consensus areas of what data stewardship is/should be to defining specific areas that should be standard components of data stewardship. (QASC)	②			①	X	X	X	X	X	X	X
23	Advance standardized approaches to data exchange and aggregation. (Multiple private and public sector initiatives in this area)	②			①		X	X	X	X		X
24	Develop viable frameworks for episodic measurement, that take into account interoperability and privacy standards, that will allow the exchange of information to develop and collect longitudinal measures and support patient-centric quality improvement. (NQF, Measure Developers, Federal Government)	②		①	①			X	X	X		X
25	Facilitate development of a legal framework for health information exchange that also addresses security and privacy issues, in accordance with Federal and State laws. (Federal and State Government, and State-level stakeholders)	②		①	①		X	X	X	X		X
26	Drive research into, and development of, incentives that support adoption and use of interoperable health IT. (Congress, CMS)	②		①					X	X		
27	Establish a Quality Data Set to help advance health IT enabled quality measurement and improvement. (NQF HITEP)	②			①				X	X		
29*	Promote capabilities to support longitudinal data collection, including genetic/genomic data and sentinel events, with sufficient patient privacy protections in order to support clinical practice, quality improvement, research, and personalized healthcare.	①		②		X	X		X	X	X	X
30	Prioritize interoperability standards to link research standards to those utilized in clinical settings, so that data from electronic health records can be used to support clinical research. Information flows between the clinical laboratory, prescribing physician, and patient, as well as pharmacogenomic-based dosing interpretation of clinically validated test/drug combinations within e-prescribing should be included.	①		②			X		X		X	X
31*	Prioritize interoperability standards for pharmacogenomics and e-prescribing that supports pharmacogenomics lab test results and/or interpretation messaging at the point of prescribing and dispensing.	①					X		X		X	
32	Balance the desires of the research community to have secure and authorized access to clinical databases with protections for the consumer and clinician by developing technical solutions to ensure that genetic/genomic information will be used appropriately, with consumer consent or other appropriate privacy protections, and for the benefit of their health.	①		②			X	X			X	X
33	Consumer education about the potential benefits and risks associated with genetic/genomic tests. (Consumer Groups)			②	①		X	X			X	
34	Facilitate certification of Family Health History standards for primary care collection of family health history information.	①		②			X	X	X		X	
35	Develop clarifying guidance regarding HIPAA and CLIA and related state regulations that may affect the timely transmission of newborn screening results. (State agencies)		②	①	②		X	X			X	X
36	Develop incentive structures for the development and evaluation of new genetic/genomic tests and their incorporation		①						X	X	X	

Description of Actions Needed (<i>Other Owners</i>)		Potential Organization Types / Homes for AHIC Workgroup Gaps or Future Activities				Related Topic Areas						
		AHIC Successor, Inc.	Federal Advisory Committee	Federal Government	Other Organizations	Chronic Care	Confidentiality, Privacy & Security	Consumer Empowerment	Electronic Health Record	Quality	Personalized Healthcare	Population Health
	into routine clinical practice.											
37	Develop templates and standards for submitting electronic research data to databases to facilitate both voluntary and required data submission to databases for research. (SDOs)			②	①		X			X	X	X
38	Address uncertainties about FDA regulation of clinical decision support (CDS) tools and algorithms. (Future CDS Alliance)			①	②				X	X	X	
39*	Determine priority domain areas for population health and prioritize value case development for those domains while taking into account other relevant domain areas that may overlap with those that are prioritized.	①					X	X	X		X	X
40*	Conduct gap analysis between data elements needed to support priority domain areas for population health telehealth and data elements that are currently available through EHRs.	①					X		X			X
41	Develop a business case for data/information exchange between public health and clinical care; include the business case for bidirectional flows to and from the EHR such as for automated electronic case reporting.			①	①		X		X			X
42*	Prioritize interoperability standards for telehealth, in its broadest definition, which includes any type of remote and virtual care supported by remote devices and tele-communication.	①				X	X	X	X	X	X	X
43*	Develop and implement a model for a standard CDS Knowledge Repository that can collect, organize, and distribute clinical knowledge and CDS interventions, including information regarding associated IT standards and technical capabilities. (CDS Coordination/Support Entity)	①	②		①	X			X	X	X	X
44	Identify approaches that encourage incorporation of consumer preferences into CDS systems. (CDS Coordination/Support Entity)	①		②	①		X	X	X	X	X	
45	Work with CCHIT and other bodies to add "the ability to utilize content from standard CDS Knowledge Repositories" as criteria for certified EHRs. (CDS Coordination/Support Entity)	①	②		①				X	X		
46	Develop a better understanding of the components of CDS, e.g., rules that relate to core medical knowledge vs. those that relate to process/workflow and adaptation to a particular care setting and system platform. (CDS Coordination/Support Entity)	②			①	X			X	X		X
47	Identify priority areas for CDS knowledge/intervention development to drive improvements in key care processes and outcomes. (Vendors, Federal Government, Research Community, Professional Societies, Malpractice Insurers, and/or public-private entity with broad representation across these stakeholders)	②			①	X				X	X	X
48	Develop a business case for allocating R&D resources to CDS. (CDS Coordination/Support Entity)			②	①	X			X	X	X	X
49	Develop guideline authoring tools that encourage precision and "implementability" of decision steps and actions in practice guidelines to facilitate translation to computable rules. (CDS Coordination/Support Entity)	②	②		①				X	X		
50*	Develop plan for NHIN oversight and facilitation, including governance and development of organizational policies related to CPS.	①				X	X	X	X	X	X	X

* Denotes actions that have been identified by ONC as priorities for the AHIC Successor, Inc. to take on during its first year of operations.

4. Approaches for Operationalizing Transition

As the AHIC Successor, Inc. begins to organize its Board of Directors (BOD) and membership into committees and other structures to help fulfill its purpose and carry out the activities defined in its scope, it will need to decide how it will incorporate activities identified for transition from the current AHIC into its operations. This section suggests several approaches to facilitate transition of the current AHIC activities to the new organization within the first three months of operations.

One approach is to establish an ad hoc committee focused on facilitating transition over the first three months of its operations. Such a committee could work along side the BOD as it makes decisions regarding the organizational model and committee structures to operationalize its efforts to carry out the activities defined in its scope. This ad hoc committee might examine transition recommendations from all sources and identify priorities. It could then identify optimum working committee structure(s) to carry out the prioritized work.

Another possibility is to proceed immediately to set up some initial committees. These might be modeled on known approaches, such as the domain work groups of the original AHIC, or the “perspective” committees used by HITSP. The latter comprise the consumer, provider, and population perspectives, to which the AHIC Successor might add a research perspective. In any of these approaches, cross-cutting committees, such as one focused on confidentiality, privacy and security would be useful.

Any of these committee approaches, which might be initiated before the membership has been developed, could be facilitated by including individuals who have been working in the areas being transitioned to the new organization. They could include people from both the public and private sectors.

American Health Information Community

Healthcare Information Technology Standards Panel: Accomplishments 2006-2008

John D. Halamka, MD
Chair, HITSP

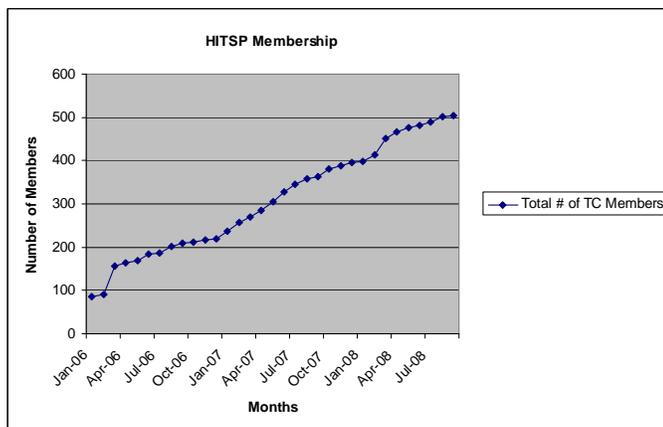
November 12, 2008

Creating a Culture

- HITSP has become the established convener for standards harmonization
- 600 participating organizations
- Silos are disappearing and conversations have brought stakeholders together to resolve their differences
- Volunteer hours continue to grow

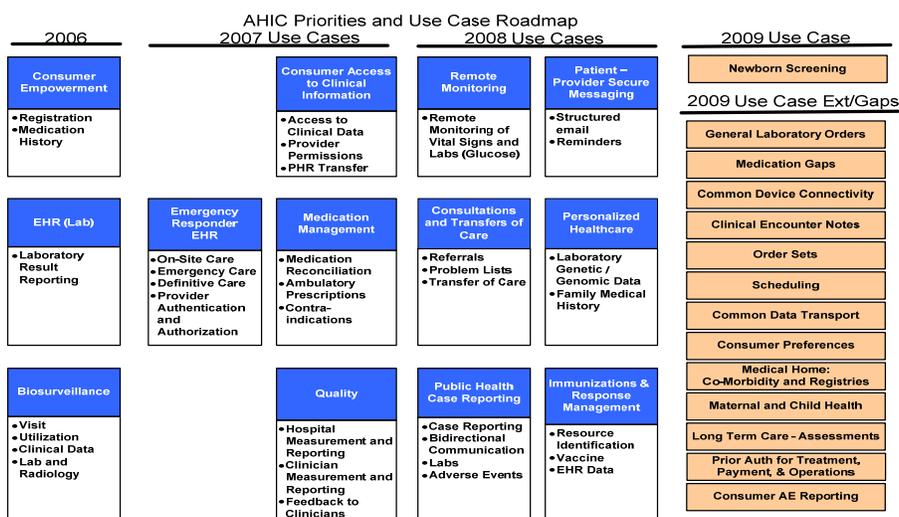
Technical Committee

Steady growth of Technical Committee participation level since January 2006



3

AHIC Priorities and Use Case Roadmap



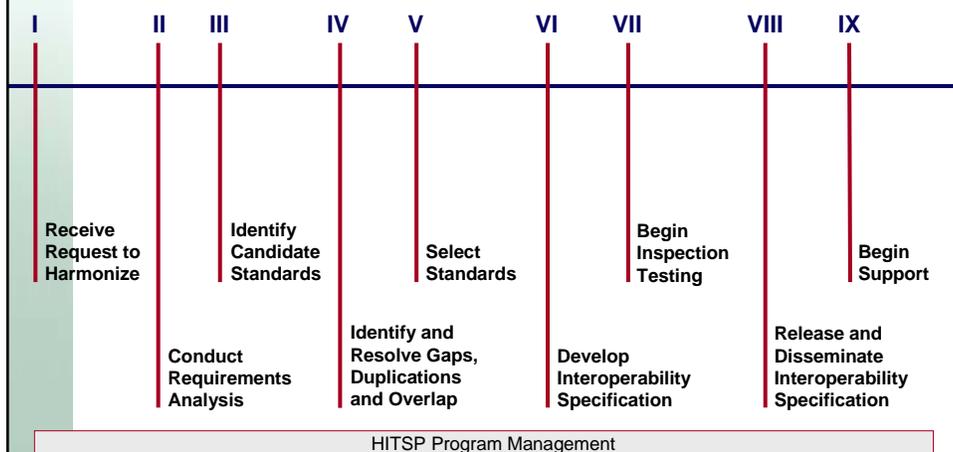
4

Organized for Rapid Delivery

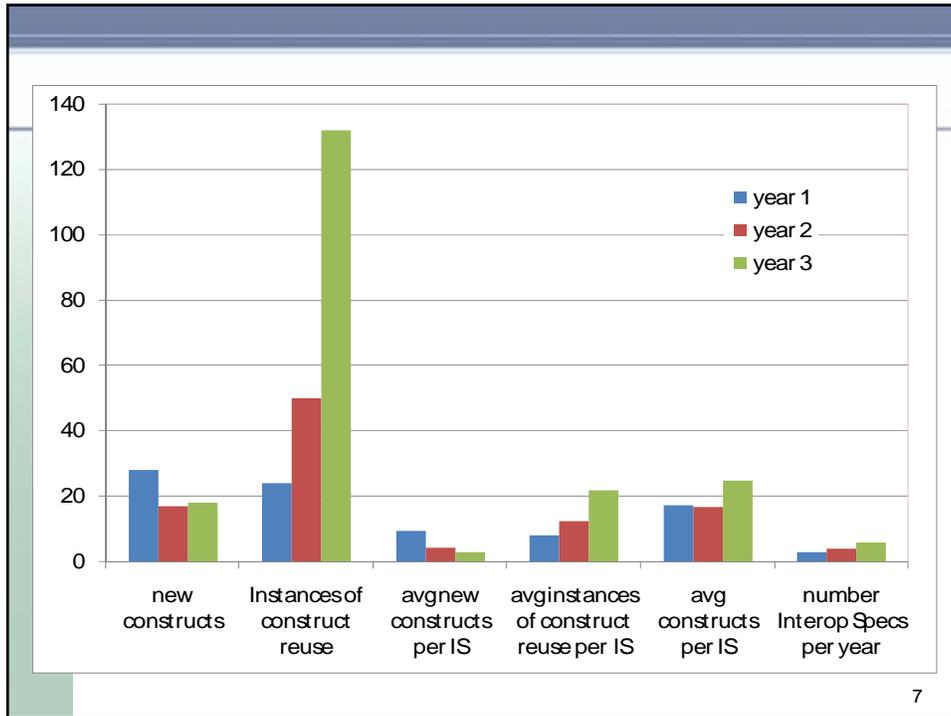
- Domain Committees select the most appropriate reusable standards using objective criteria
- Perspective Committees ensure interoperability specifications meet the needs of the use cases and are maintained
- Foundations Committee plans future innovation
- Increased Use Case throughput by 100% over three-year period
 - 3 in 2006
 - 4 in 2007
 - 6 in 2008

5

Optimized Processes



6



7

Poised for the Future

- Educating all stakeholders and accelerating adoption
- Creating testing tools and enhanced implementation guides
- An essential component of the NHIN
- Collaborating with CCHIT
- Aligned with the AHIC Successor
- Taking on additional work (Clinical Research) with AHIC guidance
- Strategy, Structure and Staffing are in place for long term success

8

American Health Information Community

Update on the Certification Commission for Healthcare Information Technology (CCHIT)

Mark Leavitt

Certification Commission for Healthcare Information Technology

November 12, 2008

Topics

- Certification Update
 - Certification Programs Launched
 - Certification Results
 - New Certification Programs Ahead
 - Sustainability
- Progress Assessment from CCHIT Perspective
 - Progression of HIT Adoption
 - Incentives for Adoption

Certification Update



Certification Programs Launched

Domain	Certification Options (Add-on to Base Domain)	Status
Ambulatory EHR		Launched May 06 Updated May 07 Updated July 08
Ambulatory	Child Health	Launched July 08
Ambulatory	Cardiovascular Medicine	Launched July 08
Inpatient EHR		Launched August 07 Updated August 08
Emergency Dept		Launched August 08
Amb+Inpt+ED	Enterprise	Launched August 08
Health Information Exchange (HIE)		Launched Oct 08

Certification Results

- > 150 EHR products certified
- > 50% of all vendors
- > 75% of EHR market
- Good selection of certified products in all segments:
 - Ambulatory care -- small, medium and large
 - Hospitals -- small, medium and large
 - Emergency Departments
 - Child Health and Cardiovascular optional certifications
- “Level playing field” with small, medium, and large companies competing to offer certified products
- Certification to the *latest standards* becoming a competitive advantage

5

Certification Programs Ahead

Domain	Status
Personal Health Records (PHR)	Under development Launch planned July 2009
Stand-alone ePrescribing	Under development Launch planned July 2009
Behavioral Health EHR	Under development Launch planned July 2010
Long Term Care EHR	Pre-development planning Probable launch 2010
Additional Domains	Environmental scan to update priorities Dec 08 – Mar 09

6

Sustainability of Health IT Certification

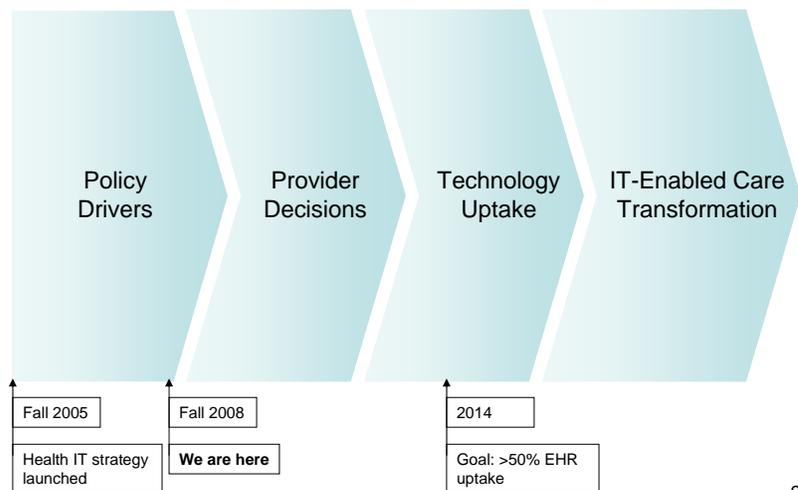
- Vitality of volunteer efforts
 - Robust supply of volunteers
 - Stakeholder diversity
- Stakeholder engagement
 - Endorsements by provider professional societies
 - Active participation in public comment process
 - Communication channels well-established

7

Progress Assessment from CCHIT Perspective



Progression of Health IT Adoption



9

Incentives for EHR Adoption

In just two years since certification was launched:

- 44 new EHR incentive programs keyed to certification
 - Federal, regional, and state programs
 - Private payers
- 54 new EHR rollouts, representing 147 hospitals, under Stark safe harbor rule
- 46,000 physicians receiving or eligible for EHR purchase assistance
- Estimated dollar value of incentives: > \$700 million

10

Increasing Provider Awareness of EHR Incentives

The screenshot displays the 'EHR Decisions' website with several key sections and callouts:

- Navigation:** HOME | ABOUT EHR DECISIONS | INCENTIVE PROGRAMS | SUBSCRIBE
- URL:** www.ehrdecisions.com/incentive-programs
- Incentive Programs:** A section titled 'Incentive Programs' by CCHIT STAFF, explaining the certification process for EHR products since 2006 and providing a 'State selector' with a map of the United States for state-by-state information.
- Physician's Guide to Certification:** A resource updated to help physicians understand the value of the latest of Ambulatory EHR criteria, explaining the benefits of certification and what more physicians need to consider when choosing EHR.
- CCHIT Incentive Index:** A resource that is a constantly updated resource, tracking incentive programs that help physicians and clinics adopt certified EHR through financial assistance and incentives.

Thank you!

Q & A

American Health Information Community

Electronic Health Records Workgroup Workgroup Summary & Recommendations

Jonathan Perlin M.D., Ph.D., MSHA, FACP, FACMI
Hospital Corporation of America

Karen Bell, M.D., MS
Office of the National Coordinator

November 12, 2008

Electronic Health Records Workgroup Members

Co-Chair:

- Lillie Smith Gelinis, RN, MSN, FAAN
- Jonathan Perlin, M.D., Ph.D., MSHA, FACP, FACMI

VHA Inc.
HCA, Inc.

ONC Director:

- Karen Bell, M.D., MS

DHHS/ONC

Members:

- Bonnie Anton, RN, MN
- Carolyn Clancy, M.D.
- LTC Nhan Do, M.D., MS, FACP
- Peter L. Elkin, M.D., MACP, FACMI
- Linda Fischetti, RN, MS
- COL Bart Harmon, M.D., M.P.H.,
- Richard W. Hays, CAE
- John Houston, J.D.
- Robert Juhasz, D.O., FACOI
- Charles Kahn, M.P.H
- Mark Lewis, MBA
- George Lynn
- Alan Mertz
- Blackford Middleton, M.D., MPH, MSc
- Jack Price
- Pam Pure
- Robert Smith, M.D.
- Barry Straube, M.D.
- John Tooker, M.D., MBA, FACP
- Robert Wears, M.D., MS

University of Pittsburgh Medical Center
HHS/AHRQ
Department of Defense
Mount Sinai School of Medicine
Veterans Health Administration
Department of Defense
American College of Cardiology
NCVHS
American Osteopathic Association
Federation of American Hospitals
EMC Corporation
American Hospital Association
American Clinical Lab Association
Partners Healthcare System
HIMSS Analytics
McKesson
Veterans Health Administration
HHS/CMS
American College of Physicians
University of Florida Health Center

ONC Workgroup Lead:

- CDR Alicia A. Morton, MS, RN-BC

DHHS/ONC

Electronic Health Records Workgroup

- VISION:
A health delivery system that can offer safe, effective, efficient, timely, equitable, patient-centric, coordinated care to its patients by virtue of its ability to share health data and information seamlessly among all of its providers and with patients through use of state of the art, interoperable EHRs.
- BROAD CHARGE:
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.

3

EHR Workgroup: History

- **Active: January 31, 2006—November 2008**
- **25 public meetings**
- **85 public testimonies**
- **44 recommendations**

4

EHR Workgroup: Key Issues/Needs

Privacy & Security

- Privacy policies, principles, and protections; standards to enable the exchange of health related data using adequate security protections for accurate patient identification, authorization for those generating and using the information, and authentication of individuals permitted access
- Clear and accepted guidelines for disclosure, particularly for secondary purposes, of health information

Technology

- Well tested interoperable vocabulary, messaging and implementation standards for clinical care which are incorporated into the EHR certification process
- Technological progress towards improved functionality, usability and interoperability

Financial / Business Case

- A financial/business model that engages and brings value to multiple stakeholders while sustaining adoption, implementation and maintenance of EHRs in multiple provider settings

5

Key Issues/Needs (cont.)

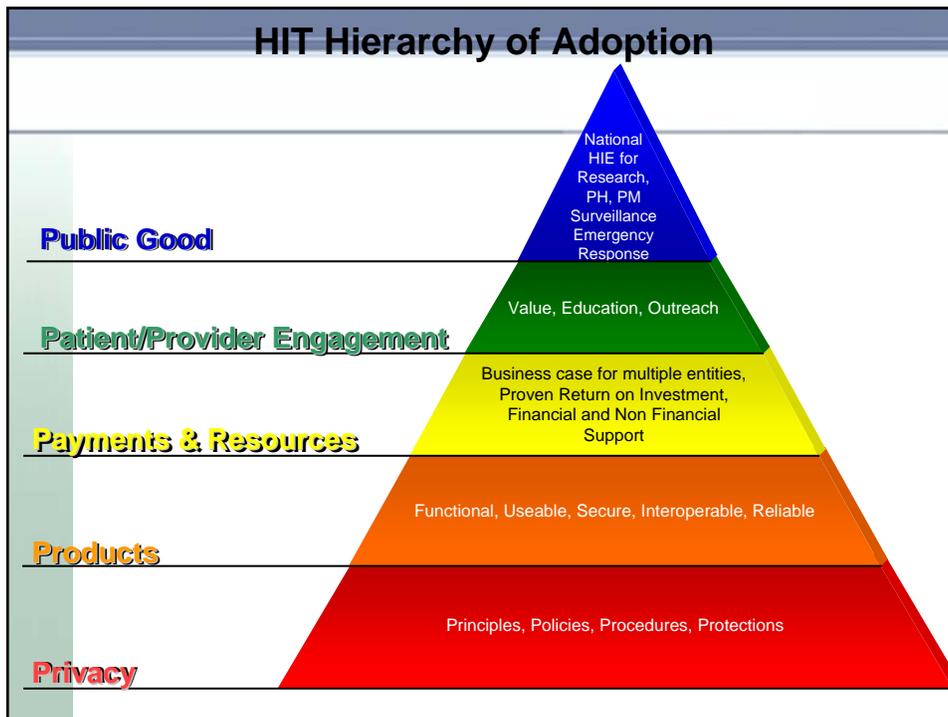
Organizational Issues

- Creation of a well trained workforce to develop, implement and/or use HIT effectively
- Workflow changes to support safer, more effective, efficient, timely and patient-centric care for both the professional workforce and patient populations in an EHR/ PHR enabled environment

Legal/ Regulatory Concerns

- Review of both Federal and state statutes and regulations to address those that impede appropriate and authorized sharing of information
- Mitigation of medical/ legal liability from accessing and maintaining large amounts of clinical information, beyond that of the “standard” medical documentation that constitutes today’s legal medical record

6



EHR Workgroup: Key Recommendations/Accomplishments

Privacy & Security

- A Confidentiality, Privacy and Security cross-cutting AHIC workgroup was formed. *(Rec. 4.0 May 2006)*

Technology/ Product

- The HITSP EHR-Laboratory Results Reporting Interoperability Specification (version 2.1) and the CCD were recognized by the Secretary in January 2008. *(Rec. 2.0 May 2006)*
- Executive Order 13410: ONC is working with all agencies that contract for health care services on behalf of the federal government to assure consistent language in health plan contracts. *(Rec. 2.1 & 2.2 May 2006)*
- The Emergency Responder-EHR use case was developed and finalized & harmonized HITSP standards were accepted in January 2008, *(Rec. 1.0 Aug 2006)*

8

Key Recommendations/Accomplishments (cont.)

Financial/ Business Case/ Payments

- CMS launched the EHR demonstration project. (Rec. 1.0, 1.1 & 1.2 June 2007)
- ONC has been collaborating with the malpractice insurance industry & CCHIT to encourage premium reductions for those physicians who adopt CCHIT certified EHRs. (Rec. 3.0 & 3.1 April 2007)
- At the request of the AHIC, the EHR Workgroup developed recommendations that would give the Secretary of HHS the authority to incent and subsequently mandate use of certified e-prescribing technologies when caring for Medicare beneficiaries. (Recommendations from Nov 2007)

Organizational Issues/ Provider and Patient Engagement

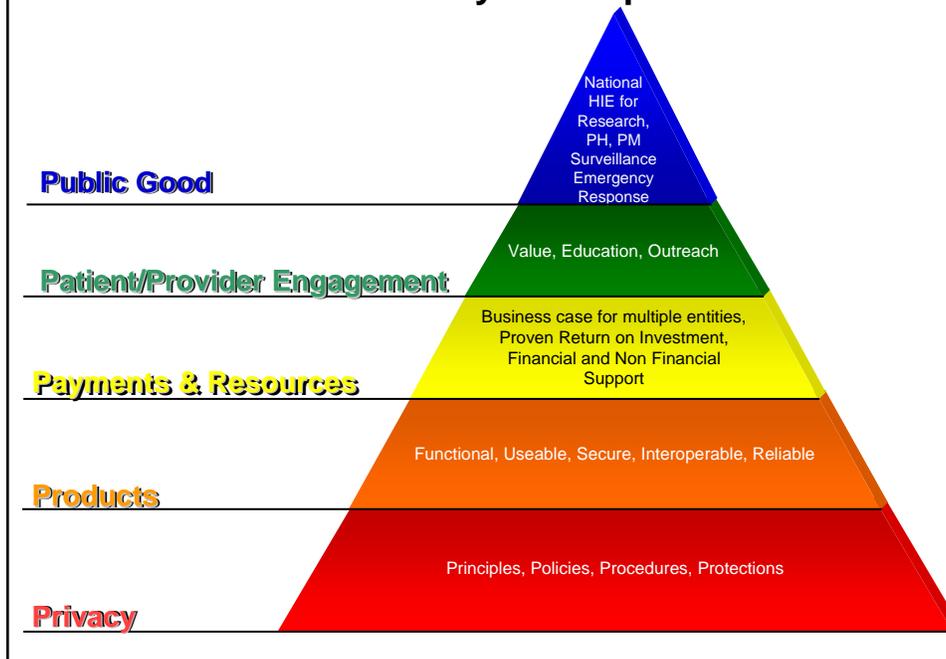
- Active discussions and planning for continued support for and additional development of DOQ-IT University are underway. (Rec. 2.0 April 2007)
- All Workforce recommendations in progress (1.0-8.0 Jan 2008)

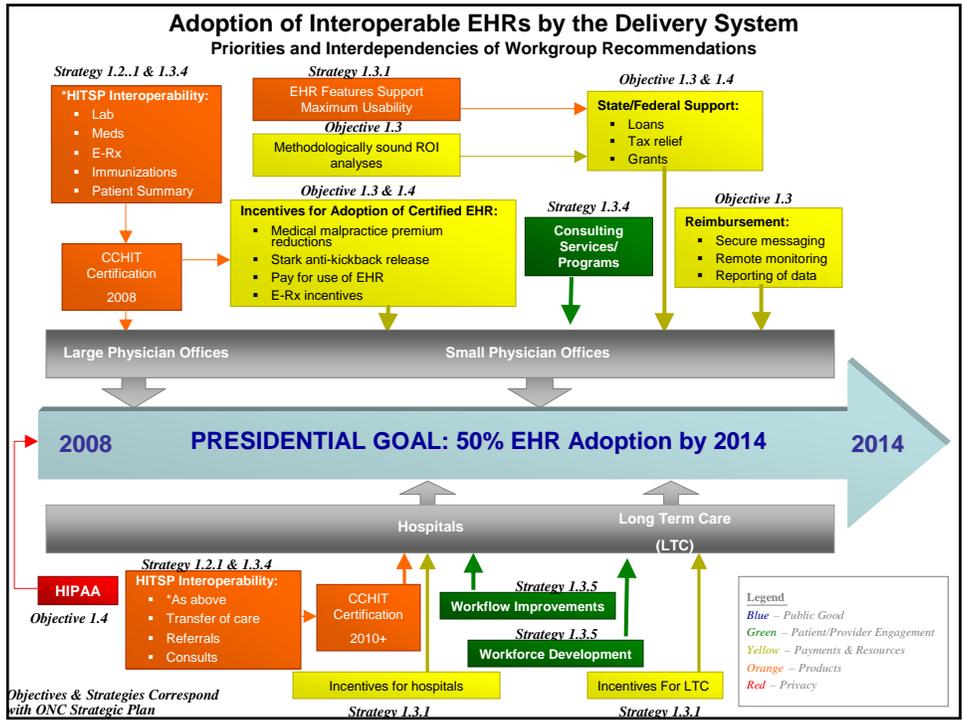
Legal/ Regulatory Concerns

- ONC and CMS continue to work on CLIA/ HIPAA issues. (Rec. 3.0 May 2006)
- ONC has engaged NGA on state-level issues relative to CLIA (Rec. 3.1 May 2006).
- CCHIT continues to develop criteria that will mitigate legal risk for clinicians (Rec. 3.0 April 2007)

9

HIT Hierarchy of Adoption





Department of Health & Human Services
Office of the National Coordinator for Health Information Technology

Electronic Health Records Workgroup

Future Work & New Recommendations

Future Work

Technology:

- Develop a strategy to “grow and maintain” standardized coding and classification systems and standard terminologies/ ontology's for adoption and uniform use in EHRs
- Align functionality, design principles, and usability of EHRs with best workflow and use practices within care delivery settings to improve safety, quality & efficiency
- Ensure adequate standards and supporting technology for eRx, including CDS
- Continued certification of EHRs and other HIT technologies such as eRx, PHRs, etc
- Develop an overarching strategy of how EHR adoption aligns with other types of health information technologies (PHR, RHIO, NHIN, ...)

Financial/ Business Case:

- Development of a standard set of core metrics and methods for assessing improved quality and cost savings associated with HIT in various health care settings and to various stakeholders
- Develop the business case and financial incentives for EHR adoption and use for multiple settings
- Focus on gap between small care delivery units and larger organizations

Organizational Issues

- Develop support networks for the adoption, implementation and use of EHRs tailored to specific care settings
- Develop HIT support network for consumers and patients

Other:

- Develop a suite of recommendations to encourage/support hospital HIT adoption
- Form group to coordinate and champion adoption of eRx

13

Electronic Health Records Workgroup Recommendations

Recommendation 1.0: HHS should commission an expert panel to investigate and clarify documentation and data required by regulatory, licensing, accrediting, quality reporting, and payer entities.

Recommendation 1.1: The expert panel should determine how these requirements can be most efficiently met using HIT/EHRs without imposing undue burden on clinicians already documenting information for clinical care purposes.

14

Electronic Health Records Workgroup Recommendations

Recommendation 1.2: HHS should support a national effort to create standardized and structured templates to address these requirements in order to reduce redundancy across the U.S. healthcare system.

Recommendation 1.3: HHS should make available standardized and structured templates that can be used for regulatory, licensing, accrediting, quality reporting, and payment purposes.

15

Electronic Health Records Workgroup Recommendations

Recommendation 2.0: HHS should establish and maintain a national repository to house structured templates, based on evidence based practice where applicable, which have already been developed and implemented for clinical purposes by multiple organizations. This national repository should also be responsible for the development and implementation of a mechanism to support collaboration and development of new standardized, structured templates for clinical care purposes.

16

Electronic Health Records Workgroup Recommendations

Recommendation 3.0: HHS should identify, develop, and make available, a standardized methodology for measuring both the direct and the indirect costs of EHR adoption across various types of hospital settings.

17

Electronic Health Records Workgroup

Action Requested

- The EHR Workgroup recommends that the AHIC endorse and submit these recommendations to the Secretary for HHS consideration.

Accept

Table

Reject

18

November 12, 2008

The Honorable Michael O. Leavitt
Chairman
American Health Information Community
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Chairman:

The Electronic Health Records (EHR) Workgroup was formed on January 17, 2006, to address both the broad and specific charges formulated by the American Health Information Community (AHIC):

Broad Charge for the EHR Workgroup: Make recommendations to the Community on ways to achieve widespread adoption of certified Electronic Health Records (EHRs), minimizing gaps in adoption among providers.

Specific Charge for the EHR Workgroup: 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 are deployed for clinical care by authorized parties.

For the past year, the EHR Workgroup has addressed the broad charge, focusing on widespread adoption of certified EHRs in the inpatient setting. Throughout their deliberations, the EHR Workgroup continued to structure its work, consistent with previous efforts, in the key areas of:

1. Privacy and Security
2. Technology
3. Financial/ Business Case
4. Organizational Issues
5. Legal/ Regulatory Concerns

This final EHR workgroup recommendation letter addresses the specific needs for the adoption of health information technology (HIT) in the acute care setting.

BACKGROUND AND DISCUSSION

During the recent September 10, 2008, EHR Workgroup meeting, a panel of experts provided testimony on their experience with the implementation of EHRs, particularly, acute care documentation in the inpatient setting. The panel of invited experts consisted of:

- Bonnie Anton, RN, MN, Electronic Order Set Coordinator, University of Pittsburgh Medical Center
- Daphne Bascom, M.D., Managing Director, e-Cleveland Clinic
- Craig Joseph, M.D., Physician - Clinical Informatics, Epic

- Christoph U. Lehmann, M.D., Director, Clinical Information Technology, Johns Hopkins University
- Deb Rislow, Chief Information Officer, Gundersen Lutheran Health System
- James M. Walker, M.D., Chief Health Information Officer, Geisinger Health System
- David Whiles, Director, Information Systems & Margaret Robinson, RN, Vice President Patient Care Services, Midland Memorial Hospital

The following are several key themes that emerged from their testimony:

Vision and Commitment

- Enthusiastic support by the CEO, other top leaders and physician champions for developing and implementing an EHR system is critical.
- Any EHR project should be conceived of in terms of process transformation. Technology should be seen as the means to an end (e.g., improving patient care, improving the quality of care, enhancing operational efficiency, improving accuracy in billing, creating new knowledge), not the goal.
- Leaders should not underestimate the forces that maintain the status quo. In planning, leaders should take into account the fact that people experience change differently which affects personal adoption rates.
- There are both direct and indirect costs (hardware, software, facilities changes, training, workflow, incentives for training) associated with the implementation and use of EHR systems in hospitals.
- Across a wide range of hospital size, some with more modest resources than others, costs were not a major obstacle to the implementation of an EHR system. This finding is counter to the popular belief that cost is a significant barrier.

Design

- Assure broad involvement by all user groups (e.g., physicians, nurses, and support staff) in the selection and design of the EHR system.
- Establish a clear project structure and goals at the outset.
- Start the design of tools with reports needed to meet end user needs, such as recording clinical findings and planning care, supporting clinical decision making, communicating with other members of the clinical team, supporting billing and payer requirements, accumulating quality data and providing a defensive tool against lawsuits.
- Conceptualize any clinical document up front before spending a lot of time and energy building it in the system. Develop a mock up and obtain broad approval prior to implementation.
- Get significant input before creating templates. Physicians and other clinicians often resist efforts to standardize and structure data collection because they feel they “lose the patient story” with templates.
- Eliminate redundancy. Use a granular data structure that allows data (e.g., vital signs, allergies, medications, past medical history) to be pulled from previously created documents and modified for reuse.

Implementation

- Mandate or incent use of the EHR system to minimize the frustration of working in a hybrid environment (paper and electronic).
- Provide training and ongoing support for staff before, during, and after the EHR system goes live.
- Recognize that the time commitment needed to learn a new EHR system and perform documentation is daunting. Incentives for clinicians may be needed to motivate them to learn and use the system.
- Some clinicians rerecord information available elsewhere in the patient's EHR because they are concerned about satisfying documentation requirements, a practice that leads to "note bloat".
- All members of the care team (e.g., doctors, nurses, respiratory therapists, social workers) must participate in the documentation process, so that the final document is a product of the team.
- Monitor progress and make changes in the EHR system as needed. Have frequent and realistic discussions about the impact of changes. Use strategies such as an online suggestion box to facilitate staff input on system improvements, weekly issues meetings to discuss and prioritize suggestions, and weekly update emails to notify staff of any changes.

RECOMMENDATIONS

Recommendation 1.0: HHS should commission an expert panel to investigate and clarify documentation and data required by regulatory, licensing, accrediting, quality reporting, and payer entities

- **Recommendation 1.1: The expert panel should determine how these requirements can be most efficiently met using HIT/EHRs without imposing undue burden on clinicians already documenting information for clinical care purposes.**
- **Recommendation 1.2: HHS should support a national effort to create standardized and structured templates to address these requirements in order to reduce redundancy across the U.S. healthcare system.**
- **Recommendation 1.3: HHS should make available standardized and structured templates that can be used for regulatory, licensing, accrediting, quality reporting, and payment purposes.**

Discussion: The EHR WG heard testimony and had considerable discussion regarding the numerous documentation requirements put forth by groups such as CMS, The Joint Commission, The Healthcare Facilities Accreditation Program, private insurance payers, and other organizations requiring patient care information and data to meet quality, patient safety, reimbursement, and legal/ regulatory criteria.

Healthcare organizations and HIT vendors find these requirements confusing, duplicative, and a hindrance for adoption of electronically enabled acute care documentation because of:

- The administrative burden they impose to achieve compliance
- The source of potential billing errors due to inadequate documentation and coding, leading to subsequent revenue loss
- The lack of uniform EHR implementation due to the need for multiple specific, unaligned mandates.

The EHR WG felt strongly that an expert panel should be convened to discuss and define the most efficient approaches to meet these external documentation requirements. At a minimum, the expert panel should consist of representatives from CMS (including Quality Improvement Organizations), The Joint Commission, The Healthcare Facilities Accreditation Program, private payers, professional licensing boards, HIT/EHR vendors, large hospital systems, academic medical centers, large independent hospitals, small community hospitals, informaticists, and clinicians.

Recommendation 2.0: HHS should establish and maintain a national repository to house structured templates, based on evidence based practice where applicable, which have already been developed and implemented for clinical purposes by multiple organizations. This national repository should also be responsible for the development and implementation of a mechanism to support collaboration and development of new standardized, structured templates for clinical care purposes.

Discussion: The EHR WG heard considerable testimony regarding the numerous manpower hours spent constructing structured templates for acute care documentation that meet the needs of clinicians, legal and financial entities, while utilizing evidence based practice guidelines and Clinical Decision Support tools.

Considering there is no national repository or sharing effort for these resources, there is enormous redundancy and wasted assets, as all organizations develop their own templates in this parallel, duplicative effort. Establishment of a national, structured documentation clearinghouse would greatly diminish the cost and inefficiency that is currently plaguing the HIT/EHR adopters, while having the added benefit of providing up to date records as well as best practices that have been uniformly implemented nationwide.

Recommendation 3.0: HHS should identify, develop, and make available, a standardized methodology for measuring both the direct and the indirect costs of EHR adoption across various types of hospital settings.

Discussion: The EHR WG heard testimony that the actual cost of software and hardware is very small, about 20% of the amount of the cost of EHR adoption. The majority of the costs include other direct, and MANY indirect costs, which are significant. These high

related costs pose significant barriers and challenges for those hospitals wanting to adopt EHRs.

In addition, there was discussion related to the diversion of nursing expertise away from clinical care in order to meet administrative documentation requirements. This scenario is also costly, as it takes nurses away from the bedside at a time of the current nursing shortage and the expense impact to the hospital as well as the U.S. healthcare system overall is not well understood.

Presently, there is no accurate, well accepted method to measure these and other numerous indirect costs, many of which have not been fully illuminated. As we focus on the benefits, business case and standardized methods for measuring adoption, we should also fully explore both the related direct and indirect costs. The true expense related to health information technology adoption in the hospital setting must be fully understood to make clear both the value and business case to multiple stakeholders.

Thank you for the opportunity to serve for the past three years with this outstanding workgroup. It has been our privilege to lead such a talented, diverse group whose members' exhibit commitment and dedication to advancing the nation's health information technology goals. Our work now concluded, we respectfully submit these final electronic health record recommendations and look forward to discussing them with you and the members of the American Health Information Community.

Sincerely yours,

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Co-chair, Electronic Health
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**ELECTRONIC HEALTH RECORDS WORKGROUP
SUMMARY AND FINAL REPORT
January 2006 – November 2008**

November 12, 2008

The Honorable Michael O. Leavitt
Chairman
American Health Information Community
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Chairman:

To address the needs of clinicians and consumers, the American Health Information Community (the Community) recommended on January 17th, 2006, the formation of a Workgroup on Electronic Health Records (EHR). The Community charged the EHR Workgroup with the following:

Broad Charge for the EHR Workgroup: Make recommendations to the Community on ways to achieve widespread adoption of certified EHRs, minimizing gaps in adoption among providers.

Specific Charge for the EHR Workgroup: 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 are deployed for clinical care by authorized parties.

Over the past almost three years, the EHR Workgroup has heard multiple public testimonies, discussed all relevant issues, and made recommendations to advance the charges stated above. As the Department of Health and Human Services (HHS) prepares to transition the initial American Health Information Community to its successor, the EHR Workgroup has prepared the attached summary of its deliberations, recommendations and their status, and opportunities for future work.

The WG wishes to express its gratitude for the opportunity to bring the vision of person centric health closer to reality through use of secure, reliable health information technologies. We hope that this summary will prove useful to those who will continue the outstanding effort that commenced under your leadership.

Sincerely yours,

/s/

Jonathan B. Perlin, M.D., Ph.D.,
FACP, MSHA, FACMI
Co-chair, Electronic Health
Records Workgroup

Sincerely yours,

/s/

Lillee Smith Gelinias, R.N., M.S.N., FAAN
Co-chair, Electronic Health
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1 INTRODUCTION

1.1 VISION

The crystal ball of the true health system visionary depicts a time when all types of health related data and information exist electronically and can be reliably and securely accessed by any number of authorized parties and entities to improve the health of an individual, a specific population, or the US at large. The Electronic Health Records (EHR) Workgroup envisions a critical milestone towards that ultimate goal: a delivery system that can offer coordinated care to its patients by virtue of its ability to share health data and information seamlessly, among all of its providers and with patients, through use of state of the art, interoperable, EHRs, which support the aims of the Institute of Medicine's characterization of high quality: care that is safe, effective, efficient, timely, equitable, and patient-centered.

Inherent in the workgroup's vision is the recognition that EHRs embody specific attributes: they are interoperable with each other, controlled by the providers, and can incorporate interoperable data elements generated by patients and remote devices that can record and transmit clinical data. In addition, this vision assumes widespread adoption of these interoperable EHRs among the majority of providers (physicians, a myriad of other clinicians, hospitals, and post acute care settings) as well as supported by ancillary services (labs, pharmacies, health plans, etc.)

While technical solutions must and are being developed with respect to interoperability, usability, functionality, and security of EHRs; multiple other barriers and enablers must be considered: confidentiality and privacy, the business case for provider purchase and adoption of EHRs, organizational issues such as workflows and workforce, and legal/regulatory concerns. Without addressing these critical areas, a patient focused care delivery system will not be possible.

1.2 WORKGROUP CHARGES

In order to realize the vision of a patient-centered health care delivery system supported by electronic access to all relevant health information, the EHR Workgroup received both a broad and specific charge from the American Health Information Community (AHIC):

1.2.1 BROAD CHARGE FOR THE WORKGROUP

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

1.2.2 SPECIFIC CHARGE FOR THE WORKGROUP

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 are deployed for clinical care by authorized parties.

In order to meet these charges, EHR Workgroup heard public testimony from 85 presenters, deliberated recommendations through 25 public meetings, and formally presented 44 recommendations to the AHIC. (*See Appendix A for a complete list of workgroup recommendations and AHIC decisions; See Appendix B for a complete list of public testimony*).

2 SPECIFIC CHARGE ACTIVITIES

The Workgroup first focused on the specific charge and explored a number of barriers and enablers of electronic access to current and historical laboratory results by authorized parties.

2.1 RATIONALE

Laboratory results have the unique feature of currently existing in electronic format. Nonetheless, they are generally transmitted to physician offices by fax and paper. Since these results are a component in 70 percent of clinical decisions, timely and easy access to comprehensive laboratory information is of high value to clinicians. EHRs must be able to directly receive electronic laboratory test results when requested by an authorized health care provider. The lack of easily implemented, interoperable standards is a primary barrier to this flow of critical information. Laboratory-to-practice connectivity has been an elusive goal that has frustrated clinicians and vendors seeking to implement EHR systems. Much has been blamed on the high cost of custom interfaces that are estimated at \$30,000 to \$50,000 per laboratory and up to \$20,000 per group practice office¹.

The ultimate goal is to make laboratory data available in a patient-centered model, where a patient's laboratory results data are available to ALL authorized providers of care regardless of where or when the information is generated. This would enable patients to benefit from more coordinated and comprehensive health care delivery, and it would reduce the cost associated with unnecessary duplicative tests. This patient-centered model extends availability of information beyond the existing business environment, where laboratory data results are available only to the specific physician ordering tests on a specific patient. The EHR workgroup recognized that an

¹ Walker J, Pan E, Johnston D, Adler-Milstein J, Bates DW, Middleton B. *The value of health care information exchange and interoperability*. Health Affairs Web Exclusive. Available at: <http://content.healthaffairs.org/cgi/content/full/hlthaff.w5.10/DC1>. Accessed November 3, 2008.

evolutionary path from the current provider-centric model (from one laboratory directly to one clinician) to the patient-centered model (data flow from multiple sources to multiple recipients through an intermediary) requires the adoption and use of data standards that allow more efficient flow of information. This will enable the suppliers and users of electronic laboratory results data to promote interoperability and lower costs of specialized interfaces to meet the needs of the current environment, while adopting the tools and technologies to support the future patient-centric model as these tools and technologies are developed and implemented.

2.2 WORKGROUP DELIBERATIONS

The Workgroup's deliberations highlighted a number of key issues with respect to the specific charge of enabling clinician access to interoperable laboratory results. These deliberations and any subsequent recommendations were structured according to five key areas, which also provided the framework for addressing the broad charge.

2.2.1 PRIVACY & SECURITY

The exchange of laboratory results data must incorporate adequate security and privacy protections as well as accurate patient identification, authentication and authorization processes for those generating and using the information.

2.2.2 TECHNOLOGY

The lack of easily implemented, usable standards is a primary barrier to laboratory results data exchange. There exists an urgent need for endorsed, adopted, and interoperable vocabulary, messaging and implementation standards that can be applied to enable the exchange of laboratory results data. These standards, once available, need to be incorporated in the EHR certification process.

2.2.3 FINANCIAL / BUSINESS CASE

The business case and incentives for adoption of interoperable technologies must be aligned among the many stakeholders benefiting from the widespread implementation and use of these products and services.

2.2.4 ORGANIZATIONAL ISSUES

Historical laboratory data must be available to all authorized providers of care in a patient-centered model, care regardless of where or when the information was generated. This model would enable more coordinated care and reduce many unnecessary and duplicative tests. This

will require changes in provider workflows and attention to documentation of business relationships and patient preferences.

2.2.5 LEGAL/ REGULATORY CONCERNS

Access to historical lab test results will require discovery and addressing of the potential barriers posed by the Clinical Laboratory Improvement Amendments of 1988 (CLIA) and Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations that may hinder electronic laboratory results data exchange in a patient-focused manner, particularly in States that have more stringent privacy laws.

2.3 KEY SPECIFIC CHARGE RECOMMENDATIONS AND ACCOMPLISHMENTS

The most notable accomplishments stemming from the workgroup's recommendations with respect to its specific charge are highlighted below. *(See Appendix A for a complete list of workgroup recommendations and AHIC decisions).*

2.3.1 PRIVACY & SECURITY

A Confidentiality, Privacy and Security cross-cutting AHIC workgroup was formed to analyze the confidentiality and security policy issues relevant to all the Community charges. The recommendations developed by this group should establish an initial policy framework and address issues such as:

- Methods of patient identification.
- Methods of authentication.
- Mechanisms to ensure data integrity.
- Methods for controlling access to personal health information.
- Policies for breaches of personal health information confidentiality.
- Guidelines and processes to determine appropriate secondary uses of data.
- A scope of work for a long-term independent advisory body on privacy and security policies. *(Rec 4.0 May 2006)*

2.3.2 TECHNOLOGY

- The HITSP EHR-Laboratory Results Reporting Interoperability Specification (version 1.2) was accepted officially by the Secretary in December 2006. In January 2008, these achieved full HHS recognition status as version 2.1, which incorporated minor and technical updates. Also, CCHIT and HITSP have formed a joint workgroup to plan for the incorporation of HITSP Interoperability Specifications in CCHIT interoperability certification criteria. *(Rec. 2.0 May 2006)*
- President issued Executive Order 13410 to ensure that all applicable Federal agencies and departments incorporate the harmonized interoperability standards recognized by the HHS

Secretary. ONC is working with all agencies that contract for health care services on behalf of the federal government to assure consistent language in health plan contracts. (*Rec. 2.1 & 2.2 May 2006*)

2.3.3 LEGAL/ REGULATORY CONCERNS

- ONC and Centers for Medicare and Medicaid Services (CMS) continue to identify the possible models for current and historical lab results exchange to determine whether and which would require CLIA/ HIPAA guidance. (*Rec 3.0 May 2006*)
- ONC has engaged the National Governors Association on state-level issues relative to CLIA (*Rec 3.1 May 2006*).

2.4 SPECIFIC CHARGE RECOMMENDATIONS: “IN-PROGRESS” AND “TABLED”

Several recommendations were tabled if they were likely to be implemented in the private sector and/or outside of the jurisdiction of the Secretary of HHS.

2.4.1 FINANCIAL/ BUSINESS CASE

- **Tabled:** May 2006 “Recommendation 5.0: HHS, in collaboration with all key stakeholders, should both assess the value proposition and develop the business case for current and historical laboratory results data sharing across all adoption models, considering the unique needs and alignment of incentives for all stakeholders.”
- **Tabled:** May 2006 “Recommendation 6.0: By March 31, 2007, AHRQ, in collaboration with the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare & Medicaid Services (CMS), should develop a proposed study methodology to measure the extent and effectiveness of the adoption of the first stage of HITSP standards, as well as the adoption and utilization of aggregated patient-centric data as they become available.”

2.4.2 ORGANIZATIONAL / CULTURAL

- **Tabled:** May 2006 “Recommendation 6.1: By December 31, 2007, AHRQ, in collaboration with the CDC and CMS, should research best practices in the implementation and utilization of patient-centric laboratory data stores and how to implement this knowledge.”

3 BROAD CHARGE ACTIVITIES

3.1 RATIONALE

Widespread adoption of certified Electronic Health Records is a goal of the President, the American Health Information Community, and this workgroup. Broad, effective use of EHRs, has the potential to positively influence both the quality and cost of health care for the Nation. The EHR can improve quality by presenting clinical information and comprehensive patient data to the clinician at the point of care. This allows for more informed decisions in a shorter time frame. Additionally, the cost of care can be decreased by streamlining data collection, decreasing the likelihood and associated cost of medical errors, and by reducing duplicative or unnecessary testing and procedures.

Despite these benefits, the Nation has been slow to adopt EHRs. Recent data from the HIT Adoption Initiative, a survey of ambulatory physicians, found that overall physician adoption was approximately 17% for EHRs with basic functionality, with a subset of only 4% for fully functional EHRs.² Hospital adoption in the non-public sector is also slow with 12% partial adoption of EHRs and less than 2% with fully implemented EHR systems in 2008 (*AHIC, Nov 2008*), though most hospitals have implemented some HIT functions, such as access to laboratory results or computerized physician order entry.

3.2 WORKGROUP DELIBERATIONS

The Workgroup/s deliberations highlighted a number of key issues with respect to the broad charge of widespread adoption of certified EHRs. Their focus primarily centered on adoption for primary care purposes by physician offices and hospitals. In order to achieve widespread adoption of EHR's as a key intermediate step towards a fully interoperable, patient-centered healthcare system, the Workgroup organized its deliberations according to the framework cited above.

3.2.1 PRIVACY & SECURITY

There is need for clear and accepted guidelines for disclosure of electronic personal health information, particularly for secondary purposes. *These issues were referred to the cross-cutting CPS workgroup formed for this purpose.*

² C. Desroches et. al., New England Journal of Medicine. Volume 359:50-60 July 3, 2008.

3.2.2 TECHNOLOGY

EHR products must meet the needs of the clinician for easy access to critical health information. Technological progress towards improved functionality, usability and interoperability are paramount. Discussion focused on the following three areas led to a number of supporting recommendations.

- Recommendations from the “Federal Response to Katrina Lessons Learned” report calling for widespread use of interoperable EHR systems for emergency responders were discussed and led to a recommendation for a Use Case on access to clinical information for patient care in emergency response situations.
- Interoperability of data necessary for clinical care must be a high priority for the HITSP process, with certified EHRs incorporating these HITSP interoperability specifications as they become recognized.
- Emphasis must be placed on EHR features and functionalities that increase usability and decrease administrative burden

3.2.3 FINANCIAL/BUSINESS CASE

A misaligned business case is one of the major barriers to EHR adoption. The majority of the financial benefits of EHR adoption do not go to the providers of care, yet they bear the majority of the cost. A multi-stakeholder financial/business model that can sustain clinician and hospital adoption, implementation, and maintenance of EHRs will be the major enabler of widespread adoption of interoperable EHRs. The Workgroup heard public testimony and discussed multiple ways in which this could be addressed.

- Pay-for-Performance programs that pay for structure, process, and better outcomes along the continuum of EHR adoption (such as Bridges to Excellence and Pacific Business Group/Integrated Healthcare Association) are preferred to those that reward for outcomes alone and should be more widely used to support adoption and narrow the widening adoption gap of EHR adoption in the both the public and private sectors. The federal government, through its contracts with health plans and insurers, could foster financial incentives for pay-for-use programs to incent the adoption and effective use of CCHIT certified EHRs.
- Clear, focused, easy to find documentation of health information decreases overall costs of claims paid by malpractice coverage entities. While some have therefore decreased premium rates for those physicians with specific (CCHIT certified) EHRs, this practice should spread more widely
- Incentives for e-prescribing systems that are either embedded or can interface with certified EHRs would further adoption of EHRs

3.2.4 ORGANIZATIONAL ISSUES

Change is necessary in both the professional workforce and patient populations with respect to new and different approaches to accessing and receiving care in an EHR/ PHR enabled environment. Physician offices need guidance and support as they embark upon the EHR selection, adoption and implementation process. Challenges will arise as they reorganize their workflow process, redirect their staff, and attempt to minimize disruption of patient care during the EHR implementation process. A well developed HIT workforce will be necessary to actualize widespread benefit from EHRs.

- There is an ongoing need for programs that can support clinicians as they go through the adoption process: decide to implement, what to implement, how to contract, and how to redesign office workflows to maximize the potential of interoperable EHRs.
- Workforce deficiencies should be addressed in order to assure that the development, implementation, and use of HIT by all health professionals and consumers are appropriately supported.

3.2.5 LEGAL/ REGULATORY CONCERNS

Physicians are concerned about the accuracy of information coming from other sources, responsibility for large amounts of electronic information that they had not anticipated, and the increasing demands for personal health information that they maintain for specific patients being made available for secondary purposes, not related to direct patient care (e.g. quality reporting, research, etc.). Mitigation of medical/legal liability from accessing and maintaining large amounts of clinical information, beyond that of the “standard” medical documentation that constitutes today’s legal medical record is an important enabler of widespread adoption of EHRs among clinicians.

3.3 KEY BROAD CHARGE RECOMMENDATIONS AND ACCOMPLISHMENTS

As of November 2008, the EHR Workgroup has held 25 public workgroup meetings and formally presented 44 recommendations to the AHIC. The most notable accomplishments stemming from the Workgroup’s recommendations with respect to its broad charge are highlighted below. *(See Appendix A for a complete list of workgroup recommendations and AHIC decisions)*

3.3.1 TECHNOLOGY

- The Emergency Responder-EHR use case was developed and finalized in December 2006. The HITSP ER-EHR Interoperability Specification was accepted by the AHIC in December

2007. In January 2008, it was officially accepted by the Secretary as an Interoperability Standard, with the intent to recognize it in January 2009. (*Rec. 1.0 Aug 2006*)

3.3.2 FINANCIAL / BUSINESS CASE

- CMS launched the EHR demonstration project which will provide bonuses for reporting on the use of specific functions of CCHIT certified EHRS, reporting on various process and outcome measures, and ultimately for improved outcomes. (*Rec. 1.0, 1.1 & 1.2 June 2007*)
- ONC has been collaborating with the malpractice insurance industry to encourage premium reductions for those physicians who adopt CCHIT certified EHRs. CCHIT has published several white papers on reducing malpractice risk, available at: <http://www.cchit.org/about/whitepapers/index.asp> (*Rec. 3.0 & 3.1 April 2007*)
- At the request of the AHIC, the EHR Workgroup developed recommendations that would give the Secretary of HHS the authority to incent and subsequently mandate use of certified e-prescribing technologies when caring for Medicare beneficiaries. (*Recommendations from Nov 2007*)

3.3.3 LEGAL/ REGULATORY

- The CCHIT continues to develop criteria that will mitigate legal risk for clinicians (*Rec. 3.0 April 2007*)

3.4 BROAD CHARGE RECOMMENDATIONS: “IN-PROGRESS” OR “TABLED”

3.4.1 TECHNOLOGY

- **In Progress:** November 2008: “Recommendation 1.0: HHS should commission an expert panel to investigate and clarify documentation and data required by regulatory, licensing, accrediting, quality reporting, and payer entities.”
- **In Progress:** November 2008: “Recommendation 1.1: The expert panel should determine how these requirements can be most efficiently met using HIT/EHRs without imposing undue burden on clinicians already documenting information for clinical care purposes.”
- **In Progress:** November 2008: “Recommendation 1.2: HHS should support a national effort to create standardized and structured templates to address these requirements in order to reduce redundancy across the U.S. healthcare system.”
- **In Progress:** November 2008: “Recommendation 1.3: HHS should make available standardized and structured templates that can be used for regulatory, licensing, accrediting, quality reporting, and payment purposes.”

3.4.2 FINANCIAL

- **In Progress:** November 2007: All Electronic Prescribing recommendations (1.0-8.0)
- **In Progress:** November 2008: “Recommendation 3.0: HHS should identify, develop, and make available, a standardized methodology for measuring both the direct and the indirect costs of EHR adoption across various types of hospital settings.”

3.4.3 ORGANIZATIONAL ISSUES

- **In Progress:** April 2007:“Recommendation 2.0: HHS should provide continued support to DOQ-IT University for new module development; upgrades; maintenance; and CME credit management beyond the 8th SOW funded by CMS. The program should be supported by a learning management system that is user friendly, has search functionality, and provides links to other key sites.”
- **In Progress:** January 2008:All Workforce recommendations (1.0-8.0)
- **In Progress:** November 2008: “Recommendation 2.0: HHS should establish and maintain a national repository to house structured templates, based on evidence based practice where applicable, which have already been developed and implemented for clinical purposes by multiple organizations. This national repository should also be responsible for the development and implementation of a mechanism to support collaboration and development of new standardized, structured templates for clinical care purposes.”

4 DISCUSSION

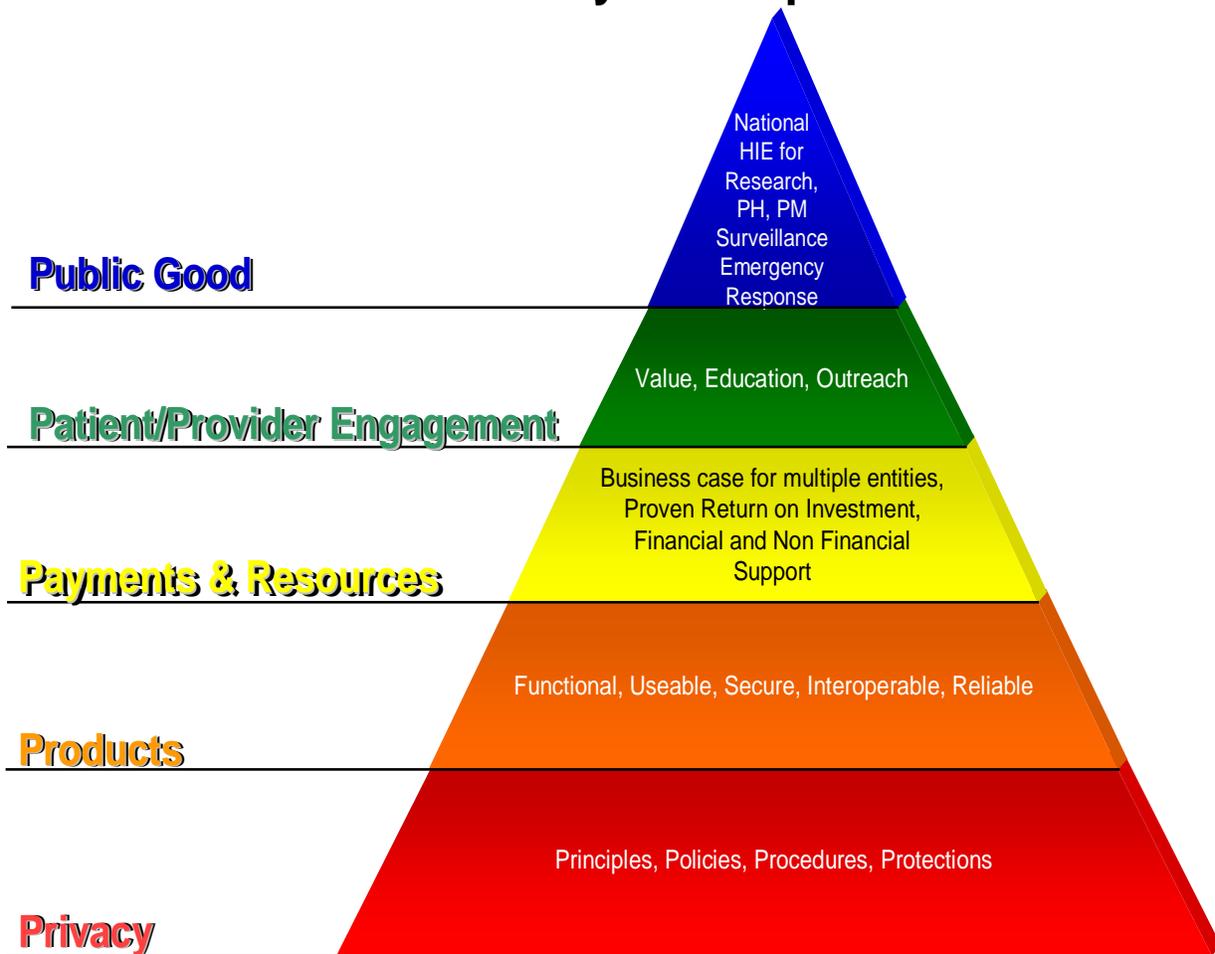
Between its formation in January, 2006 and its sunset in November of 2008, the EHR Workgroup identified the key barriers and enablers of widespread adoption of interoperable EHRs within the delivery system and made 44 recommendations on how these could be addressed. At its final two meetings, it discussed how these recommendations might be implemented in a coordinated fashion in order to take into account key priorities and interdependencies.

Using the same framework that it had adopted to deliberate recommendations, the Workgroup supported the development of a diagrammatic approach to summarizing and depicting its discussions and recommendations. The following pyramid is modeled on Maslow’s hierarchy of human needs:

- Sharing of clinical data is predicated first and foremost on trust in a solid framework of privacy policies and protections.
- Privacy policy must align with state of the art security in HIT products. HIT products must also meet other technological needs and standards in order to be of value to multiple stakeholders.
- Once privacy and products meet the needs of various constituents, necessary and appropriate financial alignment among multiple stakeholders for investment in EHR products and services is needed.

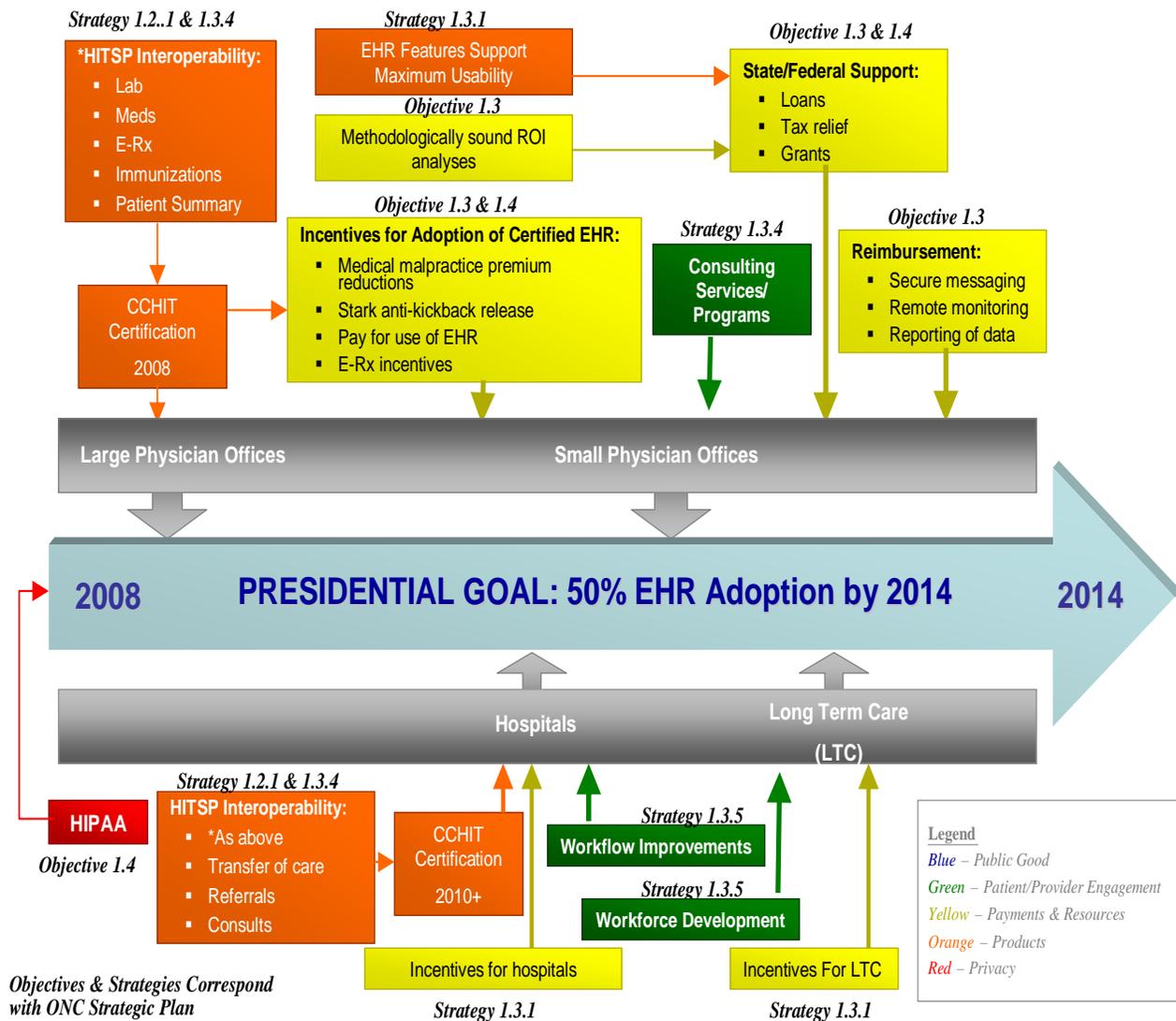
- Optimal use is as important as optimal technology, engagement of both providers and consumers are essential.
- The ability to share personal health information for use of clinical information for public health, research, quality improvement, and other aspects of improved health of our population will be realized as more widespread adoption of all forms of HIT is realized and health information exchange (HIE) becomes more widely available.

HIT Hierarchy of Adoption



This hierarchy can be the basis for developing a more strategic approach to implementation of the Workgroup’s recommendations. The following blueprint depicts a relative timeline that takes into account both priorities and interdependencies. *{The Consumer Empowerment Workgroup has developed a companion blueprint, “Interdependencies & Relationships among Essential Elements for Adoption of Personal Health Records (PHRs.)”}*

Adoption of Interoperable EHRs by the Delivery System Priorities and Interdependencies of Workgroup Recommendations



EHR adoption rates among various settings vary in 2008. Large medical groups of over 50 physicians have an EHR adoption rate of over 50%, physicians in small practices are less than 10%, with overall adoption of a *basic* EHR at 17%. Adoption rate of a fully functional EHR is only 4% nationwide among physicians.³ Hospital adoption is similarly low, 12% for a *basic* EHR system and 4% for a fully functional EHR (*AHIC, Nov 2008*). Adoption within the long term care community is even lower.

The following define in greater detail the elements depicted on the blueprint.

- **HIPAA** – While privacy policies and protections do not cover all potential users of electronic personal health information, HIPAA does govern the sharing of clinical data among clinicians for patient care purposes and payers for operational purposes.
- **HITSP Interoperability** – A number of use cases have been developed to specifically support information exchange for clinical care. The first of these have led to a set of recognized interoperability standards that will allow efficient health information exchange among providers who incorporate these standards or use certified EHRs.
- **CCHIT Certification** -- The Certification Commission for HIT has developed criteria for EHR functionality, security, and interoperability. Certified products thus are transparent regarding these important aspects of operation. As HITSP standards are recognized annually, they are incorporated into the annual CCHIT certification process, thus upgrading the degree of interoperability available to EHR users each year.
- **Incentives for Adoption of Certified EHRs** – A number of diverse incentives are currently available to clinicians in certain areas. These are likely spurring adoption in the geographic areas where they are available, though there is no comprehensive approach to supporting clinicians whose major barrier to adoption is cost.
- **EHR Features Support Maximum Usability** – How clinical information is organized and presented to EHR users determines value to the clinician who benefits from greater efficiency and to the patient who benefits from more comprehensive access to his/her information. These features are currently poorly understood. There is need for comprehensive analysis on best approaches to addressing this important aspect of EHR design and to design EHRs which include them.
- **Methodologically Sound ROI Analyses** – Given the cost of EHR purchase, implementation, and maintenance, there is need for an analytically sound and accepted approach to evaluating the return on this investment to various stakeholders.
- **Consulting Services/Programs** – The adoption process is complicated and time consuming. Without some form of support which helps physicians decide what to implement, how to negotiate a contract, efficiently implement, and redesign the practice to take optimum advantage of the EHR, adoption rates will continue to lag and desired outcomes will not be achieved. This was demonstrated in Denmark, where these types of services were key towards achieving widespread adoption of EHRs throughout the country.
- **State/Federal Support** – Without some form of consistent and universally available financial support, it is unlikely that we will achieve our goal of most clinicians using interoperable EHRs by 2014. This support, however it may be structured, must be predicated on the availability of certified EHRs that include the usability features described above, widespread

³ C. Desroches et. al., New England Journal of Medicine. Volume 359:50-60 July 3, 2008

availability of consulting services and program, and a sound methodology for determining cost savings to the program.

- **Reimbursement Reform** – HIT allows clinicians to communicate with and care for their patients wherever the latter may be. It also can make more data available for public health, research, and monitoring of quality. Reimbursement for the time and expertise expended on caring for patients in a comprehensive manner (outside of the office setting) and for time spent on reporting data that benefit the population as a whole would dramatically improve the business case for adoption of EHRs among providers.
- **Incentives for Hospitals and Long Term Care** – Adoption rates are low in both of these care settings, and the indirect costs of adoption are high: up to 80% of total. Without financial incentives, similar to those offered in the ambulatory sector, there will be limited adoption of EHRs in these settings.
- **Workflow Improvements** – Hospitals and long term care facilities integrate care from multiple types of providers around each patient. Use of an EHR will change how these providers communicate and work with one another. A better understanding of how these changes can lead to more efficient and effective care is critical to achieving those outcomes.
- **Workforce Development** – In addition to assuring that the current providers of care are positioned to use the new health information technologies that are being presented, we need a workforce that can continue to develop state of the art products and services, can support their use by all stakeholders, will conduct research, will use HIT in the public health arena, and will educate future users.

5 SUMMARY AND RECOMMENDATIONS FOR FUTURE WORK

The EHR WG first tackled its specific charge: *Make recommendations to allow access by authorized providers to historical laboratory results.* It focused on the necessary steps to assure that this information could flow using a patient-centered approach, which would allow lab results to flow from multiple sources to multiple providers. It also identified the need for harmonized interoperability standards, CLIA guidance, and the importance of aligning Federal health information systems with this initiative. Lastly, it identified areas of medical/legal vulnerability and made recommendations to mitigate.

The Broad Charge called for recommendations to advance *widespread adoption of certified EHRs.* These recommendations built on those of the specific charge, and were initially focused on small physician office practice, then on EHRs in the hospital setting. Key recommendations related to the development of a pay for performance demonstration project sponsored by CMS which included a pay for use of CCHIT certified EHRs in year one; the need for support services for the entire adoption process (particularly in small physician offices); Secretarial authority to mandate e-prescribing (and the antecedent steps that should be taken); workforce augmentation and education; and malpractice credits for use of certified EHRs.

Should all of the Workgroup's recommendations lead to action, it is likely that significant progress will be made towards reaching the President's goal of most American's having access to an Electronic Health Record. There is, however, more work to be done. The following, is

work that the Workgroup wishes to advance which they strongly feel is essential to meeting their broad charge.

5.1 TECHNOLOGY

5.1.1 DEVELOP A STRATEGY TO “GROW AND MAINTAIN” STANDARDIZED CODING AND CLASSIFICATION SYSTEMS AND STANDARD TERMINOLOGIES/ ONTOLOGY'S FOR ADOPTION AND UNIFORM USE IN EHRs

Comment: It is not enough to simply identify standards that should be used. A strategy must be developed to maintain standard terminologies and classification system. Also needed is a feedback mechanism so these continue to meet the needs of clinicians as they are uniformly implemented in EHRs/HIT.

5.1.2 ALIGN FUNCTIONALITY, DESIGN PRINCIPLES, AND USABILITY OF EHRs WITH BEST WORKFLOW AND USE PRACTICES WITHIN CARE DELIVERY SETTINGS TO IMPROVE SAFETY, QUALITY & EFFICIENCY

Comment: The WG heard considerable testimony about the workflow challenges encountered as entities adopt EHRs/ HIT. EHRs/HIT must be developed using the best design principles for usability to enhance clinician workflow and efficiency when utilizing EHRs.

5.1.3 ENSURE ADEQUATE STANDARDS AND SUPPORTING TECHNOLOGY FOR eRx, INCLUDING CDS

Comment: The WG wishes to see the continued development and maintenance of standards to enable interoperable e-prescribing, including appropriate CDS.

5.1.4 CONTINUED CERTIFICATION OF EHRs AND OTHER HIT TECHNOLOGIES SUCH AS eRx, PHRs, ETC.

Comment: The EHR WG has heard considerable testimony from the CCHIT and is an enthusiastic supporter of the effort. The WG sees considerable value in this effort as a major enabler of EHR/HIT adoption and wishes to see continued certification efforts for ambulatory and inpatient EHRs, specialty settings, e-prescribing, and PHRs.

5.1.5 DEVELOP AN OVERARCHING STRATEGY OF HOW EHR ADOPTION ALIGNS WITH OTHER TYPES OF HEALTH INFORMATION TECHNOLOGIES (PHR, RHIO, NHIN, ETC.)

Comment: Given the broad charge of widespread EHR adoption, and the numerous parallel and enabling efforts taking place, an overarching strategy of how EHR adoption interacts with these other efforts will be essential for success.

5.2 FINANCIAL/ BUSINESS CASE

5.2.1 DEVELOPMENT OF A STANDARD SET OF CORE METRICS AND METHODS FOR ASSESSING IMPROVED QUALITY AND COST SAVINGS ASSOCIATED WITH HIT IN VARIOUS HEALTH CARE SETTINGS AND TO VARIOUS STAKEHOLDERS

Comment: Presently, we lack a standardized methodology for quantifying the financial savings and quality gains per stakeholder and per setting.

5.2.2 DEVELOP THE BUSINESS CASE AND FINANCIAL INCENTIVES FOR EHR ADOPTION AND USE FOR MULTIPLE SETTINGS

Comment: Although some components of the business case for adoption have been well documented and we are seeing more financial incentives for EHR adoption in the ambulatory sector, considerable work remains to fully delineate the business case and to provide adoption incentives in the hospital, long term care, and home health settings.

5.2.3 FOCUS ON GAP BETWEEN SMALL CARE DELIVERY UNITS AND LARGER ORGANIZATIONS

Comment: Increase attention, research and the development of an action plan is needed to address the adoption gap that exists between small and large physician offices and hospitals.

5.3 ORGANIZATIONAL ISSUES

5.3.1 DEVELOP SUPPORT NETWORKS FOR THE ADOPTION, IMPLEMENTATION AND USE OF EHRs TAILORED TO SPECIFIC CARE SETTINGS

Comment: Adopters will benefit from having a venue to share experiences, lessons learned and best practices with their peers.

5.3.2 DEVELOP HIT SUPPORT NETWORK FOR CONSUMERS AND PATIENTS

Comment: As consumers and patients become engaged in utilizing HIT they will need a venue to share their experiences and gather additional information.

5.4 OTHER

5.4.1 DEVELOP A SUITE OF RECOMMENDATIONS TO ENCOURAGE/SUPPORT HOSPITAL HIT ADOPTION.

Comment: Several recommendations being advance to the AHIC on 11/12/08 provide a good starting point for encouraging & supporting HIT/EHR adoption in the hospital setting. Yet, hospital adoption also remains low and much more work remains to address the specific needs of this sector.

5.4.2 FORM GROUP TO COORDINATE AND CHAMPION ADOPTION OF eRx.

Comment: As e-prescribing becomes more widely adopted, particularly with the new CMS incentives, and given its complexity, an expert group should be established to coordinate and champion all aspects of eRx.

6 CONCLUSION

During the nearly three years the Electronic Health Records workgroup has been active; it has held 25 public meetings and received 85 formal presentations from industry experts. This public testimony, along with rich and robust workgroup discussions, led to 44 recommendations necessary to achieve the broad and specific charges (*See Appendix A for a complete list of workgroup recommendations and AHIC decisions; See Appendix B for a complete list of public testimony*).

Although the workgroup's primary focus has been the adoption of EHRs for the purposes of primary care in both the ambulatory and acute care setting, they are well aware that many specialties and settings of care also have significant barriers to EHR adoption. This Workgroup has illuminated many broad issues and made numerous recommendations that have led to significant adoption enabling efforts. Yet, much more work remains to fully address the privacy and security issues; develop interoperable products that meet the users needs; define and realign the business case; influence the culture of the health care organization; and address new legal/regulatory issues in an HIT enabled health care environment.

At its 25th and final meeting the Workgroup finalized a set of twelve activities for future work that they wish to advance that they strongly feel is essential to meeting their broad charge. This future work primarily falls in the areas of the business case for adoption, technology,

organizational issues. Unlike their focus of primary care in the ambulatory and inpatient settings, these activities broaden the focus to consumers and patients, and other settings of care.

APPENDIX A
Recommendations from the Electronic Health Records Workgroup

As of November 2008, the EHR workgroup formally submitted 44 recommendations to the AHIC. Thirty-two were accepted, six were tabled and none were rejected, *(six pending from 11/12 AHIC)*.

All EHR Workgroup recommendations were made with the focus of advancing the EHR workgroup's charges:

Broad Charge: 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 are deployed for clinical care by authorized parties.

1 MAY 2006 RECOMMENDATIONS

1.1 PROVIDER & PATIENT-CENTRIC MODELS

1.1.1 RECOMMENDATION 1.0

The U.S. Department of Health and Human Services (HHS) should take immediate steps to facilitate the adoption and use of endorsed standards and incentives needed for interoperability of lab results within the current provider-centric environment. The Office of the National Coordinator for Health Information Technology (ONC) shall work with multiple stakeholders to develop a detailed work plan to achieve patient-centric information flow of laboratory data by March 31, 2007. **AHIC decision:** *Accepted*

1.2 STANDARDS

1.2.1 RECOMMENDATION 2.0

HITSP should identify and endorse vocabulary, messaging, and implementation standards for reporting the most commonly used laboratory test results by September of 2006, so as to be included in the CCHIT interoperability criteria for March 2007 certification. HITSP should consider CLIA and HIPAA regulatory requirements as appropriate. **AHIC decision:** *Accepted*

1.2.2 RECOMMENDATION 2.1

Federal health care delivery systems (those which provide direct patient care) should develop a plan to adopt the HITSP-endorsed standards for laboratory data interoperability by December 31, 2006. **AHIC decision:** *Accepted*

1.2.3 RECOMMENDATION 2.2

Federal Agencies and Departments with health lines of business should include/incentivize the use of HITSP-approved standards in their contracting vehicles where applicable. *AHIC decision: Accepted*

1.3 CLIA/HIPAA OPTIONS

1.3.1 RECOMMENDATION 3.0

By September 30, 2006, ONC should review the possible models for the exchange of both current and historical lab information and determine which would require CLIA/HIPAA guidance, regulatory change, and/or statute change. *AHIC decision: Accepted*

1.3.2 RECOMMENDATION 3.1

Based on the findings from Recommendation 3.0, by December 31, 2006, ONC should engage the National Governors Association and other State-based organizations to resolve variations in “authorized persons” under the various State statutes, regulations, policies, and practices as a resource for clinical laboratories seeking to define access rights to electronic laboratory data. *AHIC decision: Accepted*

1.4 PRIVACY AND SECURITY

1.4.1 RECOMMENDATION 4.0

The Community should create a consumer empowerment subgroup comprised of privacy, security, clinical, and technology experts from each Community Workgroup. The subgroup should frame the privacy and security policy issues relevant to all the Community charges and solicit broad public input and testimony to identify viable options or processes to address these issues that are agreeable to all key stakeholders. The recommendations developed should establish an initial policy framework and address issues including but not limited to:

- Methods of patient identification
- Methods of authentication
- Mechanisms to ensure data integrity
- Methods for controlling access to personal health information
- Policies for breaches of personal health information confidentiality
- Guidelines and processes to determine appropriate secondary uses of data
- A scope of work for a long-term independent advisory body on privacy and security policies. *AHIC decision: Accepted*

1.5 *ADVANCING ADOPTION*

1.5.1 RECOMMENDATION 5.0

HHS, in collaboration with all key stakeholders, should both assess the value proposition and develop the business case for current and historical laboratory results data sharing across all adoption models, considering the unique needs and alignment of incentives for all stakeholders. *AHIC decision: Tabled*

1.6 *ASSESSMENT, MONITORING, AND RESEARCH*

1.6.1 RECOMMENDATION 6.0

By March 31, 2007, AHRQ, in collaboration with the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare & Medicaid Services (CMS), should develop a proposed study methodology to measure the extent and effectiveness of the adoption of the first stage of HITSP standards, as well as the adoption and utilization of aggregated patient-centric data as they become available. *AHIC decision: Tabled*

1.6.2 RECOMMENDATION 6.1

By December 31, 2007, AHRQ, in collaboration with the CDC and CMS, should research best practices in the implementation and utilization of patient-centric laboratory data stores and how to implement this knowledge. *AHIC decision: Tabled*

2 AUGUST 2006 RECOMMENDATIONS

2.1 *EMERGENCY RESPONDER USE CASE RECOMMENDATION*

2.1.1 RECOMMENDATION 1.0

Under the leadership of the Office of the National Coordinator for Health Information Technology, an emergency responder use case should be developed and prioritized for the attention of the Health Information Technology Standards Panel and the other ONC lead initiatives. The use case should describe the role that an emergency responder electronic health record will provide, comprising, at a minimum, demographic, medication, allergy and problem list information that can be used to support emergency and routine health care activities. The use case should leverage the work in related activities from the AHIC EHR Working Group and elsewhere. In order to meet the needs of a variety of follow-up activities, this use case should be available in October of 2006. *AHIC decision: Accepted*

3 APRIL 2007 RECOMMENDATIONS

3.1 BUSINESS CASE ALIGNMENT

3.1.1 RECOMMENDATION 1.0

As the Federal Government develops language in its contracts with health plans and insurers to support the widespread adoption of HITSP interoperability standards, this language should foster the use of Pay for Performance programs for physicians that include structural measures to incent the adoption and effective utilization of certified EHRs. This emphasis on structural measures may be limited to a specific time frame with the ultimate goal of using process and outcome measures to assess performance. *AHIC decision: Tabled*

3.1.2 RECOMMENDATION 1.1

These pay for performance programs should use reliable, standardized and validated tools which are currently available to assess structural measures as defined by the Medicare Payment Advisory Commission (MedPAC), such as the NCQA's Physician's Practice Connections or CMS' publicly available Office System Survey. This emphasis on structural measures may be limited to a specific time frame with the ultimate goal of using process and outcome measures to assess performance. *AHIC decision: Tabled*

3.2 WORKFLOW AND CULTURE

3.2.1 RECOMMENDATION 2.0

HHS should provide continued support to DOQ-IT U for new module development; upgrades; maintenance; and CME credit management beyond the 8th SOW funded by CMS. The program should be supported by a learning management system that is user friendly, has search functionality, and provides links to other key sites. *AHIC decision: Accepted*

3.3 MEDICAL-LEGAL CONCERNS

3.3.1 RECOMMENDATION 3.0

HHS should work with the CCHIT to obtain medico-legal counsel to assure that its functional criteria include documentation, security, and other approaches that will mitigate malpractice risk. *AHIC decision: Accepted*

3.3.2 RECOMMENDATION 3.1

HHS should meet with malpractice insurers throughout the country to encourage premium reductions for those physicians who have adopted certified EHRs. *AHIC decision: Accepted*

3.4 OVERARCHING RECOMMENDATION

3.4.1 RECOMMENDATION 4.0

HHS should develop a schedule for implementing differential reimbursement to Medicare physicians for use or non-use of EHRs. While we would defer to Departmental expertise, we note that this might be achieved by paying full Medicare rates and market-basket updates (and possibly an “EHR premium”) to physicians using certified EHRs, while physicians using paper-based records are paid at discounted rates achieved by non-qualification for full market basket updates or other measures. *AHIC decision: Tabled*

4 JUNE 2007 RECOMMENDATIONS

4.1 REVISED BUSINESS CASE ALIGNMENT RECOMMENDATIONS (1.0 & 1.1) FROM APRIL 2007 AHIC

4.1.1 RECOMMENDATION 1.0

As the Federal Government develops language in its contracts with health plans and insurers to support the widespread adoption of HITSP interoperability standards, this language should foster, but not mandate, the use of financial incentives or Pay-for-Use programs to incent the adoption and effective utilization of CCHIT certified EHRs. Structural measures should be included in these programs, which may be limited to a specific time frame with the ultimate goal of using process and outcome measures to assess performance. *AHIC decision: Accepted*

4.1.2 RECOMMENDATION 1.1

These Pay-for -Use programs should use reliable, standardized and validated tools which are currently available to assess structural measures: for example, the NCQA’s Physician’s Practice Connections or CMS’ publicly available Office System Survey. When the National Quality Forum endorses a set of structural measures, these should be employed by these programs. *AHIC decision: Accepted*

4.2 BUSINESS CASE ALIGNMENT

4.2.1 RECOMMENDATION 1.2

HHS should evaluate Pay-for-Use programs with respect to quality, cost and adoption. *AHIC decision: Accepted*

5 NOVEMBER 2007 RECOMMENDATIONS

5.1 ELECTRONIC PRESCRIBING

5.1.1 RECOMMENDATION 1.0

The Secretary of Health and Human Services should seek authority from Congress to mandate e-prescribing, pursuant to standards defined by the Medicare Modernization Act (MMA) for e-prescribing 1. This authority should be specific to e-prescribing and not extend to other health care processes. *AHIC decision: Accepted*

5.1.2 RECOMMENDATION 2.0

Prior to exercising authority to mandate e-prescribing, the following requirements should be met: *AHIC decision: Accepted*

5.1.3 RECOMMENDATION 2.1

Flexibility must be maintained, since mandated e-prescribing may not be applicable to all patients, all prescriptions, and all circumstances. *AHIC decision: Accepted*

5.1.4 RECOMMENDATION 2.2

With appropriate Congressional authority, all pharmacies and pharmacy benefit managers must participate in such mandatory e-prescribing. *AHIC decision: Accepted*

5.1.5 RECOMMENDATION 2.3

All prescriptions must be electronically transmissible to the pharmacy of the patient's choice. *AHIC decision: Accepted*

5.1.6 RECOMMENDATION 2.4

The Certification Commission for Healthcare Information Technology (CCHIT) should develop a certification process for e-prescribing systems that are: (i) interoperable with certified EHRs; (ii) include clinical decision supports to improve safety, efficacy, and efficiency; and (iii) can be extended to integrate with fully functional EHR systems, thus assuring that the e-prescribing investment is a step towards adoption of certified EHRs. *AHIC decision: Accepted*

5.1.7 RECOMMENDATION 2.5

With the appropriate Congressional authority, CMS should develop and institute incentives for both physician/clinician and pharmacy adoption of certified EHRs and/or

certified e-prescribing systems early in 2008 before authority to mandate e-prescribing can be granted and exercised. *AHIC decision: Accepted*

5.1.8 RECOMMENDATION 2.6

Continue the successful pilot work undertaken by CMS to make ready important emerging standards, and supplement that work to address sustainability issues such as practice workflow, usability, clinical decision support, and safety surveillance. *AHIC decision: Accepted*

5.1.9 RECOMMENDATION 2.7

Pursuant to Patient Safety legislation of 2005, the Agency for Healthcare Research and Quality (AHRQ) should designate Patient Safety Organizations to monitor and address possible patient issues that may arise as a result of e-prescribing, and patient safety criteria should be included in an e-prescribing certification process. *AHIC decision: Accepted*

6 JANUARY 2008 RECOMMENDATIONS

6.1 WORKFORCE

6.1.1 RECOMMENDATION 1.0

HHS should support funding for a collaborative group to research and better quantify discipline-specific workforce deficits (calibrated to different rates of HIT implementation) and to develop an approach for supporting informatics workforce needs. *AHIC decision: Accepted*

6.1.2 RECOMMENDATION 2.0

HHS should work with the Department of Labor to develop occupational classifications for HIT professionals. *AHIC decision: Accepted*

6.1.3 RECOMMENDATION 2.1

HHS should encourage OPM to recognize health informatics professionals in the federal professional series. *AHIC decision: Accepted*

6.1.4 RECOMMENDATION 3.0

HHS should support funding for additional research within specific Federal agencies to create HIT career pathways (including occupational series & job classifications), with particular attention to clinical informatics, research informatics, translational

bioinformatics, and public health and population informatics, in support of HIT implementation; improved quality, and clinical effectiveness; systems development; and executive leadership. *AHIC decision: Accepted*

6.1.5 RECOMMENDATION 4.0

HHS should support Federal funding for research in health informatics (including clinical informatics, health information management and IT) which would increase attractiveness of academic careers in HIT and the pool of faculty for HIT curricula in health care disciplines. *AHIC decision: Accepted*

6.1.6 RECOMMENDATION 5.0

HHS should work with the DOE to institute loan forgiveness programs or other incentives to attract necessary health professions trainees to HIT careers in underserved and safety net areas. *AHIC decision: Accepted*

6.1.7 RECOMMENDATION 6.0

Appropriate Federal agencies engaged in HIT should identify and develop informatics competencies for health profession disciplines, and incorporate these in academic programs and mentorship/fellowship programs. *AHIC decision:*

6.1.8 RECOMMENDATION 7.0

For the current health care worker, public or private, participation in educational and certification programs such as AMIA 10x10 program, HIM progression and certificate programs, European Computer Driver's License equivalent, and other programs for basic/core HIT competency training and evaluation should be encouraged through bonus criteria, training programs, or other means. *AHIC decision: Accepted*

6.1.9 RECOMMENDATION 8.0

ONC should work with the states to encourage governors to increase recognition of health IT workforce needs and suggest ways to address them. This could include health professional licensing activities. *AHIC decision: Accepted*

7 NOVEMBER 2008 RECOMMENDATIONS

7.1 HOSPITAL EHR ADOPTION: ACUTE CARE DOCUMENTATION

7.1.1 RECOMMENDATION 1.0

HHS should commission an expert panel to investigate and clarify documentation and data required by regulatory, licensing, accrediting, quality reporting, and payer entities.

AHIC decision: Pending 11/12 meeting

7.1.2 RECOMMENDATION 1.1

The expert panel should determine how these requirements can be most efficiently met using HIT/EHRs without imposing undue burden on clinicians already documenting information for clinical care purposes. *AHIC decision: Pending 11/12 meeting*

7.1.3 RECOMMENDATION 1.2

HHS should support a national effort to create standardized and structured templates to address these requirements in order to reduce redundancy across the U.S. healthcare system. *AHIC decision: Pending 11/12 meeting*

7.1.4 RECOMMENDATION 1.3

HHS should make available standardized and structured templates that can be used for regulatory, licensing, accrediting, quality reporting, and payment purposes. *AHIC decision: Pending 11/12 meeting*

7.1.5 RECOMMENDATION 2.0

HHS should establish and maintain a national repository to house structured templates, based on evidence based practice where applicable, which have already been developed and implemented for clinical purposes by multiple organizations. This national repository should also be responsible for the development and implementation of a mechanism to support collaboration and development of new standardized, structured templates for clinical care purposes. *AHIC decision: Pending 11/12 meeting*

7.1.6 RECOMMENDATION 3.0

HHS should identify, develop, and make available, a standardized methodology for measuring both the direct and the indirect costs of EHR adoption across various types of hospital settings. *AHIC decision: Pending 11/12 meeting*

CPS & EHR Workgroups' review & response on the "Recommended Requirements for Enhancing Data Quality in Electronic Health Record Systems" can be viewed at: http://www.hhs.gov/healthit/documents/m20080115/11-cps-ehr_recs_ltr.html

APPENDIX B
**Summary of Public Testimony from the Electronic Health Records
Workgroup**

ELECTRONIC HEALTH RECORDS WORKGROUP
SUMMARY AND FINAL REPORT

MEETING DATE	PRESENTER	TESTIMONY SUMMARY
PRIVACY AND SECURITY		
Feb-06	John Houston	Discussed CLIA barriers. Need for a patient authorization scheme.
Mar-06	John Houston	Letter to the workgroup detailing: <ul style="list-style-type: none"> • Pt's opt-in/ opt-out • Differences in state privacy laws • Authentication/ authorization infrastructure suggestions
Mar-06	Susan McAndrew, HHS/OCR	Review of HIPAA related to CLIA and specific charge

MEETING DATE	PRESENTER	TESTIMONY SUMMARY
FINANCIAL/ BUSINESS CASE		
Jan-06	Dr. Blackford Middleton, Clinical Informatics R&D, Partners HC	Payers interested in “value-based purchasing” or “pay-for-performance” are now creating significant incentives for physicians in the Partners HealthCare System to implement EHRs (a one-time capital payment to physician groups who adopt EHR). Payers also have begun experimenting with the use of financial incentives for physicians to use EHRs to achieve quality benchmarks. Noted the misalignment of incentives. Some of the policy suggestions on the table include providing physicians both access to low-cost capital to get over the adoption hurdle and some financial incentive to reward ongoing use of EHRs
Jul-06	Dr. David Blumenthal, Institute of Health Policy, Mass General Hospital, Harvard Medical School Sarah Rosenbaum, George Washington University	(Adoption Study): (a) factors hindering adoption (lack of business case for performance, lack of business case for EHR adoption) and (b) incentives for adoption (pay for performance, public reporting of performance, pay for use of EHR, small grants or low-interest loans, in-kind assistance, performance standards).

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
FINANCIAL/ BUSINESS CASE		
Sep-06	Tom Leonard, Vice President and General Manager of Ambulatory Solutions, McKesson Provider Technologies, McKesson Corp/ Dawn Bates, Harris Interactive	"Thought Leadership Survey: Physician Alignment Through IT": 74 % of the primary care physicians and specialists surveyed are receptive to working with an affiliated hospital to deploy an ambulatory EHR in their practice. Using a variety of means to assign a quantitative value led to the conclusion that physicians would be willing to pay an average \$550 per physician per month for a vendor-hosted EHR and an average \$531 for a hospital-hosted EHR
Oct-06	Dr. Helga Rippen, Senior Advisor, Health Informatics, HHS/ASPE	ASPE Study: "Assessing the Economics of EMR Adoption and Successful Implementation in Physician Small Office Settings". <u>Financial Barriers</u> : Lack of capital investment; maintenance costs; complex contracts; lack of time. <u>Benefits</u> : improved charge capture; reduced transcription costs; reduced staff expenses; increased revenues' discounted malpractice insurance rates; improved employee satisfaction/MD quality of life; Practices spent between \$15K-\$80K (including PMS and training/ implementation assistance).
Oct-06	Dr. Blackford Middleton, Clinical Informatics R&D, Partners HC	(1) <u>Asymmetry of Risk & Reward for HIT</u> : payer does not gain; disincentives for LTC mgmt-payers & providers; disincentives for HIE--immature interfaces, no \$ for HIE, no contribution to margin, decreased ancillary services (2) <u>Market Failure for HIT</u> : no business case yields slow development of standards; hidden costs of knowledge mgmt (need standard, sharable templates, rules, etc.) (3)Early <u>Market effects</u> : early adopters and first mover disadvantages, turmoil in HIT vendor space & low functionality limit value; no network effects achievable with spare adoption; <u>Rec</u> : Reimbursement reform; capital availability; EHR Certification: Ambulatory CPOE value: summarized costs & benefits across clinical, financial and org. factors. Greatest benefit: Rx, lab then radiology--only 11% benefit to provider. <u>HIEI Findings</u> : standardized, encoded, electronic HIE would save the US HC system \$337B over 10yr implementation period & \$78B each year thereafter; total provider net benefit=\$34B, payers \$22B, Labs=\$13B, Rad \$8B, Pharm \$1B, Public Health\$0.1B. + Business case for standardized HIE and interoperability.

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
FINANCIAL/ BUSINESS CASE		
Oct-06	Dr. Mark D. Jacobs; Chair, Board of Directors EHRRI	Electronic Health Records of RI --founded as a unique collaboration between historical competitors. Goal: bring down costs through volume discount; select ONE product to simplify interconnectivity, support, training and interfaces; develop uniformity of reporting for P4P and disease mgmt; provide leadership and build relationships with other physicians and groups. Seed money: \$200K. EHRRI resells eClinicalWorks--EHR and PMS integrated. One large financial backer--looking for more and grant \$.
Oct-06	Dr. Ron Bangasser; Beaver Medical Group, Past President CA Medical Association	CA P4P program overview: >1/2 practicing physicians 40K; 7 health plans, 228 physician organizations. \$54 million paid out so far. Focus: Clinical--50%; Patient experience 30%; IT 20%. Practices don't have to have a full EHR but have to be able to respond back to HP and physician. His practice, Beaver Medical gave \$1.2M in 2005 for P4P Quality improvement bonuses--1/2 went for IT improvement, 1/2 went to physician bonuses (\$5-10K). Many solo and small group physicians do not know about P4P or feel threatened by it. Cost is the biggest barrier to their adoption--even if the other barriers are overcome. Most have administrative systems, going the next step to EHRs will be \$ challenging, may require new office staff and a new office system. Without an EHR Dr's could participate in P4P via a simple registry enabled by Excel--small steps/ incremental successes. This will not be enough \$ to fund an EHR but would be a start--has to be enough to get the Dr. to participate (at least 2%). Misaligned benefits--most to businesses, health plans & government so those reaping the savings should help with the \$.

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
FINANCIAL/ BUSINESS CASE		
Oct-06	Dr. Richard Baron; President, Greenhouse Internists	\$35K per Dr to buy; \$7.5K second year; \$12K/yr for support; 1.6% revenue DECREASE in implementation year (4-5% income decrease to Drs). Practices revenue growth slowed--.55% over the 2 year implementation period, with costs increasing at a fast pace. Annual savings: transcription eliminated \$12.5K; 2.5 FTE's; 400sq ft file space; reduced office supplies \$3K/ Dr.; 3yr ROI without revenue adjustment or consideration of opportunity costs. <u>Ideas to WG</u> : business case not there; how can others that benefits contribute financial/ material support (working products may be better than \$); Must work in primary care first--68% of care delivered there; is central to the future survival of primary care; P4P: to work will need interoperability and structured data collection from the EHR.
Oct-06	Francois de Brantes; National Coordinator, Bridges to Excellence	What is known about P4P: incentives work; practices need help reengineering; better quality can cost less but need the right measures; self-assessment of performance leads to focused QI but it's resource-intensive to pull charts; critical mass can impact physician behavior but you need the plans/payers to make it work. The Physician Office Link: practices need to demonstrate they have reengineered and made changes in: clinical information systems (registries), Patient Education and Support, Care Management. Bonuses tied to continuous improvement toward full "system-ness" which includes adoption certified EHRs. Profiled a NY multi-specialty physician practice. This practice saw savings in reduced staff, transcription, materials and overtime.
Feb-07	Jack King & Kathy Scroth; Physicians Insurance Agency of MA (PIAM)	Independent malpractice insurance broker. Credit Structure: Claims-Free Credit – Up to 10%; Note: Participants need to have a a good claims history to be eligible for EHR credit- (75% of practice needs to be claims-free for 5+ years.) EHR Credit – 5% 2.5% QI/Incident Reporting Program Credit 2.5% Office Self-Evaluation Credit Total Credits Available: Up to 20%

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FINANCIAL/ BUSINESS CASE		
Feb-07	Denise Funk; Connecticut Medical Insurance Company & Micky Tripathi, MAeHC	Connecticut's total payments were \$103,900,750 in 2005. Connecticut's average payment was \$731,695 - the Nation's highest. Massachusetts's total payments were \$123,023,250 in 2005. CMIC's 2005 legal defense cost for paid cases was \$4,050,000. Benefits of a Fully Integrated EHR: Legible, accurate and complete treatment documentation; Systematic follow-up for tests, procedures, medications; Prevention of medical record alteration; Continuity of care for all physicians treating the same patient; Eliminate misfiling of critical medical information; Track patient visits, missed appointments and compliance
Mar-07	Dennis Stricker, CMS	Overview & Update on Vista Office EHR Project, goal to provide ambulatory physicians with a low cost alternative for EHRs. On conclusion of the development work it is anticipated that WorldVista will take over the distribution and ongoing support of the software.
Mar-07	Dr. Jim Sorace & Sue Fleck; CMS	Update on the DOQ-IT Project and the Office Systems Survey (OSS). The OSS is a baseline and re-measurement survey to monitor EHR adoption and care management processes in small physicians' practices, with Quality Improvement Organization (QIO) intervention between the surveys.
May-07	Kristin Welsh, American Hospital Association.	Reported on a recent AHA survey of hospitals' use of HIT. The survey covered topics such as information technologies used by hospitals, the functions of hospitals' EHRs, information exchange, and barriers to greater adoption of information technology. Of the survey respondents, more than 2/3 of those hospitals have fully or partially implemented EHRs. Hospitals without EHRs tend to be the smaller, rural, non-teaching, and non-system hospitals with more limited resources than hospitals that have implemented EHRs.

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FINANCIAL/ BUSINESS CASE		
May-07	Dr. Kristiana Raube, Berkley University	Presentation on the Integrated Health Care Association’s pay-for-performance (P4P) program in California. This program, which involves seven major commercial HMOs and point-of-service plans in California, began making payouts in 2004 to improve the quality of clinical care and patient experience. The program’s experience suggests that it is possible to use financial rewards to create incentives for the adoption and use of HIT in physicians’ offices. It also suggests that better HIT may be related to improved clinical care.
Jul-07	Dr. William Stead, Vanderbilt Medical Center, Associate Vice Chancellor for Strategy & Information and Chief Financial Officer	(1) HIT cannot be simply inserted in the old way of practice. Greatest efforts go into redesigning practices around evidence-based systems of care. (2) It is not a destination but a journey requiring iterative and continuous evolution of peoples’ roles, processes, and technology. (3) Technical approach is important, more effort should be put into using HIT and EHRs) to work at the macro system level (4) Most of the work in implementing change processes and adoption occurs outside an institution’s IT department. (5) The financial returns from HIT are not straightforward. Categories of return on HIT: (1) results in a direct and quantifiable improvement to the bottom line; (2) improves productivity but affect the bottom line indirectly in ways that are not easily quantified, either because they involve parts of a full-time equivalent position or something in which there is no clear way of measuring the impact on productivity; and (3) better management choices, improved long-term outcomes, the right as opposed to necessarily the most profitable use of profit centers, the right transparency, and patient engagement.

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FINANCIAL/ BUSINESS CASE		
Jul-07	Dr. Jim Walker, Geisinger Health, Chief Medical Officer	Over the past 12 years, GHS has developed organizational capabilities (including the capability for workflow analysis and redesign) and incentives for dramatic changes in healthcare processes using HIT. Leadership has been critical to this endeavor. Physician and non-physician champions view HIT not as an end in itself but as a tool that can be used to transform and improve the care the health system provides (e.g., improve reimbursable performance, improve patient experience, facilitate safe and effective processes, decrease the unit cost of care, improve employee satisfaction). Trying to implement HIT all at once proved to be a fiasco. For that reason, HIT was implemented in phases, beginning with lab results and e-mail, followed by documentation and order entry, and then other capabilities once the staff had improved their skills and experienced the power of the technology. To spur the adoption of new processes, GHS provides financial and other incentives for individuals, managers, and HIT teams to provide higher quality, or affordable quality care.
Jul-07	Margaret Robinson, Midland Memorial Hospital, Vice President for Patient Care Services & David Whiles, Director of Information Technology	Began in 2002, decided to implement a HIS based on the open-source VistA to avert a financial crisis, known as Electronic Data and Information Technology for Health Care (EDITH). The time commitment and effort required to customize and implement EDITH was daunting, but the system has enabled Midland Memorial to enhance patient safety, support quality initiatives, give physicians better information, and make a contribution to the healthcare industry. Midland phased in the implementation of EDITH, beginning with pharmacy in October 2005; following with lab entry, order entry, clinical documentation, and bar code medication administration; and then transitioning to a full EHR in February 2007. Conversion was challenging for staff, especially when there were both paper and electronic records. To get physician buy-in, Midland Memorial gives physicians remote access to the EHR from home and pays them for time they need to get familiar with EHR if they demonstrate they are using it. The original VistA project budget, with no cost for software, was about \$7 million.

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LEGAL/ REGULATORY		
Mar-06	July Yost, CMS	Discussion of CLIA Regulations, potential barriers
Jul-06	Dr. David Blumenthal, Institute of Health Policy, Mass General Hospital, Harvard Medical School Sarah Rosenbaum, George Washington University	Legal and regulatory factors that weigh on providers following HIT adoption: legal questions related to the adoption process such as “Stark” and related fraud considerations, antitrust; legal consequences that come from information transparency and broader information use; and legal consequences related to custodial control of large volumes of data – privacy and security, liability considerations
Aug-06	Dr. Peter Basch-- Medical Director, MedStar e-Health	Dr. Basch noted that if a sustainable business case for information management and quality were successfully developed by reducing fragmentation and reforming reimbursement, several barriers to the optimal use of HIT/HIE would remain. These barriers, however, are not insurmountable: (a) <u>workforce barriers</u> (reactive medical model, need to train/retrain physicians to provide proactive/population-based care), (b) <u>software immaturity</u> (lack of many EHRs with embedded granular/actionable clinical decision support; robust tools for determining, aggregating, and reporting performance measures; forms/structure for following episodes of care over time; forms for care coordination; interoperability sufficient to share information with colleagues, patients, payers, and quality improvement organizations; dashboards for monitoring preventive/chronic care adherence), (c) <u>lack of clinical protocols for interconnectedness</u> (lack of a model for point-to-point data transmission that includes context, responsibility, and handoffs)

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LEGAL/ REGULATORY		
		(d) Unresolved <u>medico-legal</u> questions related to the use of an EHR and HIE (Does access to an EHR elevate the standard of care? Will information accessible via an HIE be considered part of a medico-legal record or just a source of information?), (e) application of an outdated documentation schema to 21st-century medicine (need to work on a new clinical progress documentation schema based on enhancing quality, longitudinal care, called for by Sec. 941 of the Medicare Modernization Act of 2003), and (f) anticipating new errors cause by HIT/HIE-enabled medical care (e.g., new errors from EHRs due to faithful propagation of errors, dropdown list errors; a narrow focus on outcomes; measure-centric rather than patient-centric care).
Sep-06	Tom Leonard, Vice President and General Manager of Ambulatory Solutions, McKesson Provider Technologies, McKesson Corp	Presented McKesson sponsored national survey entitled "Thought Leadership Survey: Physician Alignment Through IT". Purpose of survey was to gauge physician interest in leveraging hospital IT infrastructure.
Sep-06	Nicholas Terry, J.D., Chester A. Myers Professor of Law, and Co-director Center for Health Law Studies, St. Louis University, MO	Four clusters of medical-legal issues: those r/t architecture; state records laws; adoption transition; general liability; Addressed Privacy and security concerns. HIPAA limitations; Distributed an article soon to be published in the University of IL Law Review; Suggested steps: minimize potential perceptions of harm; maximize legal protections
Oct-06	Dr. Blackford Middleton*, Clinical Informatics R&D, Partners HC	Recommendations enabling policy: Relaxation of Stark; Establish federal policy on clinical data ownership and stewardship; Establish policy framework for Regional Health Information Authorities; Establish U.S. National licensure in the health professions

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
LEGAL/ REGULATORY		
Nov-06	Jodi Daniel, ONC	Ms. Daniel updated the workgroup on the progress made by ONC and CMS regarding identifying barriers to patient-centric lab results data exchange. Their work continues to examine the potential models for exchange and potential barrier remedies. She highlighted an ONC contract with the National Governors Association's Center for Best Practices to create a State alliance for e-health that will review state laws that might preclude sharing of lab data with physicians involved in a patient's treatment with a view toward changing those laws.
Jan-07	Michael L. Kidney, Partner Hogan & Hartson	Specializes in tort law. Noted 3 issues <ol style="list-style-type: none"> 1. Potential increased liability related to extent of record availability. He noted there are 3 published opinions on this. 2. Potential increased liability for Dr's to update and maintain EHRs. 3. Potential decreased liability secondary to EHR use and decreased adverse events
Jan-07	Mark F. Tatelbaum, General Counsel, GWU Medical Faculty Associates	<ol style="list-style-type: none"> 1. Highlighted the cost savings and benefits of EHR adoption 2. Felt burden and privacy/security risks are no different that paper. EHRs are increasing the standard of care.
Jan-07	Bruce Wolff, Partner, Manatt, Phelps, & Phillips, L.L.P.	<u>RHIO experience</u> <ol style="list-style-type: none"> 1. Felt there are no real legal barriers, only perceived. 2. Referenced Professors Nicholas Terry's testimony to the WG to highlight areas where additional questions/ policies may need to be addressed. <ol style="list-style-type: none"> a. What do you do with all the "old" pre-EHR records? b. How to assure data is the system is accurate and reliable? Assurances on CDS—certification? c. Privacy and security practices broader than the provider to include the consumer and record custodian.

ELECTRONIC HEALTH RECORDS WORKGROUP
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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
LEGAL/ REGULATORY		
Feb-07	Legal Panel Follow-up letter	Distributed in meeting; posted in archives--group answered f/u questions. 1. Group felt that use of a certified EHR could potentially decrease liability. Should also address utility--esp. for structuring and viewing large quantities of data. 2. Failure to use what is available (i.e. turning of CDS prompts) is akin to turning away from information that could be vitally important and in accordance with the best available clinical guidelines. 3. Group did not feel that liability was any different in the HIT environment vs. the paper environment with regards to acting or failing to act on information provided by another provider's EHR or PHR.
Mar-07	Betsy Ranslow; ONC/ OHITA	Update on the State Alliance for e-health. 3 Task Forces: Health information protection (Privacy & Security issues); Health information communication & data exchange task force (public paying programs, including Medicaid); Health care practice task force (issues involving regulatory, legal, and professional standards that have an impact on the practice of medicine and create a barrier to interoperable health information exchange). Currently working on licensure laws, CLIA and liability issues. Gave an update of the Stark Exceptions and IRS--American Bar Assoc. and American Hospital Assoc. white paper expected.

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
LEGAL/ REGULATORY		
<p>Apr-07</p>	<p>Panel: Lawrence Hughes, Regulatory Counsel and Director, Member Relations, American Hospital Association</p> <p>Andreanna Ksidakis, Vice President & Deputy General Counsel, Sutter Health</p> <p>Jeffrey Micklos, Senior Vice President, Business Operations & General Council, Federation of American Hospitals</p>	<p>Panel re: Stark and anti-kickback regs & hospitals’ HIT arrangements with physicians. a. Implementation Concerns:– Lack of specific guidance from IRS with regard to tax exemptions pertaining to HIT provided to physicians. Regulations’ restrictions on permissible donations of IT (notably, the exclusion of hardware & security infrastructure); the evolving definition of interoperability & its value as a fraud and abuse concept; 12-month certification requirement and its impact on multiyear rollouts; definition of equivalency; and cost-sharing requirements. b. Stark Regulations Case Study – Noted challenges in Sutter's EHR implementation: the no loans to physicians Stark provision & how to handle those physicians that don't pay on time; the 15% cost sharing requirements; and security issues with regards to what comprises the legal medical records and its ownership. c. How to Improve the EHR Fraud Exceptions – Cost-sharing requirement should be modified to say “at least 15%” and denote what that 15% entails. More flexibility in definition of interoperability and to adopt an exception similar to Stark for the civil monetary penalties law. Some states fraud and abuse rules are inconsistent with the federal standards.</p>
<p>May-07</p>	<p>Dr. Karen Bell, ONC</p>	<p>Updated WG and reviewed the anticipated IRS Memo: “Hospitals Providing Financial Assistance to Staff Physicians Involving Electronic Health Records”</p>

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MEETING DATE	PRESENTER	TESTIMONY SUMMARY
LEGAL/ REGULATORY		
Dec-07	Dr. Reed Gelzer	<p>RTI/AHIMA team that, under contract to ONC, has been detailing how EHR systems can be used to enhance data integrity and address concerns about fraud and T abuse. In June 2007, the RTI/AHIMA team released Recommended Requirements for Enhancing Data Quality in Electronic Health Record Systems, which is the third report in a series. The first report focused on computer-assisted coding. The second report focused on the use of HIT to enhance and expand health care anti-fraud activities and suggested that at least 3 percent of annual U.S. health care expenditures and possibly as much as 10 percent was lost to outright fraud. It also identified law enforcement/auditing priorities for EMR function supports for the management of health care fraud. The third and most recent report proposed 14 recommendations for enhancing data quality in EHR systems. Discussed specifically: Requirement 5: Evaluation and Management (E&M) Coding & Requirement 6: Proxy Authorship. EHR WG members agreed to support Recommendations 5.2 through 6.2 as written---minor revisions offered to 5.1</p>

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SUMMARY AND FINAL REPORT

MEETING DATE	PRESENTER	TESTIMONY SUMMARY
TECHNOLOGY		
Feb-06	Dr. Walter Sujansky & Jonah Frohlich	ELINCS Presentation & Overview
Feb-06	Dr. Robert Kolodner, VA	<p>2002: put in place the Federal Health Information Exchange (FHIE) that allowed for the one-way exchange of health information from DoD to the VA for military service members at the time of the service members' separation from the military. This model, which allowed the exchange of lab, rad, outpatient Rx, and other information, was compliant with HIPAA as it was understood at the time. DoD has discharged 3.3 million unique service members from military service with clinical data; the VA has registered 2.4 million of them in its system. About a year ago, the VA and DoD built the Bidirectional Health Information Exchange (BHIE), which allows them to exchange lab and other data in real time. The bidirectional system is currently operational at 7 VA sites. Currently, there are about 5,000 inquiries per week going back and forth from the VA to DoD. The system has information on over 43 million lab results. Eventually, the VA hopes to incorporate data on veterans from private sector providers, with the caveat that patients get to decide whether they want their information to be moved back and forth.</p>
Feb-06	Dr. Carolyn Clancy, AHRQ	<p>AHRQ's Six RHIO Demonstrations are in six States, including Colorado, Delaware, Rhode Island, Indiana, Delaware, Tennessee, and Rhode Island. There is some variability in how States and Regions are setting up RHIO relationships. The model in Tennessee is one based on a relationship with trusted core facilities, including both some hospitals and large clinics. Other States, with a different mix of providers and business relationships, are using different strategies. <u>The RHIOs are enthusiastic about ELINCS.</u></p>

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Feb-06	Colonel Bart Harmon, DoD	Two challenges that DoD and the VA faced in developing their systems were (1) identifying people in consistent ways across enterprises (both the recipients of service and persons gaining access to information) and (2) making sure that they were handling things in an appropriate way in regards to HIPAA and privacy laws. These fundamental challenges will undoubtedly arise in scaling up any EHR projects to the national level.
Feb-06	Pam Pure, McKesson	Presented Vendor/Private Industry Perspective, focusing on Hospital-centric exchange of laboratory results data.
Mar-06	Dr. Scott Young, AHRQ	Reviewed AHRQ State and Regional Demonstration Projects; focusing on specific charge of laboratory results data.
May-06	Dr. Edward Barthell, American College of Emergency Physicians	Presented tables detailing data needs of first responders in pre-hospital and EDs; routine and disaster. Also outlined mechanisms for Making Data Available to First Responders.
May-06	LTC David Parramore, Department of Defense (DoD)	Lieutenant Colonel Parramore reported that last year, during Operation Iraqi Freedom, DoD delivered electronic health systems in the deployed environment. He said that he really had nothing additional to add to the requirements put forth by Dr. Barthell. DoD's requirements are essentially the same.

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May-06	Dr. Roxanne Townsend, Louisiana Department of Health and Hospitals	Dr. Townsend said she fully agreed with Dr. Barthell’s summary of the essential data elements needed by first responders, she but noted that the more difficult question is, “How do you create a portable EHR to for use during an emergency response, especially when, at the time of a crisis such as Hurricane Katrina, the normal methods of communication are not available?” Dr. Townsend reported that Louisiana has been developing a health information exchange with funding through a contract with ONC. Although the system will not be fully robust by the time hurricane season starts in less than a month, they are locating electronic information that is already available (e.g., claims data, as proven in KatrinaHealth.org; data from some major hospitals) and using that to recreate and reconstruct some of the medical information for a lot of the evacuees
May-06	Aarron Reinert, Executive Director, Lakes Region EMS (Minnesota)	EMS Agenda for the Future: Implementation Guide – a consensus document published by the National Highway Traffic Safety Administration in 1996 – frames what data elements are needed for EMS to play a larger role than it has in the past, as both an extension of emergency medicine and an arm of public health. A dataset encompassing some 500 data elements – the National EMS Information System (NEMESIS) – includes demographic data, medications, patient’s history, allergies, laboratory values, etc., but also many other variables. Now that the NEMESIS dataset exists, Mr. Reinert said, the greatest need is for connectivity to allow EMS to exchange the information in the dataset.
Jul-06	Dr. David Blumenthal, Institute of Health Policy, Mass General Hospital, Harvard Medical School & Sarah Rosenbaum, George Washington University	Factors related to the state of technology (ease of use and standardization): (a) factors hindering adoption (lack of interoperability, lack of interconnectedness even within organizations) and (b) incentives for adoption (standards for interoperability, product certifications, and support for Regional Health Information Organizations).

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Aug-06	Marc Williams, Director, Intermountain Healthcare Clinical Genetics Institute	Dr. Williams, a medical geneticist at Intermountain Healthcare in Utah, distributed a three-page paper entitled “Family History and the Electronic Health Record” signed by several geneticists and organizations. Dr. Williams asked the EHRWG to consider adding family history to the roadmap for development of EHR standards in the United States.
Aug-06	Colonel Bart Harmon, DoD	EHR Data Elements Needed for Clinicians to Exchange Information. U.S. Department of Defense (DoD) and U.S. Department of Veterans Affairs have identified the most important data elements that would enable clinicians to share information: (a) information that identifies the patient, (b) a medication list and medication allergies, (c) lab results, (d) a problem list, (e) clinical encounters and clinical notes, (f) anatomic pathology results, (g) vital signs, (h) radiology reports (text only), and (i) family history and health factors. DoD starting point was a commercial version of many of the Intermountain Health tools.
Oct-06	Dr. Blackford Middleton, Clinical Informatics R&D, Partners HC	HIT Standards Setting: Specify essential standards for EHR (data, messaging, reference architecture); Specify a minimal clinical data set; Specify minimal function standards for HIT systems

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Oct-06	Dr. Helga Rippen, Senior Advisor, Health Informatics, HHS/ASPE	ASPE Study: "Assessing the Economics of EMR Adoption and Successful Implementation in Physician Small Office Settings" . Technical Barriers: Difficulty or inability to evaluate and select EHR; Concern over the technical ability to use an EHR; Lack of training; Creating a migration plan; Meeting technical/clinical requirements/usability; EHR solutions are fragmented Lack of uniform standards (including terminologies); Risk of vendor going out of business; Mistrust of vendors; Lack of support. Financial benefits of implementing EMRs are reported to accrue within 1-2 years. One report showed the more advanced EMR the greater the net benefits. Usability also has implications for performance, costs and benefits--can have a significant influence on physician use of an EMR. Usability does not appear to be well measured, assessed or reported on in the literature. Degree of EMR <u>adoption appears to be inversely related to functionality</u> . Sites visited shared the following functionalities: scheduling, documentation, order entry, pt history, report generation, basic CDS for pharmacy.
Jan-07	Dr. Robert Smith & Dr. Fletcher	Demonstrated the functionality of the VA's EHR
Jan-07	Dr. Howard Hays	Demonstrated the functionality of the IHS's EHR
Jan-07	Colonel Bart Harmon, MD	Demonstrated the functionality of the DoD's ALTA EHR
Feb-07	Dr. Blackford Middleton, Clinical Informatics R&D, Partners HC	Demonstrated the functionality of Partners EHR

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Jul-07	Ken Gebhart, BearingPoint	Planning for AHIC 2008 Use Cases & Prioritization. Update on seven use cases completed or underway in 2006 and 2007, six possible use cases for 2008, and a lengthy list of unmet needs for use case development in 2009 and beyond. Mr. Gebhart asked EHR WG members for their input on the six use cases for 2008: (1) remote monitoring, (2) remote consultation, (3) referrals and transfer of care, (4) personalized healthcare, (5) public health case reporting, and (6) response management. Also asked the EHR WG to reexamine and revise the list of unmet needs for use case development in 2009 and beyond.
Dec-07	Dr. John Loonsk, ONC	Round Four, 2009 Use Case Prioritization presentation/ discussion. Update on the Use case process.
Feb-08	Dr. Catherine Desroches, Massachusetts General Hospital Institute for Health Policy	Update on the HIT Adoption survey. Mail survey of health IT adoption by physicians in ambulatory care settings that she and her colleagues at the Massachusetts General Hospital Institute for Health Policy, Harvard School of Public Health, and George Washington University have been conducting. Data from the survey of 5,000 practicing physicians randomly selected from the American Medical Association's (AMA) Physician Master File indicate that the availability of an EHR to physicians in ambulatory settings varies depending on the definition of an EHR is used, as well as by practice size, specialty practice, and primary setting of specialty practice. The survey has identified some major barriers to physicians' adoption of EHRs, as well as several incentives for the adoption of EHRs. Dr. DesRoches and her colleagues are now collaborating with the American Hospital Association to field an additional survey to learn about hospitals' adoption of EHRs and other health IT.

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Feb-08	Dr. Blackford Middleton, Partners HealthCare System	Update from AHIC's Ad Hoc Clinical Decision Support Planning Group. Requested Workgroup members' feedback on some draft recommendations offered by the group. The Ad Hoc CDS Planning Group headed by John Glaser was formed in May 2007 to develop recommendations to address barriers and enablers of CDS, with the objective of improving clinical outcomes through better shared decision-making by providers and consumers. Overarching draft recommendation is to establish a public-private task force to plan and provide guidance for implementing CDS recommendations. Other draft recommendations are grouped in seven specific areas: A standard CDS knowledge repository of common computable rules, algorithms, and agreed upon clinical practice guidelines; CDS oversight, accreditation, evidence, data quality, and transparency; Integration of CDS with EHR systems and incentives for adoption of CDS systems; Workflow issues; Ambulatory care; Consumer preferences; Driving measurable progress toward priority performance goals.
Feb-08	Dr. Bell & Use Case Team	Review and detailed feedback session on "Consults and Transfers of Care" & "Immunizations and Response Management" Use Cases.

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Apr-08	Dr. John Halamka, Dr. Bob Dolin, Dr. Mark Leavitt (<i>Panel: Interoperability needs of primary care</i>)	<p>What is most needed now to drive the adoption and use of EHRs are financial (& other) incentives for providers to share information from EHRs. Without incentives for sharing information, people may adopt EHRs solely to make their offices more efficient. Unless health care providers use HIT for HIE with entities outside their own offices, the potential benefits of HIT will not be realized. the goal should be to have the minimum set of necessary HIT standards needed to be able to have interoperable health information. Rather than the quantity of HIT standards, what should be measured is the richness of clinical information flowing between providers, the reduction in patient risk and medical errors, and the improvement in quality and convenience. Basic EHR data set: problem list, medications, allergies, notes and reports, laboratory values, radiology (reports and images), EKGs (reports and wave forms), and vital signs. Reported that HITSP has addressed standards for the interoperability of many of the basic EHR</p>

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Feb-06	Ms. Connie Laubenthal	Adoption Tool Kits: A summary/ listing of tool kit and HIT adoption assistance from AAFP, ACP, eHI.
Jul-06	Dr. David Blumenthal, Institute of Health Policy, Mass General Hospital, Harvard Medical School Sarah Rosenbaum, George Washington University	Organizational factors: (a) factors hindering adoption (lack of accountability for quality, lack of trained workforce in many organizations, timidity among leaders, lack of size, availability of surplus or capital) and (b) incentives for adoption (internal reporting requirements, workforce training certification, training of health care leaders, assistance to small providers, assistance to safety net providers).
Aug-06	Fred Ralston Jr. MD FACP Regent Chair, Board of Governors 2005-06 American College of Physicians	Implementation experience. Functions valued: no lost charts, reports not in disarray, scheduling is linked to the record, lab integration, ability for nurses and physicians in the office to engage in asynchronous communication, Internet access, the ability to order and document a patient's prescription refills, and the ability to order outside tests (e.g., mammograms). Desired improvements include (a) improved interfaces with other entities (b) reports via e-mail rather than fax or scanned, (c) improvements in eRx and refill requirements (d) a Palm-type synchronization process for different office and hospital EHR systems. Noted that making a business case for EHRs when Drs pay the costs but benefits are shared by others is more difficult than it would be if every party were paying for a share of the costs of the EHR. Doubted that any hospital would be able to offer an EHR product that would be well-suited for the multitude of different specialty practices. He added that specialty medical societies could have an important role to play in helping physicians select EHR products.

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Aug-06	Chuck Parker—MassPro Chief Technology Officer / DOQ-IT	MassPRO has heard from small-to-medium-sized physician offices in the field that the cost of purchasing EHRs and staffing issues remain a challenge, that negative reports on EHR adoption slow adoption, that a lack of technical knowledge permits bad EHR selection practices, that workflow redesign is key to improvement, and that culture change is key to adoption. Physicians also report concerns about various legal issues (e.g., issues related to who updates a community record, concerns about what legal implications the availability of additional data via HIEs or patient-centered aggregation of information may have for physicians’ decision making, concerns that too much information may create data blindness). Finally, there are issues related to local/regional health information organization stratification (e.g., the need for greater concentration of data transfer within a local community or practice than at a regional health information organization, exchanging information between physicians who have EHRs and physicians who do not have them, the need for other data streams to move to pay for performance).
Sep-06	Tom Leonard, Vice President and General Manager of Ambulatory Solutions, McKesson Provider Technologies, McKesson Corp	"Thought Leadership Survey: Physician Alignment Through IT". : (1) attitudes regarding IT services currently provided by their hospital; (2) attitudes regarding implementing an ambulatory EHR in their practice; (3) attitudes toward working with hospitals to deploy an EHR in their practice; and (4) overall attitude toward the value of an EHR. 74 percent of the physicians said they are likely to purchase an ambulatory EHR over the next 3 years. Generally, physicians ranked the clinical benefits of EHRs higher than financial factors. Eighty percent ranked “coordination of care across care settings as the primary benefit.

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Oct-06	Dr. Helga Rippen, Senior Advisor, Health Informatics, HHS/ASPE	<p>ASPE Study: "Assessing the Economics of EMR Adoption and Successful Implementation in Physician Small Office Settings" . Practices b/t 1-9 Dr's account for over %80 physicians--they range from 13%-19.9% adoption; Practice Size 10-19 have 28% using EHRs; 20+ 38.9%. Previously accumulated human capital may be a significant factor in EMR adoption: Prior experience with EMR; Knowledge and experience with computer-related technology; Multi-disciplinary education and training (e.g. medicine and electrical engineering). Physicians face uncertainty in the selection process. Information from a variety of sources plays a key role in the decision process.</p> <p>Physician Perceptions R/T EMR :Barriers:: Concerns over privacy; Lack of evidence of effectiveness; Don't see value; Difficult building a strong business case; Concern over loss of productivity; Technology burdensome; Lack of support from practice physicians. Benefits: Physician champion; Improved decision making; Access to information; Decreased medical errors; Clinical guidelines; Increased patient volume; Improved workflow; Improved drug refills capabilities; Eliminate/reduce chart pulls; Decrease phone call turnaround time; Improved customer service; Increased time with patients; Improved quality of life. Decision to adopt, practices relied on: reviewing the literature, attending conferences or trade shows, consulting specialty societies, peers/colleagues, visiting sites. They did not believe this research was a barrier to adoption.</p>

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Oct-06	Dr. Richard Baron; President, Greenhouse Internists	Decision to adopt: #1 He had experienced the using HIT; Opportunity created by one time cash windfall from changing malpractice; Dubious about financial return; believed would enable better care of patients, customer stratification and communication; <u>Cost of adoption:</u> global incompetence due to workflow changes; patient unhappiness; need for parallel work flows; every patient had to be entered as a "new" patient (suggestion to allow for charge capture of this-- i.e., new patient visit to compensation for data conversion); need to est. new business relationships like IT support, telecommunications, etc. They value: accessibility of data to all and ability to do so remotely, email between patients and Dr., info contextually presented, Rx refills, prepopulated forms like authorization, pre-op, Liked the least/ Desired: more \$ for support/ training; working interfaces at time of implementation (took 3 mos); ongoing/escalating tech costs; downtimes; absence of financial return; absence of interoperability; administrative work shifting to Drs. Recommendation: Linking professional certification to HIT.
Oct-06	Dr. Blackford Middleton, Clinical Informatics R&D, Partners HC	Recommendation: Educational, Marketing and Supporting Activities: Est. education and marketing campaign for the public; Est. education campaign for health professionals; Est. education campaign for healthcare management; Create a National HIT Resource Center

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Jan-07	Chuck Parker—MassPro Chief Technology Officer / DOQ-IT	Mr. Parker reported that MA physicians' experiences with e-prescribing applications depend on whether they use (a) standalone e-prescribing applications, which are not integrated with the patient's EHR; (b) e-prescribing applications that are independent modules of EHR systems; or (c) CCHIT-certified EHRs that have e-prescribing built in. The standalone e-prescribing applications have several disadvantages (e.g., they necessitate a duplicate workflow; they do not allow drug-to-allergy checking; they do not involve the full practice) and do not provide an easy path to transition to a full EHR. <u>Consequently, Masspro has been steering physician practices away from the standalone applications toward the other two types of e-prescribing applications.</u> Physicians can get bonuses from payers for using full EHRs with the e-prescribing portion turned on first; then they can move to use other functions of the EHR
Jan-07	Dr. David Kibbe, Senior Advisor Center for HIT at AAFP	Presentation, "The Ecology of Health IT". The AAFP estimates that in 2003, about 10 percent of AAFP members were using EHRs, mostly to document their clinical encounters. Today, an estimated 40 percent of AAFP members are using EHRs, and most of them are focused on workflow changes. One of the most important workflow changes for family physicians is e-prescribing. Comments on the AAFP's EHR listserv and in focus groups suggest that AAFP members do not want a single-purpose e-prescribing application; they want a multipurpose EHR application with e-prescribing as a component. He did not feel that adoption of standalone eRX led to full EHR adoption.
Feb-07	Chuck Parker—MassPro Chief Technology Officer / DOQ-IT	Reviewed ASP EHR adoption and the DOQ-U learning tool. Within DOQ-It the 34 org. structures they are currently working with, all but two are creating or contracting for some level of ASP. (50% of these didn't begin until the relaxation of Stark)

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Mar-07	Chuck Parker—MassPro Chief Technology Officer & Sue Ordway / DOQ-IT	DOQ-IT University Demonstration--highlighted the different learning modules, learning goals, quizzes and surveys. With a focus on care management, these modules provide Drs with the tools necessary to assess their readiness for HIT/ EHR adoption.
Sep-07	Linda Kloss (Panel Leader), CEO of the American Health Information Management Association (AHIMA)	DOL forecast that 202,000 “medical records and health information technicians” would be needed by 2010. Meeting this goal would require 10,000 graduates a year - far more than the current 2,500 graduates a year. AHIMA has been promoting the migration from paper to EHR & funded the creation of Internet-based e-HIM Virtual Lab to provide state-of-the-art training for HIM students. In 2005, AHIMA and the AMIA hosted a summit & developed initial strategies to address workforce challenges related to EHRs and the NHIN. Developed national workforce action agenda and the publication of Building the Work Force for Health Information Transformation, a report with several recommendations for the Federal Government, employers, vendors and the healthcare workforce. AHIMA and AMIA have agreed to build on this report by working together to define a multiyear workforce research agenda, define basic competencies for those who use EHRs in their daily work, engage education leaders to prepare a vision of the academic resources and network needed, and seek federal and private funding to support these initiatives. Suggested several short-term actions to improve the HIT resource pipeline: (1)Conduct “boot camps’ for health information management technicians (2) Expand workflow management training for healthcare workers (3) Explore opportunities for vendor-sponsored apprenticeships (4)Institute teaming models: Clinical informaticists working with managerial or operations level HIM managers and technicians.(5) More training & faculty for the two-year prepared HIM technicians as they have been shown to be really effectively, multi-skilled workers in particularly smaller physician practices.

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Sep-07	Don Detmer, MD, President and CEO, American Medical Informatics Association (AMIA)	<p>AMIA's agenda is twofold: (1) transform health & care with informatics and (2) make informatics an identified health profession rather than an avocation. The field includes four major domains: (a) clinical informatics (implementing and using EHRs), (b) research informatics, (c) translational bioinformatics, and (d) public health and population informatics. All health professionals need basic knowledge and skills, chief information officers need applied clinical informatics, and public health and research informaticians need master's- or doctoral-level training. There are 37 or more formal informatics programs with 50 to 80 physicians in the pipeline a year and separate nursing informatics programs with 30 to 60 people in the pipeline a year. Dr. Detmer believes we have the capacity to triple output of informaticians. In 2005, AMIA announced its 10x10 Program to develop the capacity to train 10,000 health care professionals in informatics by 2010. About 500 people have been trained in this program to date.</p>

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Sep-07	William A. Yasnoff, MD, PhD, representing HHS/ Office of the Assistant Secretary for Planning and Evaluation (ASPE)	<p>Presented results of a ASPE NHIN Workforce study to develop a quantitative estimate of the additional human resources needed to install the NHIN for “anywhere, anytime health care information and decision support.” Heavily dependent on assumptions and expert input. 2 expert panels were convened to develop a detailed approach and framework for the study. A key assumption was that the size of the workforce needed to install the NHIN would be related to three independent NHIN activities: (a) EHRs in providers’ offices, (b) EHRs in hospitals and other institutions, and (c) the health information infrastructure in communities needed to create complete records. The expert panels identified 15 categories of personnel that would be needed for these three activities. Produced a flexible tool that can work with a variety of assumptions and scenarios to estimate the additional workforce needed to install the NHIN--would depend on the time frame of the implementation process. Assuming a five-year NHIN implementation period, estimate that installing EHRs for the 400,000 additional physicians EHRs would require 3,900 to 11,300 Full-Time Employees (FTEs), and attrition could make much higher. Installing EHRs for 4,000 hospitals would require 28,600 FTEs. Installing infrastructures for 300 communities would require 416 FTEs. These #s represent estimates of the additional workers who would be needed just to install the NHIN and are therefore extremely conservative. The study did not find data on the number of existing personnel and was not designed to address the question of whether there is a shortage of personnel needed to build the NHIN. There is not anything in this study that contradicts the general sense that there is a workforce shortage, especially if implementation of the EHRs takes off rapidly. Given that only 100,000 physicians have EHRs installed, it seems self-evident that the workforce needed to install EHRs for an additional 400,000 currently does not exist.</p>

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Sep-07	Don Schoen, CEO, MediNotes Corporation, and Chair, Healthcare Information and Management Systems Society (HIMSS) EHR Vendors Association	Workforce: Staffing requirements are directly related to EHR system functionality, practice size, or hospital and integration needs. Skills required by vendors:(a) IT staff (network expertise, systems integration and interfaces), (b) applications analysts, and (c) project managers with an understanding of clinical workflow and business. The personnel and skills required by health care providers are (a) IT staff (whether an ASP or onsite data center), (b) applications analysts (clinical or business background with understanding of organizational structure and workflow), and (c) other staff depending on whether the provider is rural or urban. Market forces will drive EHR vendors' workforce needs. As technology and standards evolve, IT staffing levels and skill sets may level out some. EHRs will improve care delivery for providers, making more staff available for IT projects. Vendors will seek HIT workers via recruitment of new workers from the existing workforce; recruitment from other health care org; realignment of health care staff from office to vendor staffing; and universities.
Sep-07	Carole A. Gassert, PhD, RN, Co-chair, Alliance for Nursing Informatics (AMIA Representative), TIGER Representative	3 million nurses practicing in the US represent 55 percent of all health care workers and are therefore a critical component of successful HIT adoption. The T.I.G.E.R. Initiative: enable practicing nurses & students to use technology and informatics to improve the delivery of care. Summit in 2006 developed a collective vision for HIT for the next 10 years, along with a 3-year action plan.. ANI represents a united voice for 26 distinct nursing informatics groups.The Technology Targets Study being conducted by the AAN is seeking to create an improved process for identifying technology and HIT solutions to improve the efficiency of care delivery in medical-surgical units, incorporating nurses' viewpoints. The HIMSS 2007 Nursing Informatics Survey found that 41 percent of nurse informaticists had no formal training in informatics, and 25 percent got their informatics training on the job. Are only 12 degree-granting programs in nursing informatics in the United States. More programs are needed but-- shortage of n

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Sep-08	<p><u>Implementation of EHR Systems in Acute Care Hospitals Panel:</u></p> <ul style="list-style-type: none"> - Bonnie Anton, RN, UPMC - Dr. Daphne Bascom, Managing Director, e-Cleveland Clinic - Dr. Craig Joseph, Epic, Physician, Clinical Informatics - Dr. Christoph U. Lehmann, Director, Clinical Information Technology, Johns Hopkins - Deb Rislow, Chief Information Officer, Gundersen Lutheran Health System - Dr. James M. Walker, Chief Health Information Officer Geisinger Health System - David Whiles, Director, Information Systems & Margaret Robinson, Midland Memorial Hospital 	<p>Key Themes: • Enthusiastic support for developing and implementing an EHR system from the hospital’s CEO and other top leaders, as well as from physician champions, is critical. • Any EHR project should be conceived of in terms of process transformation. Technology should be seen as the means to an end (e.g., improving patient care, improving the quality of care, enhancing operational efficiency, improving accuracy in billing, creating new knowledge), not the goal. • Leaders should not underestimate the forces that help maintain the status quo. In planning, leaders should take into account the fact that people experience change differently. • There are both direct and indirect costs (hardware, software, facilities changes, training, workflow, incentives for training) associated with the implementation and use of EHR systems in hospitals. Across a range of hospitals, some with more modest resources than others, costs were not a major obstacle to the implementation of an EHR system. • Involve everybody (e.g., physicians, nurses, support staff) in the selection and design of the EHR system. • Establish a clear document project structure and goals at the outset. • Start the design of tools with reports needed to meet needs such as recording clinical findings and plan of care, supporting clinical decision-making, communicating with other members of the clinical team, supporting billing and payer requirements, and providing a defensive tool against lawsuits. • Conceptualize any clinical document up front before spending a lot of time and energy building it in the system. Mock it up and obtain general approval prior to implementation. • Get lots of input before creating templates. Physicians often resist efforts to standardize and structure data collection because they feel they “lose the patient story” with templates. • Use a granular data structure that allows data (e.g., vital signs, allergies, medications, past medical history) to be pulled from previous documents so that they can be modified and used again. • Mandate use of the EHR system. A hybrid environment (paper and electronic) exacerbates frustrations. • Provide training and ongoing support for staff before and after the EHR system goes live. • Recognize that the time commitment needed to learn a new EHR system and perform documentation is daunting and that incentives for physicians may be needed to learn and use the system. Some physicians rerecord information available elsewhere in the patient’s EHR, because they are concerned about documentation requirements, leading to “note bloat.” • Have everybody on the care team (e.g., doctors, nurses, respiratory therapists, social workers) participate in the documentation process, so that the final document is a product of the team. • Monitor progress and make changes in the EHR system. Have frequent and realistic discussions about the impact of changes. Use tools such as an online suggestion box so staff can say how to improve system, weekly issues meetings to discuss suggestions and prioritize them), and weekly update emails to notify staff of any changes.</p>

APPENDIX C
Use Case Activities from the Electronic Health Records Workgroup

The AHIC workgroups, including the EHR, were instrumental in establishing priorities for the development of use cases to drive the standards harmonization and interoperability specifications development of ANSI-HITSP. To date, there have been three rounds of priority setting and use case development completed and the fourth round is currently underway.

Round 1: WG Priority: EHR WG specific charge: Laboratory results data (2006)

Use Cases:

1. Electronic Health Records (Laboratory Results Reporting) Harmonized Use Case
2. Harmonized Consumer Empowerment (Registration & Medication History) Use Case
3. Harmonized Biosurveillance (Visit, Utilization, and Lab Result Data) Use Case

Round 2: WG Priorities: Patient Identification; Medication List/ Allergy; (2007) Laboratory Results; Problem List; Clinical / Encounter Notes; Anatomic Pathology Results; Vital Signs; Family History/ Health Factors Radiology Reports: Not including images; Immunizations

Use Cases:

4. Emergency Responder EHR
5. Consumer Empowerment: Consumer Access to Clinical Information
6. Medication Management
7. Quality

Round 3: WG Priorities: same as Round 2 (2008)

Use Cases:

8. Remote Monitoring
9. Patient - Provider Secure Messaging
10. Personalized Healthcare
11. Consultation and Transfers of Care
12. Public Health Case Reporting
13. Immunizations & Response Management

Round 4: WG Priorities: Medication Management extension (CDS, drug-drug (2009) interaction, drug allergies, etc.); Lab orders; Expanded lab results (anatomic pathology, waveforms, radiographic images) Expanded eligibility

Use Case: Extensions & Gaps (round 1):

14. General Laboratory Orders

**ELECTRONIC HEALTH RECORDS WORKGROUP
SUMMARY AND FINAL REPORT
APPENDIX C**

- 15. Order Sets
- 16. Clinical Encounter Notes
- 17. Common Device Connectivity
- 18. Medication Gaps

Use Case: Extensions & Gaps (round 2):

- 19. Newborn Screening Use Case
- 20. Scheduling Extension/Gap

Use Case: Extensions & Gaps (round 3):

- 21. Consumer Adverse Event Reporting
- 22. Long Term Care - Assessments
- 23. Medical Home
- 24. Prior-Authorization

American Health Information Community

Electronic Health Records in U.S. Hospitals

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November 12, 2008



Background

- Level of adoption of EHRs in U.S. hospitals was unknown
 - Reported rates vary from 5% to 57%
- Prior surveys have produced unreliable estimates:
 - Mired with methodological problems including:
 - Unclear or poor definitions
 - Non-random samples
 - Poor response rate

Development of a Standardized Survey

- New inpatient survey of EHR adoption
 - Synthesis of prior surveys
 - Expert input
- Clearer definitions of functionalities
 - Data on where functionalities are implemented
 - Percentage of patients that receive care electronically

Survey Implementation

- **Target:** All acute care hospitals in the U.S.
- **Implementation:** American Hospital Association
 - Information Technology Supplement to the Annual Survey
 - Mailed and electronic survey with phone follow-up
- **Field Period:** February through September, 2008
- **Current analysis:** Approximately 3037 responded
- **Response rate:** 63%

Defining EHR Systems for Hospitals: Input from ECP

	Comprehensive EHR	Basic EHR Definition 1	Basic EHR Definition 2
Electronic Clinical Documentation			
Patient demographics	X	X	X
Physician notes	X	X	
Nursing Assessments	X	X	
Problem lists	X	X	X
Medication lists	X	X	X
Discharge summaries	X	X	X
Advance directives	X		
Results Viewing			
Lab reports	X	X	X
Radiology reports	X	X	X
Radiology images	X		
Diagnostic test results	X		
Diagnostic test images	X		
Consultant reports	X		

Defining EHR Systems for Hospitals... Asking our ECP

	Comprehensive EHR	Basic EHR Definition 1	Basic EHR Definition 2
Computerized Provider Order Entry			
Laboratory tests	X		
Radiology tests	X		
Medications	X	X	X
Consultation requests	X		
Nursing orders	X		
Decision support			
Clinical guidelines	X		
Clinical reminders	X		
Drug allergy alerts	X		
Drug-drug interactions alerts	X		
Drug-lab interactions alerts	X		
Drug dosing support	X		

Preliminary Data Analysis

	Comprehensive EHR	Basic EHR Definition 1	Basic EHR Definition 2
Among non-Federal U.S. acute care hospitals	1.7%	7.9%	12.0%

Results

	Fully Implemented Across All Units	Fully Implemented in At Least One Unit
Electronic Clinical Documentation	%	%
Patient Demographics	78	7
Physician Notes	13	15
Nursing Assessments	36	20
Results Viewing		
Lab Reports	76	7
Radiology Reports	77	7
Computerized Provider Order Entry		
Laboratory Tests	22	12
Medications	18	11

Discussion

- Very few hospitals have a comprehensive EHR
- Only 1 in 10 hospitals have basic EHR
 - CPOE for medications is the main barrier
- Many hospitals have key functions in place
 - Good place to start
- Improving quality and efficiency will require more advanced features
 - Including widespread CPOE, decision support

Limitations

- Preliminary analyses
- Non-response bias
- Distinctions between “have” and “use”

Summary

- Most hospitals in the U.S. do not have an EHR
- Infrastructure still in development
- Cost is likely a major barrier

American Health Information Community

Chronic Care Workgroup Workgroup Summary and Recommendations

Brian L. DeVore
Director of Industry Affairs
Intel Corporation

November 12, 2008

Chronic Care Workgroup Members

Co-Chairs:

- Craig Barrett, Ph.D. Intel Corporation
- Stewart Streimer, MPA HHS/Centers for Medicare and Medicaid Services

ONC Director:

- Karen Bell, M.D., MS DHHS/ONC

Members:

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- Sandeep Wadhwa, M.D., MBA University of Colorado

ONC Workgroup Lead:

- Yael Harris, Ph.D. DHHS/ONC
- Cinyon Reed DHHS/ONC

Chronic Care Workgroup

- **VISION:**
Care is available when ever the patient may need it.
Care is rendered wherever the patient may be (home, work, school, or while traveling).
- **BROAD CHARGE:**
Make recommendations to deploy widely available, secure technologies and solutions for remote monitoring and assessment of patients and for communication between clinicians about patients.
- **SPECIFIC CHARGE:**
Make recommendations so that widespread secure messaging is fostered as a means of communication between clinicians and patients about care delivery.

3

Chronic Care Workgroup History

- **January, 2006 – September, 2008**
- **26 public meetings**
- **45 public testimonies**
- **14 recommendations**

4

Key Issues

1. Reimbursement
2. Privacy and Security
3. Supporting Technology
4. Consumer and Clinician Access to Technology
5. Medical Liability and Licensure

5

Key Recommendations & Status

- Reimbursement Reform
 - Secure messaging pilot operational
 - Recommendation made to define care by service provided not setting for purposes of reimbursement
- Privacy and Security Issues
 - Forwarded to Confidentiality, Privacy & Security workgroup
- Technology
 - Use cases developed for secure messaging and remote monitoring
 - HITSP developing interoperability specifications for secure messaging and remote monitoring
 - HITSP working with private sector for remote monitoring standards

6

Key Recommendations & Status

- Provider and Patient Access to Technology
 - Federal Communications Commission (FCC) working to expand broadband nationwide for consumers and providers
 - Agency for Healthcare Research & Quality (AHRQ) funded study on health IT access among the elderly, chronically ill and underserved, nearing completion
- Medical- Legal Considerations
 - State Alliance practice task force related to state licensure and care across state lines
 - Common application for medical licensure

7

Opportunities for the Future

- The Secretary move forward with implementation of all recommendations made to date, within the parameters of their original intent.

Specifically:

- Recommendation 2.0.062007, which points to the need for reimbursement for clinician time and expertise, based on medical record evidence, independent of the physical location of either clinician or patient, if that encounter is supported by health IT which allows it to otherwise meet criteria for reimbursement; *and*
- Recommendation 2.1.062007, which underscores the need for robust, well designed studies which can demonstrate the value of care supported by clinical telecommunications among multiple settings.

8

Opportunities for the Future

- HHS leverage the experience and proven value in telehealth demonstrated by other parts of the Federal sector, notably the Veterans Affairs, the Department of Defense, and the Indian Health Service, in determining its coverage decisions.
- HITSP incorporate more private sector initiatives in its standards harmonization processes.
- AHIC 2.0 add representatives from the telehealth community to its membership list, which can ensure that this body moves toward more widespread adoption and use of telehealth capabilities.

9

Opportunities for the Future

- AHIC 2.0 be directed to recognize telehealth, in its broadest definition -- which includes remote monitoring, secure messaging, patient education programs, store and forward, and health IT supported direct care -- as a high priority with respect to transformation of our fragmented and inefficient health care system. In so doing, it should revisit the need for Value Cases related to Store and Forward and the Advanced Medical Home, both of which are built on telehealth capabilities.

10

Chronic Care Workgroup Recommendations

Recommendation 1.0

- The Secretary should use CPT-4 coding to reimburse for services such as secure messaging and remote care until we achieve widespread reimbursement reform for health care services.

Accept **Table** **Reject**

11

Chronic Care Workgroup Recommendations

Recommendation 2.0

- The AHIC, at its November meeting, should sunset the Chronic Care Workgroup, with greater emphasis now being placed on widespread adoption of the technologies available to both consumers and providers (represented by the Consumer Empowerment and Electronic Health Record Workgroups), which can improve communication between patients and their clinicians as well as better coordinate care among all their providers. It is anticipated that AHIC 2.0 will recognize and attend to the importance of telehealth, in its broadest terms, as one of its highest priorities.

Accept **Table** **Reject**

12



**CHRONIC CARE WORKGROUP
OF THE AMERICAN HEALTH IT COMMUNITY
SUMMARY AND FINAL REPORT
January 2006 – October 2008**

November 12, 2008

The Honorable Michael O. Leavitt
Chairman
American Health Information Community
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Chairman:

The Chronic Care (CC) Workgroup was formed in January 2006 to address both the broad and specific charges formulated by the American Health Information Community (AHIC):

Broad Charge for the Chronic Care Workgroup: Make recommendations to the Community to deploy widely available, secure technology solutions for remote monitoring and assessment of patients and for communication between clinicians about patients.

Specific Charge for the Chronic Care Workgroup: 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.

Over the past almost three years, the CC Workgroup has heard multiple public testimonies, discussed all relevant issues, and made recommendations to advance the charges stated above. As the Department of Health and Human Services (HHS) prepares to transition the initial AHIC to its successor, the CC Workgroup has prepared the attached summary of its deliberations, recommendations, and opportunities for future work.

The workgroup wishes to express its gratitude for the opportunity to bring the vision of person centric health closer to reality through use of secure, reliable health information technologies. We hope that this summary will prove useful to those who will continue the outstanding effort that commenced under your leadership.

Sincerely yours,

/Craig Barrett/
Craig Barrett
Co-chair, Chronic Care
Workgroup

/Stewart Streimer/
Stewart Streimer
Co-chair, Chronic Care
Workgroup

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Blue Cross/Blue Shield
Verizon Communications
HHS/Centers for Medicare & Medicaid Services
Group Health Cooperative
American Telemedicine Association
The Regence Group
American Diabetes Association
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Health Evolution Partners
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**CHRONIC CARE WORKGROUP
SUMMARY AND FINAL REPORT**

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1 INTRODUCTION

1.1 VISION

Our current health care system is fragmented, inefficient from multiple perspectives, and provider centric. Patients must find their way to various and multiple offices, clinics, and hospitals in order to access diagnoses, guidance, and treatments. We therefore think of care as being specific to a certain setting or individual clinician, not as the result of services provided by a team, which includes the patient and his/her advocates that can integrate its knowledge in order to provide the best care for that patient, wherever and whenever they need it.

True person focused care can be defined as the full array of services which are coordinated in a timely, efficient, safe, equitable, effective manner and which take into account patient preferences and circumstances. Contrary to our current approach, much of this care does not require an actual visit to a physician or facility. In most circumstances, care could be rendered wherever the patient may be (home, work, school, or while traveling) --- if appropriate information can be made available to or transmitted between that person and his/her clinician. The capacity for this type of “virtual” care is growing exponentially, as telemedicine expands to include information transmitted through monitoring devices, visual modalities, and remote diagnostic instruments. With advances in secure messaging and communication in an interoperable health IT environment, this information could be transmitted reliably, comprehensively, instantaneously, confidentially, and securely to support virtual care for anyone not requiring invasive procedures.

1.2 WG CHARGES

In order to realize this vision of person focused coordinated care supported by the ability to access and use electronic health information in caring for a patient wherever he or she may be, the Chronic Care Workgroup received both a broad and specific charge from the AHIC:

Broad Charge for the Workgroup:

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

Specific Charge for the Workgroup:

Make recommendations to the Community so that widespread use of secure messaging is fostered as a means of communication between clinicians and patients about care delivery.

2 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

The Workgroup first focused on the specific charge and explored a number of barriers and enablers of secure message communication between patients and their clinicians.

2.1 RATIONALE

Approximately 50-60 million Americans live stably with at least one chronic condition -- most have more than one. This 20% of the US population with stable chronic conditions manage a good part of their care themselves while monitoring diets, controlling weight, checking blood sugars, adjusting blood thinners, titrating asthma medications, etc. This population, above and beyond almost any other, requires frequent and easy communication with their clinicians for guidance and timely decisions so that their chronic condition can be better and more tightly managed in their home, work, and school environments with minimal disruption. As technology continues to find new and better ways to gather and transmit information through monitoring and communication devices, there will be an even greater opportunity to meet patients' needs for care wherever and whenever they require the time and expertise of their physician or clinician.

2.2 WORKGROUP DELIBERATIONS

Development of new technologies alone, however, will not lead to better care and outcomes. How it is adopted and used are critical components of success, as are the financial and social policies which either incent or disincent the adoption and use by both clinicians and consumers. After multiple presentations as public testimony ([see Appendix A](#)) the workgroup identified five areas where barriers limited the widespread adoption of secure communications between patients and their clinicians:

- **Reimbursement**

Lack of reimbursement for clinician time and expertise rendered outside of the office setting is the major barrier to widespread adoption of the use of secure messaging between clinicians and their patients.

- **Supporting Technology for Patient-Clinician Secure Messaging**

Technology solutions to support remote monitoring, assessment of patients and to allow for secure communication between clinicians, and between clinicians and patients must be based on standard transactions before they can be widely deployed as a means of chronic care improvement.

▪ **Consumer and Clinician Access**

In order to minimize disparities in health care related to the use of health information technology, it is necessary to identify barriers to use and employ strategies to ensure that secure messaging can be a viable technology for all population groups. Providers also have variable access to HIT, particularly in areas where broadband is not available.

▪ **Privacy and Security, with Respect to Patient Identification, Authentication, and Authorization**

Accurate, verifiable, unique patient identification and authentication is a foundational requirement both for supporting secure messages between patients and clinicians as well as for incorporating this information into electronic health records. This includes both records maintained by healthcare organizations as well as personal health records which may be maintained by patients.

▪ **Medical Liability and Licensure**

Existing state licensing laws prohibit a practitioner licensed in one state from providing advice/care/education using a remote communication modality to any of his/her patients residing in another state who are in their state of residence at the time of the virtual encounter.

3 RECOMMENDATIONS MADE BY AHIC, MAY, 2006 AND STATUS

The following recommendations which address technical, financial, and social barriers are specific to secure messaging between patients and their physicians and clinicians. They are, however, applicable to all types of telehealth communications.

3.1 CCI.0.052006

3.1.1 WORKGROUP RECOMMENDATION 1.0:

The U.S. Department of Health and Human Services (HHS) should develop and regularly update the evidence base for informed reimbursement policies with respect to secure messaging between clinicians and their patients. This should include monitoring and reporting the effect of secure messaging on cost, quality of care, patient and caregiver satisfaction, and medical-legal issues.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

- Sentence added to the end: “*HHS should encourage its Federal partners to do the same*”

Recommendation Status:

- In September 2007, a contract was awarded to Abt Associates to coordinate two pilot sites to test the value of secure messaging and test an approach to reimbursement of clinicians for use of this technology.
- GW/Harvard was awarded a separate contract to evaluate the pilot
- Results expected 2011.

3.2 CCI.1.052006

3.2.1 WORKGROUP RECOMMENDATION 1.1:

HHS should compile and assess the effect of various reimbursement methodologies for secure messaging on clinician workflow in various care models, and report on best practices.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

Recommendation Status:

- In September 2007, a contract was awarded to Abt Associates to coordinate two pilot sites to test the value of secure messaging and test an approach to reimbursement of clinicians for use of this technology.
- GW/Harvard was awarded a separate contract to evaluate the pilot.
- Results expected 2011.

3.3 CCI.2.052006

3.3.1 WORKGROUP RECOMMENDATION 1.2:

Public and private payers, including the Centers for Medicare & Medicaid Services (CMS), should contribute to the evidence for and information base on reimbursement strategies through direct reimbursement, pilot or demonstration studies, or coverage analysis for Internet-based patient/clinician encounters in accordance with guidelines developed by the American Medical Informatics Association, the American Medical Association, and the Massachusetts Health Data Consortium for structured secure messaging, including, but not limited to, encounters that qualify under CPT code 074T.

Final Recommendation Accepted by Secretary:

- Language revised to: “ *By 9/30/06, HHS should encourage public and private payers to consider implementing secure messaging pilots or demonstration projects based on HHS-recognized HITSP-approved standards that evaluate: a. Possible forms of reimbursement for secure messaging; b. Integration of secure messaging into*

clinician workflow; and c. Impact of secure messaging on patient involvement in their care. Specifically, ONC will work with CMS to implement this recommendation, consistent with existing statutory authorities.”

Recommendation Status:

- CMS will make a decision on Medicare reimbursement for secure messaging pending the results of the Secure Messaging pilot.

3.4 CC2.0.052006

3.4.1 WORKGROUP RECOMMENDATION 2.0:

HHS should convene the appropriate State agencies and professional societies to develop and adopt new licensing alternatives which will address the ability to provide electronic care delivery across State boundaries while still ensuring compatibility with individual State requirements.

Final Recommendation Accepted by Secretary:

- Language revised to: *“To the extent permitted under existing legal authority, HHS should convene the appropriate State agencies and professional societies to consider developing and adopting new licensing alternatives which will address the ability to provide electronic care delivery across State boundaries while still ensuring compatibility with individual State requirements.”*

Recommendation Status:

- In November 2006, NGA convened the State Alliance for e-Health to address cross-state issues including licensure.
- Health Care Practice Task Force presented recommendations relative to licensure on January 2008
- States working to develop standardized licensure criteria, beginning with physicians
- NGA to host a webinar to help inform Governors and state legislatures on this issue

3.5 CC3.0.052006

3.5.1 WORKGROUP RECOMMENDATION 3.0:

The Office of the National Coordinator for Health Information Technology (ONC) should direct the Health Information Technology Standards Panel (HITSP) to define standards for secure patient-clinician messaging transactions so that they may be interoperable with electronic health records.

Final Recommendation Accepted by Secretary:

- Language revised to: *“To the extent permitted under the existing contract with ANSI and FAR provisions, the appropriate Department contract officer should direct ANSI to direct HITSP to achieve the goal of the Community recommendation.”*

Recommendation Status:

- Remote monitoring use case was finalized February 2008
- Secure messaging use case was finalized February 2008
- Both use cases have been submitted to HITSP and will be submitted to the Secretary in January 2009.

3.6 CC3.1.052006

3.6.1 WORKGROUP RECOMMENDATION 3.1:

ONC should direct the Certification Commission on HIT to establish certification criteria for system interoperability with patient-clinician secure messaging.

Final Recommendation Accepted by Secretary:

- Language revised to: *“To the extent permitted under the existing contract with CCHIT and FAR provisions, the appropriate Departmental contract officer should direct CCHIT to achieve the goals of the Community recommendation.”*

Recommendation Status:

- Remote monitoring use case was finalized February 2008
- Secure messaging use case was finalized February 2008
- Once the Secretary recognizes the HITSP standards in 2010, they will be submitted to CCHIT for inclusion in the certification processes.

3.7 CC4.0.052006

3.7.1 WORKGROUP RECOMMENDATION 4.0:

The Agency for Healthcare Research and Quality (AHRQ) should conduct a synthesis of current knowledge from existing studies of health information technology use by elderly, ill, and underserved populations including an analysis of barriers and drivers. The barrier and driver analysis should elucidate for which subpopulations barriers can be overcome and how.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

Recommendation Status:

- AHRQ's Evidence-based Practice Center Request for Task Order “Barriers and Drivers of Health IT Use for the Elderly, Chronically Ill and Underserved” was awarded August 2007 to Oregon Health and Science University.
- Final Report due Fall 2009

3.8 CC4.1.052006

3.8.1 WORKGROUP RECOMMENDATION 4.1:

HHS will work with appropriate organizations to report on secure messaging availability to providers across the country and report on a plan and timetable to make securing messaging available uniformly.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

Recommendation Status:

- Federal Communications Commission (FCC) tasked with expanding broadband technology across U.S
- Current penetration rate is 45%
- Nationwide, 79% of households have access to high speed connections
- President's goal is broadband access available to all U.S. households by 2014
- FCC currently funding \$413 Million over three years to expand broadband technology in rural areas

3.9 CC5.0.052006

3.9.1 WORKGROUP RECOMMENDATION 5.0:

The Community should create a consumer empowerment subgroup comprised of privacy, security, clinical and technology experts from each Community Workgroup. The subgroup should frame the privacy and security policy issues relevant to all the Community charges and solicit broad public input and testimony to identify viable options or processes to address these issues that are agreeable to all key stakeholders. The recommendations developed should establish an initial policy framework and address issues including but not limited to:

- ◆ Methods of patient identification
- ◆ Methods of authentication
- ◆ Mechanisms to ensure data integrity
- ◆ Methods for controlling access to personal health information
- ◆ Policies for breaches of personal health information confidentiality
- ◆ Guidelines and processes to determine appropriate secondary uses of data
- ◆ A scope of work for a long-term independent advisory body on privacy and security policies.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

Recommendation Status:

- The Confidentiality Privacy and Security workgroup was created.
- CPS workgroup have made recommendations on methods of patient identifications.

- NHIN is working on mechanisms to ensure data integrity.

3.10 SUMMARY OF ACTIONS UNDERWAY AS A RESULT OF SPECIFIC CHARGE RECOMMENDATIONS:

As of spring, 2008, progress has been made on a number of these recommendations.

- A pilot to demonstrate the value of secure messaging is currently underway in two sites
- The National Governor's Association has convened a Task Force to address the barrier of state based licensure and the group is currently working to develop a standardized approach to licensure
- Use cases have been developed for remote monitoring and secure messaging
- HITSP standards for interoperability are being developed for secure messaging
- AHRQ funded a task order to investigate barriers and drivers of information technology use by elderly, chronically ill, and underserved populations
- The FCC is supporting widespread access to broadband access throughout the US
- The Confidentiality, Privacy, and Security Workgroup was formed in response to this and other Workgroups recommendations on the needs for clear policy and procedures to assure that appropriate privacy and security protections are maintained.

The intent of these recommendations is to enable secure messaging, and electronic health care in general, to be widely available to all. Through the implementation of these recommendations, patients will be able to take a more active role in managing their healthcare. The use of secure messaging is likely to change clinician workflow processes, but evidence indicates that the end result will likely be a beneficial outcome for both patient and clinician. The critical barrier remains the fact that clinicians will need to be reimbursed for their time and expertise in caring for patients in the virtual environment. Current reimbursement policies restrict the clinician to providing care face to face.

4 BROAD CHARGE

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

After finalizing the set of recommendations to address the specific charge, the workgroup turned its focus to the broad change.

4.1 RATIONALE

As noted, our healthcare "system" is characterized by significant fragmentation. There is little to no opportunity for any one clinician to have a comprehensive view of the

clinical information that has been generated about any one patient by multiple providers. This is particularly relevant for those with a chronic condition where lack of information on previous diagnostic or monitoring tests, medications, and other treatments, and important patient attributes (such as allergies, family history, and social history) are critical in assuring that all involved in the patient's health – clinicians, family, the patient themselves -- make the best care decisions. It is ESPECIALLY relevant for those individuals with multiple chronic conditions...where the presence of, or treatments associated with, one may have a significant effect on another.

4.2 WORKGROUP DELIBERATIONS

The workgroup heard public testimony from many sources ([see Appendix A](#)) that outlined how telehealth and remote care via remote monitoring devices can improve care for individuals with chronic conditions, leading to improved health outcomes and reduced costs and utilization. Testimony also emphasized the value of care coordination for this population and reiterated the need for interoperable health information.

A number of approaches to the use of electronic health information in the management of chronic conditions were explored. Provider-based approaches grant the physician access to the patient's comprehensive electronic data set and allow him or her to make use of functionalities which support better management of the patient's health. An second patient-based approach is the use of electronic health information by the patient, his/her family or, an alternative caregiver such as a home health agency which manages the information to provide better, more coordinated care. The third party (payer) approach involves working with entities such as disease management companies and health plans also frequently use electronic health information to track and better manage health care conditions for patients with chronic conditions. This information can be used to effectively develop care plans and identify potential problems promptly.

The barriers and enablers to support remote care and care coordination for those with chronic conditions are very similar to those for secure messaging between providers and patients: recompense for provider time and expertise on care rendered outside of the office setting, privacy and security concerns, medical legal issues, access to the technology for all populations, and interoperability standards for key data elements. An additional barrier is the need to engage multiple stakeholders in this process, not just one clinician caring for a specific patient.

The workgroup discussed several options designed to garner community support for comprehensive coordination of care and developed the following recommendations.

4.3 CCI.0.062007

4.3.1 WORKGROUP RECOMMENDATION 1.0

Secretary should make a use case for interoperability, including the interoperability of communication devices between patient and clinician electronic health products, a top priority.

Final Recommendation Accepted by Secretary:

- Recommendation accepted as is

Recommendation Status:

- Communications/Devices use case extension finalized Fall 2008
- Once HITSP has approved standards, they will be submitted to CCHIT for certification

4.4 CC2.0.062007

4.4.1 WORKGROUP RECOMMENDATION 2.0

The Secretary should support the development of legal guidance expanding the definition of a physician office by the services provided rather than the setting in which the care takes place.

Final Recommendation Accepted by Secretary:

- Accepted with the following caveats directed by the HHS Office of General Council:
 - Statutory changes may be required
 - Department can update list of Medicare- reimbursable telehealth services through Federal Regulations
 - Medicare can also explore payment that bundles these services with other care management activities

Recommendation Status:

- Workgroup has provided recommendations for new settings to be covered under Medicare's NPRM process

4.5 CC2.1.062007

4.5.1 WORKGROUP RECOMMENDATION 2.1

The Secretary should conduct a demonstration to evaluate the value of telehealth services in additional originating sites and clinical settings.

Final Recommendation Accepted by Secretary:

- Accepted with the following caveats directed by the HHS Office of General Council:
 - Based on fund availability

- Secretary should direct relevant agencies to
 - explore new demonstrations and initiatives to assess the value of telehealth
 - explore use of telehealth to improve quality and efficiency in treatment of Medicare beneficiaries
- ONC should collaborate with other HHS divisions in this effort

Recommendation Status:

- Accepted by Secretary July 2008

4.6 *CC3.0.062007*

4.6.1 WORKGROUP RECOMMENDATION 3.0

The Secretary should evaluate the benefits of remote store and forward technology to determine if these services should be expanded for Medicare reimbursement beyond Alaska and Hawaii.

Final Recommendation Accepted by Secretary:

- Accepted with the following caveats directed by the HHS Office of General Council:
 - Pertinent agencies should review data arising from use of store and forward technology.
 - Secretary should use these results to determine if benefits can be generalized to larger population.

Recommendation Status:

- ONC continues to evaluate available data sources

4.7 *CC4.0.062007*

4.7.1 WORKGROUP RECOMMENDATION 4.0:

The Secretary should conduct demonstration programs through the Medicare Advantage plans that evaluate the use of home based, remote care monitoring for the management of specific chronic conditions.

Final Recommendation Accepted by Secretary:

- Accepted with the following caveats directed by the HHS Office of General Council:
 - ONC should collaborate with other HHS agencies to leverage existing or future funded programs if relevant to home-based remote care management of chronic conditions.

Recommendation Status:

- None to date.

5 DISCUSSION

While much has been accomplished over the past several years with respect to identifying barriers and enablers to realizing the vision of a person-focused health care system, significant challenges remain. Legislative barriers continue to be paramount with respect to coordinating care with persons covered by Medicare -- the 14% of the US population most in need of these services. Without statutory change which will in some way allow reimbursement for care provided outside of specific, pre-specified locations (physician office, clinic, hospital, etc.), the American health care system will continue to focus on the type of services provided rather than the patient's response to the treatment. CMS is developing a demonstration project to evaluate the Advanced Medical Home, but results will not be available for several years. Meanwhile, science and technology have already advanced to the point where coordinated care supported by these technologies is being offered to patients in selected settings with positive results. Expanded public/private partnerships could be one way of expediting the process in specific geographic areas, but these types of relationships are still in a fledgling state.

Of note, both the Consumer Empowerment Workgroup and the EHR Workgroup have recognized the importance of patient engagement through secure messaging and patient access to information as well as the importance of clinician access to health information from multiple sources in order to better coordinate patient care and have made recommendations to the AHIC which dovetail with those of this Workgroup.

In addition, all three workgroups recognize the need for enhanced privacy principles, policies, procedures, and protections when information is shared or exchanged among multiple parties.

6 SUMMARY AND RECOMMENDATIONS FOR THE FUTURE

The CCWG has made a number of significant recommendations which, if implemented in a timely fashion, could improve the health of those with chronic conditions of all types. It has been careful to differentiate between those steps which the Federal Government may take and those which are driven by market forces, and has dovetailed its efforts with those of the Consumer Empowerment Workgroup and the EHR Workgroup by focusing on communication between patients and providers rather than widespread adoption of either PHRs or EHRs. As such, it has met the challenges of both its specific and broad charges. However, much work remains with respect to the implementation of these recommendations. The following, final set of recommendations from this workgroup, underscore the need to move swiftly and precisely towards implementation.

As AHIC 2.0 assumes the role of setting priorities for the National HIT agenda, the CCWG recommends:

- That the Secretary move forward with implementation of all recommendations made to date, within the parameters of their original intent. Specifically:
 - 1) Recommendation 2.0.062007, which points to the need for reimbursement for clinician time and expertise, based on medical record evidence, independent of the physical location of either clinician or patient, if that encounter is supported by HIT which allows it to otherwise meet criteria for reimbursement.
 - 2) Recommendation 2.1.062007, which underscores the need for robust, well designed studies which can demonstrate the value of care supported by clinical telecommunications among multiple settings.

Reimbursement reform with respect to how and where care is delivered through use of a wide array of safe, reliable, and secure health information technologies is the single most important step that can be taken to address the current crisis in healthcare costs and quality.

- That HHS use CPT4 coding to reimburse for services such as secure messaging and remote care until we achieve widespread reimbursement reform for health care services.

The use of CPT-4 coding for remote or virtual care is a critical first step towards better understanding of the value of this important technology.

- That HHS leverage the experience and proven value in telehealth demonstrated by other parts of the Federal sector, notably the VA, the DoD, and the Indian Health Service, in determining its coverage decisions.

The CCWG has heard testimony from multiple Federal agencies on the cost savings associated with the use of telehealth. This information base should be made available to others in the Federal Government responsible for coverage decisions with respect to Medicare and Medicaid.

- That AHIC 2.0 be directed to recognize telehealth, in its broadest definition which includes remote monitoring, secure messaging, patient education programs, store and forward, and HIT supported direct care, as a high priority with respect to transformation of our fragmented and inefficient health care system. In so doing, it should revisit the need for Value Cases related to Store and Forward and the Advanced Medical Home -- both of which are built on telehealth capabilities.

Most of our nation's healthcare costs are expended on those with chronic conditions or on the natural sequel of these conditions. Better management requires frequent and regular monitoring, treatment adjustments, and patient engagement – all of which

require immediate and frequent communication between patients and clinicians. Focusing on telehealth in its broadest sense may be the single most important step that AHIC 2.0 can initially take to addressing our current health care crisis.

- That AHIC 2.0 add representatives from the telehealth community to its membership list

Telehealth touches all stakeholders, and touches concerns about privacy, security and reliability of product, financing and reimbursement, access to care and use, and liability. As such it is a unique aspect of HIT and the health system that cannot be adequately represented by any of the existing membership groups.

- *AHIC 2.0 move incrementally toward assuring widespread adoption and use of telehealth capabilities*
- That HITSP incorporate more private sector initiatives in its standards harmonization processes

The private sector has been developing its own use cases, harmonizing or developing standards, and conducting detailed conformance testing. HITSP has begun to work with some of these entities, and should expand its leveraging of existing efforts.

- That the Chronic Care Workgroup sunset as of the November meeting of the AHIC, with greater emphasis now being placed on widespread adoption of the technologies available to both consumers and providers (represented by the Consumer Empowerment and Electronic Health Record Workgroups) which can improve communication between patients and their clinicians as well as better coordinate care among all their providers. It is anticipated that AHIC 2.0 will recognize and attend to the importance of telehealth, in its broadest terms, as one of its highest priorities.

7 CONCLUSION

Over the course of 25 meetings the Chronic Care Workgroup heard 45 public presentations from multiple stakeholders. This public testimony, along with rich and robust workgroup discussions, led to fourteen recommendations necessary to achieve widespread adoption of technologies known to improve outcomes associated with chronic care management.

These communication and remote monitoring technologies are technologically ready to meet the challenge, and patients with chronic conditions, or their designees, are ready to use them in order to better communicate with their clinicians. Until, however, there is

sufficient political and economic will to address the reimbursement changes necessary to care for patients in a comprehensive manner, there will be very limited use of these technologies by clinicians.

At its 26th and final meeting the workgroup developed a set of eight recommendations, including the recommendation for its sun setting. First and foremost, however, were its recommendations for widespread modification of reimbursement for care that will allow these technologies to be used for patients in any setting and at any time. The Workgroup members also made recommendations for AHIC 2.0 to recognize the key role that telehealth, in its broadest definition, plays in transforming our health care system into one that is more safe, timely, effective, efficient, equitable, and patient-centric.



APPENDIX A
Summarized Testimony from the Chronic Care Workgroup

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Financial Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
3/22/2006	Jonathan Linkous, American Telemedicine Association	<p>Implementation of Remote Health Services is impacted by cost</p> <p>Cost Factors for Evaluation (Secure Messaging)</p> <ul style="list-style-type: none"> • Patient: alternative health care costs, travel, time • Provider: reduced overhead costs, reduced time; improved productivity • Payer: reduced costs of in-office provider visits, reduced hospitalization, reduced cost of associated illnesses and extended care • Community: total health care cost reductions through improved health status
3/22/2006	Michael S Barr, MD, MBA, FACP Vice President, Practice Advocacy and Improvement American College of Physicians	<p>Framework for Reimbursement: The Advanced Medical Home Model; Acknowledges the value of both providing and receiving coordinated care in a system that incorporates the elements of the Care Model. Aligns incentives so that physicians and patients would choose medical practices that deliver care according to these concepts</p> <p>Framework for Reimbursement incremental strategy for reimbursement linked to infrastructure development; reporting of quality and cost measures; performance: outcomes.</p> <ul style="list-style-type: none"> • Coordination of care. • Adoption and use of health information technology for quality improvement • Enhanced communication access (ie...secure messaging and telephone consultation) • Remote monitoring • Reduced administrative requirements • Enhanced coverage and reduce co-insurance

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3/22/2006	Giovanni Colella, MD, Relay Health, Use of Secure Messaging in Commercial Populations: What is billable and results from Blue Shield of California pilot study on Secure Messaging	<p>The adoption of Secure Messaging currently includes 5,800 MD's and 530,000 consumers using the service. Results demonstrated substantial office-based cost reduction; less than a dollar 50 PMPM, asterisk; and high consumer and MD satisfaction.</p> <p>Adoption may be increased by providers if MDs were reimbursed for patient Web Visits based on AMA CPT code</p>
7/26/2006	Rhonda Chetney, RN, MS Director of Clinical Operations Sentara Home Care Services	<p>Findings are from a survey presented by Sentra Home Care Services</p> <ul style="list-style-type: none"> • Use of telehealth homecare visits, co-mingled with traditional in-person visits decreased the number of hospital admissions and emergency room visits; and improved the quality of life (qol) in patients with congestive heart failure (CHF) over 65 years old. • Home health cost savings: the cost per episode decreased by 49% in cost by the second episode. That is, as the patients received tele-health, the cost for the second episode was decreased by 49%. • ER visits decreased by 90% in the fist 3 months; by 76% at the 6 month marker. • Physician referrals to home health increased as a result of the cost savings demonstrated by this telehomecare program.
7/26/2006	Sandra Young, MSN, RN, BC Adult Medicine Nurse Specialist, Pitt County Memorial Hospital	<p>There was a 4 month trail of the Telehome Care program. Findings were a decrease in hospital admissions and emergency department (ED) visits with an initial cost savings of \$125,000.</p>

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7/26/2006	Justine Handelman, Blue Cross Blue Shield Association; Jeanette Thornton, American Health Insurance Plans - a. Survey of BCBS and AHIP Members	<ul style="list-style-type: none"> • One plan that responded is piloting a 10-Rreimbursement, but not reimbursing. An additional Blue plan had previously piloted using secure messaging for reimbursement with chronic conditions, but did were not able to garner a "critical mass" of support. • Most plans require a patient copay for a Web visit. • Plans were not able to quantify a return on investment since most who were doing secure messaging had only been doing it for 3 years or less.
7/26/2006	The Connected Health Initiative	Telemonitored patients required 40% fewer nursing visits to the home; 33% reduction in rehospitalization rates; improved QOL; improved appreciation for increased involvement with their care.
7/26/2006	Anand Parekh, HHS/OPHEP - Physician's perspective for remote monitoring/secure messaging demonstration	<ul style="list-style-type: none"> • Put forward a demonstration project that will outline the benefits of secure messaging to improve quality and reduce costs • Secure messaging services that may be eligible for reimbursement would depend upon the underlying reimbursement policy or care model adopted by CMS for physician services and payment. • Assessing the value of using secure messaging was drilled down to costs to CMS as potential reimbursement for each secure message. Other costs would be administrative overhead/transactions costs. • Costs will be offset by expected savings from: reduced cost/provider visit; reduced hospitalizations; reduced cost of associated illness by engaging in secure messaging.
8/16/2006	Malcolm Costello, VP Marketing, and Barbara Klein, VP Provider Sales of Kryptia Corporation	<p>Case Study 1: Out of office Patient Encounters findings Cost Savings</p> <ul style="list-style-type: none"> • Over \$30k saved in annual test results mail cost • Over \$19k saved in staff time spent managing test results • Over \$20k saved in staff time for phone follow-up per post visit • Over \$4900 saved per physician/per year for office visit follow-up

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8/16/2006	Joseph Kvedar, M.D., Partners Healthcare Telemedicine, ConnectedHealth Initiative	The hospital system reimburses the home health agency for patient monitoring, an arrangement that seems to benefit the hospitals financially in an environment of high occupancy rates.
10/16/2006	Brian Austin, MacColl Institute for Healthcare Innovation, Center for Health Studies	Resources and policies in the community influence the kind of care that can be delivered.
2/15/2007	Dena S. Puskin, Sc.D., Health Resources and Services Administration (HRSA) Office of Health Information Technology and Office for the Advancement of Telehealth, described HRSA-supported projects	<ul style="list-style-type: none"> • Real time and store and forward images have different implications for CMS reimbursement. • CMS policy allows the substitution of telecommunication for face-to-face, hands-on encounters for consultation office visits, individual psychotherapy, and pharmacological management, by specific classes of professions in Medicare-certified sites in rural areas. • Store and forward services may be reimbursed if they are the type of services for which face-to-face contact has never been required. • Not reimbursed are services that are typically face to face that now can be provided remotely.
4/26/2007	Sharon Bee Cheng, PhD, Senior Analyst at the Medicare Payment Advisory Commission (MedPAC), MedPAC: Defining role in P4P/Remote Care and Telehealth	<p>MedPAC Commission is an independent Federal body established by the Balanced Budget Act of 1997 to advise Congress on Medicare.</p> <ul style="list-style-type: none"> • In March 2005, MedPAC Commission recommended to Congress that pay-for-performance include measures of health information technology (HIT) functionality. • The Commission is working on pay-for-performance for home health recommendation to be presented to Congress June 1, 2007. • The use of telehealth in home health has the potential for reducing costs and improving case coordination. • MedPAC recommended that Congress direct CMS to include measures of functions supported by the use of HIT in Medicare initiatives to financially reward providers on the basis of quality.

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4/26/2007	Jonathan Linkous, Executive Director, American Telemedicine Association	<p>Remote health care is supported by several Federal agencies such as DoD, VA and IHS along with several others.</p> <ul style="list-style-type: none"> • Thirty-four state Medicaid programs reimburse for telehealth services and most of them do not have the geographic or provider-type restrictions that Medicare has. • Prisoners have state-supported remote services • Private payers are increasingly supporting remote services. • Private payers tend to reimburse at rates similar to those for face-to-face encounters. • Medicare use of telehealth has been very slow and there has been reduced Federal support for other telehealth programs except for earmarked military projects, coverage by State. <p>Barriers to better Medicare coverage include the following:</p> <ul style="list-style-type: none"> • Remote consultations are restricted to specific services and facilities and by geography and type of provider. • Diagnostic services are generally limited to teleradiology, telepathology, and continuous cardiac monitoring. • Incentives are not provided for home telehealth.
7/17/2007	Adam Darkins, MD, MPH, FRCS, of the VA - Evaluating Benefits of Telehealth	<p>Telehealth Evaluation findings</p> <ul style="list-style-type: none"> • With remote monitoring there was an approximately 30 percent reduction in bed days, hospitalizations, and emergency room visits • Immediate increase in outpatient clinic visits, which eventually leveled • Patient satisfaction was high

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7/17/2007	Stewart Ferguson, PhD, Director, Alaska Federal Health Care Access Network (AFHCAN) Alaska Native Tribal Health Consortium - Information on Value of Store-and-Forward Technology	<p>Benefits of telehealth “Store and Forward” technologies in rural areas, underserved and under populated areas.</p> <p>Benefits include the following:</p> <ul style="list-style-type: none"> • Cost savings in travel • Increased patient throughput • Presurgical planning • Postsurgical follow-up • Improved triage decisions • Empowerment of midlevel health workers (community health aides) • Reduced cost for care
9/27/2007	Gordon Norman, MD, MBA, Executive Vice President and Chief Science Officer, Alere Medical, Inc. - Clinical Decision Support Systems and Care Coordination.	<p>Alere is transitioning from disease management to a full personal health support service to include chronic condition management with remote monitoring, prevention and wellness services, disability and absence management, EAP integration, clinician and medical home support, and PHR and EHR. Dr. Gordon emphasized that the value of the HIT is the information provided to the physician and how that contributes to the management of the patient, not the technology.</p> <p>Services are reimbursed by the Health plans paying a negotiated fee for Alere’s services; fees are negotiated on bases such as per capita member or per capita high-risk patient.</p>

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9/27/2007	Judy Flynn, BSN, MBA, Chief Clinical & Compliance Officer, Partners Health - Patient Focus Model	<p>Judy Flynn discussed coordinating care for patients with high cost diseases, the purpose of which is to reduce hospitalizations for patients with complex conditions, as well as to provide end-of-life care. Currently, 150 persons are on telemonitoring devices. Partners' system includes several components:</p> <ul style="list-style-type: none"> • Medicaid and free care patients are connected to telephonic health coaches who provide a variety of services, including referral to home care social services. • A structured "Identify and Connect" program focused on heart failure. Doctors may "opt out." • A cardiac summit that serves as a forum for representatives from the health care team to share best practices, guidelines, and standards of care. <p>The home care system has two components: home care for heart failure and telemonitoring.</p> <p>Payers do not reimburse for telemonitoring, which is expensive; however, to the extent that it reduces the expenses for an episode of care, it is paid for. Foundation and private contributions, as well as Partners' allocations, have provided support. A CMS demonstration project is in process at one of the participating medical centers.</p>
9/27/2007	Jaan Sidorov, MD - Disease Management Model	<p>Dr. Sidorov commented that there are generally two approaches to disease management: cost savings by insurance companies versus business revenue generating. His presentation included quantitative data on the positive outcomes of disease management compared with standard care.</p> <p>He reported that new models must accommodate EHR and pay for performance and care coordination for chronic conditions. EHR needs to accommodate population analysis, and not be limited to one-on-one patient management.</p>

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11/1/2007	Jim Coan, MS, Centers for Medicare & Medicaid Services - Medical Home Demonstration	<p>Jim Coan described a three year demonstration project that is expected to start in January 2009. The design is directed toward an older, high-need population with multiple chronic conditions, but it will not examine access. The demonstration project will look at developing an operation definition of the medical home.</p> <p>Under the demonstration, Medicare will pay a fee for care management by the physician in addition to the fees for other services. The payment will be based on savings generated.</p>
1/17/2008	Eric Pan, MD, MSc, Center for Information Technology Leadership - Report on the Value of Telehealth	<p>Presentation given on the CITL report on The Value of Provider-to-Provider Telehealth Technologies.</p> <p>In his analysis he reported on the three types of telehealth used in the model and analysis which are</p> <ul style="list-style-type: none"> • Store-and-Forward is the collection and storage of clinical data or images which are later forwarded for interpretation at a time distant from a face-to-face clinical encounter. • Real-Time Video is an interactive clinical encounter performed using only live audio-video technologies. • Hybrid technology integrates store-and-forward technology with real-time video technology. <p>He described how the three types vary in initial cost, maintenance costs, benefits, and cost-benefits in several transport settings emergency department to emergency department, correctional facilities to emergency department, and nursing homes to emergency departments. The overall conclusion was that the benefit of telehealth systems outweighs the cost, and the hybrid is the most cost-effective system in the long-term.</p>

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1/17/2008	Stewart Ferguson, PhD, Alaska Native Tribal Health Consortium, John Kokesh M.D, Chris Patricoski M.D, and Phil Hofstetter - Alaska and Hawaii Store and Forward	<p>ONC commissioned the study in conjunction with a recommendation made by the Workgroup in June 2007.</p> <ul style="list-style-type: none"> • The Alaskan providers are highly satisfied with telehealth. • Store-and-forward has public health surveillance benefits. • Telehealth increases access in remote areas such as Alaska and Hawaii • By decreasing the amount of time required for a consultation, telehealth frees up time for additional consultations, thereby increasing accessibility. • In addition to the reduction in transportation costs, the savings in lost productivity (time away from the workplace) should be considered.

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Testifying Date	Testifiers Name	Points Made by Testifier
3/22/2006	Joanne Lynn, MD, RAND Corporation and CMS, Chronic Care Populations: Their needs and HIT opportunities	<p>Creating a Health IT care that can be designed around the health care needs of the population:</p> <ol style="list-style-type: none"> 1. Healthy 2. Maternal and Infant 3. Acutely ill 4. Chronic condition 5. Stable, disabled 6. EOL, short decline 7. EOL, erratic with sudden dying 8. EOL, long dwindling course <p>Themes for HIT: Decreased administrative burden, Remote access to care: e-visits and monitoring, reliable 24 7 communication, portable health information, patient slash consumer control and focus, continuity of care across settings, informed patient engagement, protections from preventable ADE's, and regionalization of records, coverage, and</p>

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		services.
3/22/2006	Daniel Sands, MD Beth Israel Deaconess Medical Center and Harvard Medical School, Zix Corporation, Guidelines for use of Electronic Communication	Policies: Social and Practical <ul style="list-style-type: none"> • Route messages to appropriate personnel • Inform patients that the other staff or providers might read messages • Senders must identify themselves and patient • Establish and enforce message turnaround time • Include prior communications thread in message replies • One topic per message • Revoke access of patients who breach policies
3/22/2006	Giovanni Colella, MD, Relay Health, Use of Secure Messaging in Commercial Populations: What is billable and results from Blue Shield of California pilot study on Secure Messaging	Physician adoption challenges.
11/8/2006	Sandeep Wadhwa, M.D., M.B.A., Vice President, Government Strategic Programs, McKesson Health and Chair, Disease Management Association of America (DMAA) Government Affairs Committee – Health Information Technology (HIT) and Medicare Health Support	Payers recognize that contemporary health systems do not provide sufficient support services for chronic care patients. They are supporting programs for disease management with the expectation that additional services will reduce avoidable use and be self-financing. Dr. Wadhwa stated, “In our calculus, we’ll generally ask for 4–5 percent of expected claims and guarantee 10 percent reductions.” “participating providers are financially vulnerable due to reimbursement policies. Their patients are extremely vulnerable because of characteristics related to poverty as well as their physical and mental status. He emphasized the need for an advanced medical home vision and stated that in-home monitoring was becoming standard practice.”
7/26/2006	Rhonda Chetney, RN, MS Director of Clinical Operations Sentara Home Care Services	Findings are from a survey presented by Sentra Home Care Services were QOL improved by 51% and older adults utilized the technology involved with telehealth well.

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7/26/2006	Sandra Young, MSN, RN, BC Adult Medicine Nurse Specialist, Pitt County Memorial Hospital	After the 4 month trial of the Telehome Care program Patient self-management skills for chronic diseases were enhanced. Increase in readiness for telehealth visits. Changes to physician [provider] workflow and changes to RBRVU and productivity are not known.
8/16/2006	Eileen Elias, U.S. Department of Health and Human Services (HHS), Office on Disability	Only 38 percent of persons with disabilities use the internet
8/16/2006	Edward Fotsch, M.D., CEO of Medem	<p>The challenge is patient engagement. When messaging is made available to patients, there is a very low uptake. Consumer engagement will require a mandate</p> <ul style="list-style-type: none"> • eConsultants as a standalone will fail • Patient engagement must be inserted in the patient-provider relationship • Replace the clipboard and engage patients online by default
8/16/2006	Joseph Kvedar, M.D., Partners Healthcare Telemedicine, ConnectedHealth Initiative	<ul style="list-style-type: none"> • Self Management to increase the quality and capacity • More effective use of providers • Motivation and Support • Patient Education

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10/16/2006	David L. Whitlinger, President and Board Chairman, Continua Health Alliance; and Director, Healthcare Device Standards, Intel Corporation	<p>Working to establish an ecosystem of interoperable personal health systems that empower people and organizations to manage their health and wellness better. The three major “themes” are:</p> <ul style="list-style-type: none"> – health and wellness, – chronic disease management – elderly monitoring <p>A major purpose across all three themes is behavioral modification.</p>
10/16/2006	Brian Austin, MacColl Institute for Healthcare Innovation, Center for Health Studies	<p>The Four aspects of care:</p> <ul style="list-style-type: none"> - Self-management support (how we help patients live with their conditions) - Delivery system design (who is on the health care team and in what ways we interact with patients), - Decision support (what is the best care and how do we make it happen every time) - Clinical information systems (how do we capture and use critical information for clinical care). <p>These four aspects of care reside in a health care system, and some aspects of the greater organization influence clinical care.</p> <p>The health care system itself exists in a larger community.</p>

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11/8/2006	Sandeep Wadhwa, M.D., M.B.A., Vice President, Government Strategic Programs, McKesson Health and Chair, Disease Management Association of America (DMAA) Government Affairs Committee – Health Information Technology (HIT) and Medicare Health Support	Three projects were described: Mississippi – Center for Medicare & Medicaid Services (CMS) and McKesson Health Solutions; Tennessee – CMS and XLHealth Corporation; and Illinois – Illinois Department of Healthcare and Family Services and McKesson Health Solutions. The case studies are nonrandomized control demonstration or research projects supported by CMS. Only preliminary output data are available at this time. Patients are characterized as having a high prevalence of co-morbidity – diabetes, congestive heart failure, mental illness, and psychosocial issues. Services include a patient registry deployed in participating physician offices, semiannual reports to monitor physicians’ guideline adherence, decision support at point of care, inclusion of reports in patient charts, patient alerts to physicians, in-home devices to monitor weight and blood pressure, and a personal emergency response system that notifies a nurse call center. Medicare claims data are fed back to providers.
4/26/2007	Jeffrey Rideout, Chief Medical Officer of Cisco Systems Employers Driving Health Care: Does It Help Activate Consumers and/or Providers?	<ul style="list-style-type: none"> • Cisco’s health management and improvement efforts have been implemented to promote healthy behaviors and increase employee productivity. • The introduction of secure messaging between providers and patients resulted in a reported 87 percent reduction in time spent away from work • the number of office visits decreased after implementation of the secure messaging program • This resulted in a net cost savings to Cisco of \$14,536 in the first year

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Cultural Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
9/27/2007	Lisa Letourneau, MD, Maine Medical Center - Care Coordination: Delivery System Model	<p>According to Dr. Letourneau, the CIR drives continuous quality improvement. It enables patient-centered, collaborative care; provides CDS; and supports practice- and system-level population data reporting. The CIR generates patient education and self-management print materials. It enables physicians to participate in local population-based reporting. The PHO established a quality rewards program that offers primary care physicians direct financial rewards for meeting certain targets. Learning collaborative were used to support implementation as physicians signed on. Dr. Letourneau noted that there were positive outcomes from patient participation in the programs.</p>
11/1/2007	Jody Blatt, Centers for Medicare & Medicaid Services - Medicare Care Management Performance Demonstration	<p>Jody Blatt described the demonstration project that CMS launch in July 2007.</p> <p>Data is being collected on 26 clinical quality measures, selected for their consistency with measures used in other settings and their applicability to the conditions of interest.</p> <p>There are three components of the incentive payments, which are based upon both achievement of quality and the use of EHR:</p> <ol style="list-style-type: none"> 1. Annual "Pay for Performance" for achieving quality benchmarks during the demonstration year based upon the proportion of benchmarks achieved 2. One-time, initial "Pay for Reporting" of baseline data, with the payment not contingent upon performance scores 3. Annual EHR reporting incentive for reporting quality measures electronically from a CCHIT-certified EHR

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Cultural Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
11/1/2007	William S. Dalton, PhD, MD, President and CEO, Moffit Cancer Center and Research Institute - Comprehensive Care Management for Cancer	Dr. Dalton described the database his organization implemented to coordinate care for survivors of cancer due to the lack of continuity of follow-up care for cancer patients. The database collects data on patients prospectively through their lifetime, and includes clinical data and molecular data from tumor, blood, and urine samples.

Technical Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
3/22/2006	Giovanni Colella, MD, Relay Health, Use of Secure Messaging in Commercial Populations: What is billable and results from Blue Shield of California pilot study on Secure Messaging	Adoption of Secure Messaging: Physician adoption has been the biggest challenge: Growing reimbursement, focus on office efficiency, and increased physician IT adoption is turning the tide.
7/26/2006	Anand Parekh, HHS/OPHEP - Physician's perspective for remote monitoring/secure messaging demonstration	<ul style="list-style-type: none"> • Determine if secure messaging or "security messaging" should be bundled in the demonstration project to determine cause and effect. (control group vs. experimental group) • Patient viewing of EHR may be too restrictive a requirement for small providers and other due to low prevalence of EHR adoption. • Technological services that could be in a demonstration under secure messaging: online consultation, remote monitoring
7/26/2006	The Connected Health Initiative	Wounds in the following categories are being imaged: statis, traumatic, surgical, and pressure. Pictures are currently captured using a commercially available digital camera. The Initiative plans to improve workflow by use of a cell phone camera.

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Technical Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
8/16/2006	Edward Fotsch, M.D., CEO of Medem	<p>Place patients on a network by default, referred to as replacing the clipboard. An interactive personal health record that replaces the clipboard creates a network. The network then connects a patient to a series of online tools, including communication with the provider.</p> <ul style="list-style-type: none"> • Patient is taken through a simple online registration process • Patient selects or confirms conditions and medications from a pick-list or drop-down menu • Patients are auto-enrolled in education programs for their meds & conditions • Patients control access to their information
8/16/2006	Malcolm Costello, VP Marketing, and Barbara Klein, VP Provider Sales of Kryptia Corporation	<p>Case Study 1: Out of office Patient Encounters findings</p> <ul style="list-style-type: none"> • Allows for fast, spontaneous, interactive physician-patient communication • Directly documented in EHR – no added steps • Asynchronous – makes solution convenient and improves confidence in secure message delivery for both physicians and patients <ul style="list-style-type: none"> • Integration of e-mail into daily workflows is key to adoption and reaching goals set out by deployment of technology • Just as e-mail catalyzed PC adoption, secure messaging has potential to accelerate clinical IT adoption
8/16/2006	Eileen Elias, U.S. Department of Health and Human Services (HHS), Office on Disability	<p>Presented secure messaging and remote monitoring from the perspective of the disability community. While telecommunication may increase access for this population, only 38 percent of person with disabilities use the Internet</p>

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Technical Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
8/16/2006	Adam Darkins, Chief Consultant, Office of Care Coordination, Department of Veterans Affairs	Described the increasing use of informatics and telemedicine to coordinate home care and provide disease management for veterans, many of whom are geographically and seasonally mobile.
8/16/2006	James D. Ralston, M.D., M.P.H., of Group Health Center for Health Studies, University of Washington	Described a research project involving secure messaging included in a patient portal to the EHR, part of an overall effort to shift from physician-centric to patient-centric care. <ul style="list-style-type: none"> • Complete access to the electronic medical record • Uploading blood glucose levels • Integrated disease management tools • Secure electronic mail • Web links for diabetes
8/16/2006	Joseph Kvedar, M.D., Partners Healthcare Telemedicine, ConnectedHealth Initiative	Patient-Centric <ul style="list-style-type: none"> • Care when and where it is needed • Patients to have access to their own health records • Remote Care delivery • Remote Monitoring • Remote Diagnostics

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Technical Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
10/16/2006	Karen Trudel, Centers for Medicare & Medicaid Services (CMS)	<p>Results of a synopsis from CMS with input from the Disease Management Association of America (DMAA) showed how HIT opportunities affect the chronic care populations and what would be useful.</p> <ol style="list-style-type: none"> 1. general educational information for patients and caregivers 2. tailored educational information for patients and caregivers 3. fall monitoring with automatic messaging 4. weight monitoring and messaging 5. glucometer monitoring and messaging 6. prescription refills 7. online appointment scheduling 8. two-way provider-patient communication 9. two-way communication between providers 10. medication compliance monitoring
2/15/2008	Marty Rice and Joanne Lynn, MD, Centers for Medicare & Medicaid Services - Overview of the CARE Tool	<p>CMS to develop and test a uniform assessment instrument to measure and compare Medicare beneficiaries' health and functional status across provider settings. Three contracts have been awarded to start the pilot study process. CARE will be a Web-based application and will use HL-7, SNOMED, and LOINC standards. It will be used across different care environments acute care, skilled nursing facilities, intermediate care facilities, and home health agencies.</p>
2/15/2008	Kate Christensen, MD, FACP, Kaiser Permanente - Interactive Care Plans	<p>Dr. Christensen described Kaiser's integrated system both online and offline Patient adoption of the online personal health record (PHR) has reportedly been rapid, with secure messaging to physicians and viewing lab results being the most frequently used aspects. A vast array of health information is available to both members and non-members at the Web site.</p>

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Medical Legal Issues		
Testifying Date	Testifiers Name	Points Made by Testifier
3/22/2006	Daniel Sands, MD Beth Israel Deaconess Medical Center and Harvard Medical School, Zix Corporation, Guidelines for use of Electronic Communication	<p>Medical legal Issues:</p> <p>Understand appropriate versus inappropriate use</p> <p>Use Web messaging or encrypted e-mail rather than insecure e-mail when practical</p> <p>Provide E-care only to established patients who agree to this form of communication</p> <p>Document agreement in record</p> <p>Save messages in the patient's record</p> <p>Log off of computers and use screensavers</p> <p>Hide recipient names when sending messages to multiple patients; BCC</p>
7/26/2005	Rhonda Chetney, RN, MS Director of Clinical Operations Sentara Home Care Services	Patients had to consent to utilize telehomecare and homecare was by physician order.
7/26/2005	Anand Parekh, HHS/OPHEP – Physician's perspective for remote monitoring/secure messaging demonstration	<ul style="list-style-type: none"> • There may be some circumstances where the care provider who interacts with the patient is a non-physician. (i.e. patient has a question another individual in the office can answer). • Fraud and abuse issues under the fee for service model. Not sure of what issues are but would like to raise the topic to maintain program integrity.
4/26/2007	Robert Waters, Partner of Drinker Biddle Gardner Carton – What Is Covered Under Current Legislation?	<ul style="list-style-type: none"> • Several opportunities to provide higher quality and less costly care. • Barriers are statutory and economic. • An experimental demonstration in which a monitoring company could keep its cost savings is needed. • In earlier demonstration projects CMS funded equipment but did not reimburse the physicians for patient encounters. This resulted in a very low level of adoption by physicians.

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Privacy, Security and Confidentiality		
Testifying Date	Testifiers Name	Points Made by Testifier
3/22/2006	Joanne Lynn, MD, RAND Corporation and CMS, Chronic Care Populations: Their needs and HIT opportunities	The following outstanding issues related to the chronic care population, their needs and HIT: Governance: who controls data flow Financing: for sustainability Privacy and security Standards and interoperability Prioritization System redundancy and backup
3/22/2006	Daniel Sands, MD Beth Israel Deaconess Medical Center and Harvard Medical School, Zix Corporation, Guidelines for use of Electronic Communication	Inappropriate Uses of Secure Messaging: Medical emergencies Time-sensitive issues Issues requiring Lengthy messages Long volleys of messages Communicating bad news Sensitive issues If weak system security
3/22/2006	Giovanni Colella, MD, Relay Health, Use of Secure Messaging in Commercial Populations: What is billable and results from Blue Shield of California pilot study on Secure Messaging	Secure messaging includes a portfolio of secure online communication services that improve consumer convenience and access, boost provider productivity, and enable payers to better manage cost and care
7/26/2006	Justine Handelman, Blue Cross Blue Shield Association; Jeanette Thornton, American Health Insurance Plans - a. Survey of BCBS and AHIP Members	For plans that provided secure messaging, the primary source was as part of the electronic health record (EHR).



American Health Information Community

Secure Messaging Pilot

Mohandas Nair

The Regence Group and
Member, Chronic Care Workgroup

November 12, 2008

Secure Messaging - What is It?

- Ability to communicate online with one's physician in a secure and reliable fashion.
- First step in engaging patients and consumers in the use of their own health information to better manage their health.
- Key barrier - lack of reimbursement for the clinician's time and expertise.
- Potential benefits: patient satisfaction, provider satisfaction, improved access, more timely care, decreased costs, improved care management.

AHIC Recommendation

- CC1.2.052006
- HHS should encourage public and private payers to participate in a pilot project demonstrating the value of secure messaging between patients and clinicians
- Accepted by AHIC: May 2006
- Accepted and signed by Secretary Leavitt: December 2006

3

Implementation

Two sites: Bangor, Maine, and Portland Oregon

East Bangor, Maine

- Eastern Maine Medical Center
- Six practice sites; 45 clinicians

Portland, Oregon

- Providence Group
- Seven practice sites; 54 clinicians
- Mohan – person on the ground to report to AHIC

Independent on-going evaluation

- Will have qualitative results in a year, quantitative in two years

4

Regence's Perspective

- Regence is volunteering without HHS funding because...
 - ❑ High cost supplier → low cost consumer
 - ❑ Complex → simple
 - ❑ Institution control → member enabled
 - ❑ Medicare → Medicare and commercial

5

Secure Messaging Pilot: Key Elements

- Clear guidelines for defining secure messaging
- Reimbursement to providers for time and expertise
- Workflow adjustments
- Ability to offer to all patients in any one practice
- Methodologically sound evaluation

6

Evaluation Metrics

- Short Term - Qualitative Measures
 - Patient satisfaction
 - Provider satisfaction
 - Timeliness
- Long Term - Quantitative Measures
 - Efficiency
 - Access
 - Costs
 - Clinical outcomes

7

Summary

- Secure messaging pilot designed to answer the outstanding concerns and questions of the value of offering reimbursement for secure messaging to the Medicare population.
- In addition, Regence is volunteering (unfunded by HHS) to study secure messaging in the commercial marketplace.
- Information from this pilot will help inform reimbursement policies in multiple types of care settings.

8

American Health Information Community

Consumer Empowerment Workgroup Workgroup Summary and Recommendations

Nancy Davenport-Ennis
National Patient Advocate Foundation
Chair, Consumer Empowerment Workgroup

November 12, 2008

Consumer Empowerment Workgroup Members

Co-Chairs:

- Nancy Davenport-Ennis National Patient Advocate Foundation
- Rose Marie Robertson, MD American Heart Association

Members:

- Jason Bonander, MA Centers for Disease Control and Prevention
- Jodi Daniel, JD, MPH DHHS/ONC
- Lorraine Doo, MSWA, MPH Centers for Medicare and Medicaid Services
- Stephen Downs The Robert Wood Johnson Foundation
- Garth Graham, MD, MPH HHS/Office of Minority Health
- Thomas Horan, PhD Claremont Graduate University
- Kevin Hutchinson Prematics
- David Lansky, PhD Markle Foundation
- J.P. Little RxHub
- Ross Martin, MD, MHA Bearing Point
- Susan McAndrew, JD DHHS/Office of Civil Rights
- Col. Davette Murray Department of Defense
- Kim Nazi Veterans Health Administration
- Nancy Nielsen, MD, PhD American Medical Association
- Jayne Orthwein National Institutes of Standards and Technology
- Charles Safran, MD, FACP, FACMI American Medical Informatics Association
- Scott Serota Blue Cross Blue Shield Association
- Steve Shihadeh Microsoft
- Linda Springer, Office of Personnel Management
- Paul Tang, MD Palo Alto Medical Foundation
- Robert Tennant, MD Medical Group Management Association
- Sarah Wattenberg, MSW SAMHSA
- Armin Weinberg, PhD Intercultural Cancer Council / Baylor College of Medicine
- Myrl Weinberg National Health Council

Consumer Empowerment Workgroup

- **VISION:**
Patient focused health enabled by consumers' ability to capture, manage, and act upon their own personal health information.
- **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.

3

Consumer Empowerment Workgroup: History

- **First meeting held January, 2006**
- **28 meetings**
- **66 public presentations**
- **32 recommendations**

4

Consumer Empowerment Workgroup: Key Issues

- **Privacy and Security**
 - Confidentiality, privacy, and security of PHRs
- **Technological Considerations**
 - Inconsistent data standards
 - Lack of interoperability
 - Access by patient proxies
- **Incentives**
 - To spur consumer use
 - To spur provider use
- **Consumer and Provider Engagement**
 - Greater consumer awareness of personal health records (PHRs)
 - Needs of specific populations
 - Perceived provider liability
 - State laws that act as barriers

5

Consumer Empowerment Workgroup: Key Recommendations -- Privacy and Security

- Charter a Confidentiality, Privacy, and Security Workgroup.
- Identify principles and best practices with respect to privacy policies and PHRs.
- Establish consumer control of information in their PHRs.
- Develop HIPAA compliant policies and guidelines for authorization of data release to PHRs, disclosure of data to third parties, and secondary uses of data for entities not currently covered by the HIPAA regulations.
- Address issues related to state variance in privacy laws as they may pertain to personally controlled health information products.

6

Consumer Empowerment Workgroup: Key Recommendations for Interoperability and Portability

- Develop standards for the minimum dataset necessary for secure and reliable electronic exchange of registration summary and medication history between PHRs and EHRs, among PHRs, and between PHRs and health plans.
- Harmonize interoperability standards that ensure interoperability of patient specific clinical data and information among PHRs, between PHRs and EHRs, and between PHRs and health plans, and for use in the NHIN trial implementations.
- Develop a CCHIT certification process for PHRs and EHRs which includes criteria for interoperability.

7

Consumer Empowerment Workgroup: Key Recommendations -- Incentives

- Evaluate and assess PHRs and incentives for adoption by consumers and patients.
- Evaluate and assess incentives for support and use of PHRs by providers.
- Ensure that the needs of the underserved and persons with disabilities for access to personal health information are appropriately met.

8

Consumer Empowerment Workgroup: Key Recommendations for Education and Outreach

- Assess the value of electronic availability of personal health information to various populations.
- Convene an expert panel on consumer engagement and social marketing, utilizing Web 2.0 collaboration tools.
- Outreach to special populations and racial/ethnic minorities to facilitate adoption.

9

Key Recommendations: Status

- **Privacy and Security**
 - Centers for Medicare & Medicaid Services (CMS) and HHS Office for Civil Rights (OCR) working on policies for HIPAA-covered entities and business associates for authorization of data release to and from PHRs.
 - ONC Office of Policy and Research working with OCR to clarify the protections provided under HIPAA regarding the rights of consumers and their proxies to timely access to their electronic personal health information requested from covered entities.
 - CPS Workgroup reporting out recommendations.
- **Interoperability and Portability**
 - CCHIT developing certification criteria for PHRs in the areas of privacy, security, and interoperability.

10

Key Recommendations: Status *(continued)*

- **PHR Pilots**

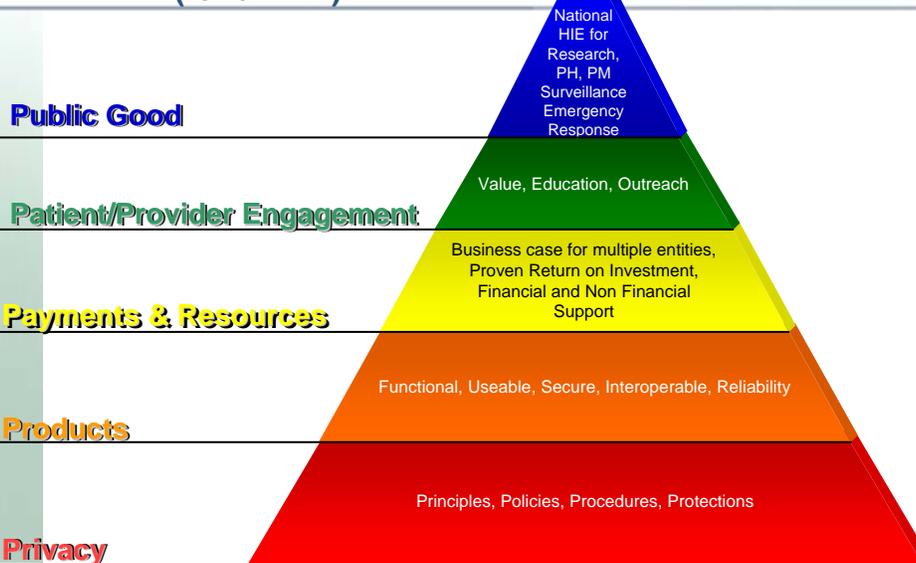
- CMS PHR pilot began in June 2007 in collaboration with AHIP and BlueCross BlueShield Association to evaluate consumer use of electronic registration summary and medication history.

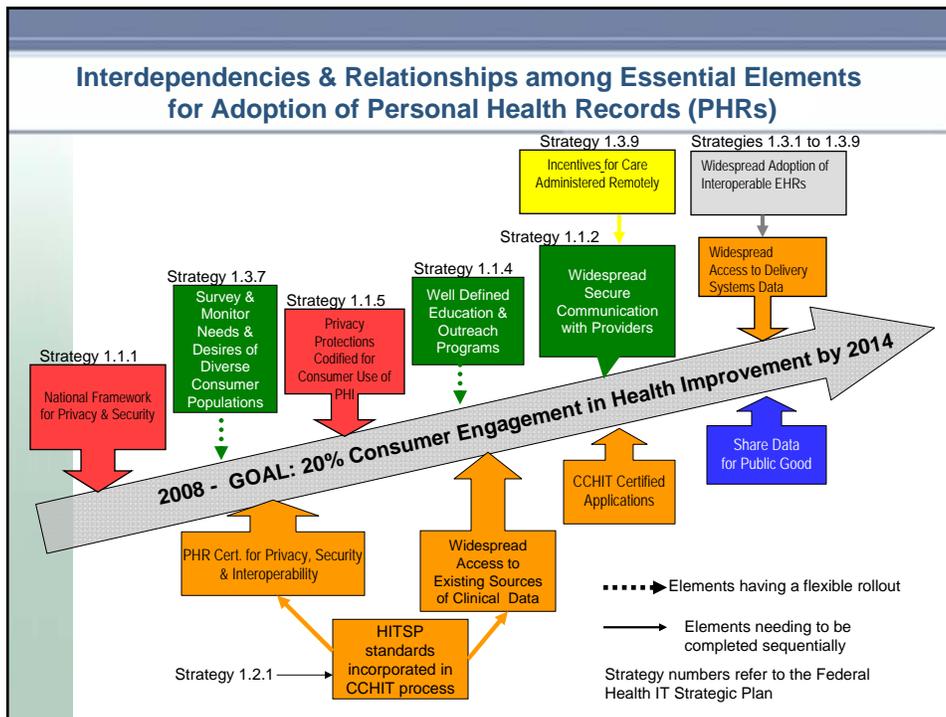
- CMS, Agency for Healthcare Research and Quality (AHRQ), and Assistant Secretary for Planning and Evaluation (ASPE) evaluating the value of PHRs to Medicare members.

- New CMS PHR program to be offered to beneficiaries by December 2008.

11

HIT Hierarchy of Implementation (for all HIT)





- ### Opportunities for the Future
- **Privacy**
 - Need for a framework for privacy and security that is applicable to all types of health IT.
 - Policies should include penalties and protections for non-compliance with privacy regulations.
 - **Security**
 - Development of technology that incorporates maximum security with respect to consumer control of their personal health information as it is shared with and among multiple users:
 - information from PHRs that is shared with providers,
 - information from PHRs that is shared with proxies,
 - information from PHRs shared with parties for uses other than patient care.
 - Certification of products should be based on technologies that support authentication and authorization through a patient identifier.

Opportunities for the Future *(continued)*

- **Purchaser Protection** : An ongoing certification process should be maintained to assure that criteria for privacy, security and interoperability among PHRs and with EHRs are incorporated.
- **Personal Health Data Mobility and Secondary Uses:** Technical capability to maintain consumer anonymity should be maximized and built into products and the Health Information Exchange (HIE) process.
- **Applications:** As new applications are developed for personal use, an oversight mechanism will be necessary to ensure that consumer protections are in place.
- **Health Education/Health Communications:** A mechanism should be in place to ensure that products clearly state their privacy and security policies. Consumers should be educated on the benefits and risks of using PHRs and EHRs.

15

Recommendations Consumer Control of Personal Health Information

Recommendation 1.0

For purposes of the federal government, the HHS Secretary should adopt the consensus definition of a Personal Health Record as presented in The National Alliance for Health Information Technology Report (NAHIT), "Defining Key Health Information Technology Terms" (April, 28, 2008).

Definition of a PHR:

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from one or more sources while being managed, shared, and controlled by the individual or designee.

Accept **Table** **Reject**

16

Recommendations Consumer Control of Personal Health Information

Recommendation 2.0

Personal health records should aspire to possess the functional and technical capability to enable consumer control of the collection, access, use, and disclosure of their individually identifiable health information (IIHI) according to the type of information, type of provider, and purposes/circumstance of the collection, access, use, or disclosure of the IIHI as it travels through the electronic health information exchange and when it is at rest, in accordance with provisions of HIPAA. As technological capabilities evolve, PHRs should aspire to include ever more granular levels of consumer control on the data that they contain, consistent with existing statutes and regulations.

This recommendation should be a priority for AHIC 2.0.

Accept **Table** **Reject**

17

Recommendations Consumer Control of Personal Health Information

Recommendation 3.0

Personal Health Records (PHRs), as defined previously, should aspire to meet the needs of all populations, including persons with special needs and low health literacy, with respect to information on how and when their personal health data may be disclosed. These efforts should facilitate access to electronic resources for education and decision support related to the potential consumer risks and benefits of information disclosure and information protection, including potential legal, health insurance, and other information domains relevant to maintenance of basic needs. These resources should be consistent with statutes and regulations, including, but not limited to, accessibility standards, in accordance with Section 503 (29 U.S.C. § 793), 504 (29 U.S.C. §794) and 508 (29 U.S.C. §794d) of the Rehabilitation Act of 1973 (Pub. L. 93-112).

Accept **Table** **Reject**

18

Recommendations Consumer Control of Personal Health Information

Recommendation 3.0

Personal Health Records (PHRs), as defined previously, should aspire to meet the needs of all populations, including persons with special needs and low health literacy, with respect to information on how and when their personal health data may be disclosed. These efforts should facilitate access to electronic resources for education and decision support related to the potential consumer risks and benefits of information disclosure and information protection, including potential legal, health insurance, and other information domains relevant to maintenance of basic needs. These resources should be consistent with statutes and regulations, including, but not limited to, accessibility standards, in accordance with Section 503 (29 U.S.C. § 793), 504 (29 U.S.C. §794) and 508 (29 U.S.C. §794d) of the Rehabilitation Act of 1973 (Pub. L. 93-112).

Accept **Table** **Reject**

November 12, 2008

The Honorable Michael O. Leavitt
Chairman
American Health Information Community
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Chairman:

The American Health Information Community (the Community) identified and prioritized several “breakthroughs,” health information technology applications and uses that could produce a specific tangible value to healthcare consumers.

The Consumer Empowerment Workgroup (CE Workgroup) was formed in January, 2006, at the direction of the American Health Information Community to address both broad and specific charges that could produce tangible value to healthcare consumers through the use of health information technologies.

Specific Charge for the Workgroup: 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.

Broad Charge for the Workgroup: To make recommendations to the Community to gain widespread adoption of personal health records (PHRs) that are easy to use, portable, longitudinal, affordable, and consumer centered.

In response to the Broad Charge, the CE Workgroup deliberated multiple issues. Concerns about privacy, security, and consumer control of personal health information continue to be the most significant obstacle to the public’s acceptance of Personal Health Records (PHRs), as demonstrated by the Markle Foundation Survey (2006). Privacy and security concerns are also a significant barrier to physician participation in electronic exchange of information. A critical foundation for public trust are the establishment of a comprehensive, privacy framework that sets clear parameters, for access, use and disclosure of health information for all entities engaged in e-health and includes protections against inadvertent or deliberate exposure. Consumers must also know what information exists about them, the purpose of its use, who can access and use it and where it resides. These challenges must be addressed while the technology is evolving and policies to safeguard consumer control of information are under development.

The CE Workgroup has made a number of recommendations regarding privacy and security throughout its tenure. These final recommendations are being proposed for consideration by the Community today, in order to ensure that these issues continue to be addressed in the future.

Recommendation 1:

For purposes of the federal government the HHS Secretary should adopt the consensus definition of a Personal Health Record as presented in The National Alliance for Health Information Technology Report (NAHIT), "Defining Key Health Information Technology Terms" (April, 28, 2008) .

Definition of a PHR:

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from one or more sources while being managed, shared, and controlled by the individual or designee.

Background: This definition applies to PHRs for governmental purposes to embody interoperability and consumer control of information included in the PHR. The rationale behind this recommendation is to assure that PHRs are under consumer control and incorporate current levels of interoperability, with each other and with EHRs.

Recommendation 2:

Personal health records should aspire to possess the functional and technical capability to enable consumer control of the collection, access, use, and disclosure of their individually identifiable health information (IIHI) according to the type of information, type of provider, and purposes/circumstance of the collection, access, use, or disclosure of the IIHI as it travels through the electronic health information exchange and when it is at rest, in accordance with provisions of HIPAA. As technological capabilities evolve, PHRs should aspire to include ever more granular levels of consumer control on the data that they contain, consistent with existing statutes and regulations.

This recommendation should be a priority for AHIC 2.0.

Background: This recommendation refers to granular consumer control of personal health information and the need for increasing technical capacity for consumer control and policy to match such that information cannot be shared beyond the initial recipient without permission. This is not consistent with HIPAA, which allows clinical information which is now in any one provider's medical record to be shared with other providers for purposes of patient care. The "compromise" position that the Workgroup developed was to focus on the "aspirational nature" of such a concept and to suggest that AHIC 2.0 recognize the controversy, and act deliberately and carefully to determine how "consumer control" can be technically developed and implemented.

Recommendation 3:

Personal Health Records (PHRs), as defined previously, should aspire to meet the needs of all populations, including persons with special needs and low health literacy, with respect to information on how and when their personal health data may be disclosed. These efforts should facilitate access to electronic resources for education and decision support related to the potential consumer risks and benefits of information disclosure and information protection, including potential legal, health insurance, and other information domains

relevant to maintenance of basic needs. These resources should be consistent with statutes and regulations, including, but not limited to, accessibility standards, in accordance with Section 503 (29 U.S.C. § 793), 504 (29 U.S.C. §794) and 508 (29 U.S.C. §794d) of the Rehabilitation Act of 1973 (Pub. L. 93-112).

Background: Given the emerging array of PHR solutions and the technological changes in the marketplace, education and outreach solutions should be readily available to consumers to assist them in understanding the risks and benefits of disclosure of personal health information. The aim is to inform consumers about preventable but unintended consequences. In addition, this information should be made available in formats that are accessible to a wide range of consumers.

In proposing the above recommendations, it is important to note that they were developed and supported by a majority of the membership, but do not represent consensus. Several workgroup members agreed that these issues were important and should be addressed in the future, but felt that it was premature to incorporate them into national policy.

These recommendations are supported by information obtained through research and testimony to the Consumer Empowerment Workgroup, which is contained in the supporting documents available at http://www.hhs.gov/healthit/ahic/consumer/ce_archive.html.

Thank you for giving us the opportunity to submit these recommendations. We look forward to discussing them with you and the members of the American Health Information Community.

Sincerely yours,

/Rose Marie Robertson/
Rose Marie Robertson
Co-chair, Consumer Empowerment
Workgroup

/Nancy Davenport-Ennis/
Nancy Davenport-Ennis
Co-chair, Consumer Empowerment
Workgroup



**CONSUMER EMPOWERMENT WORKGROUP
OF THE AMERICAN HEALTH IT COMMUNITY
SUMMARY AND FINAL REPORT
January 2006 – October 2008**

November 12, 2008

The Honorable Michael O. Leavitt
Chairman
American Health Information Community
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Mr. Chairman:

To address the needs of the consumer, the American Health Information Community (the Community) recommended (November 29, 2005) the formation of a Workgroup on Consumer Empowerment. The Community charged the Consumer Empowerment Workgroup (CE Workgroup) with the following:

Specific Charge for the Workgroup: 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.

Broad Charge for the Workgroup: To make recommendations to the Community to gain widespread adoption of personal health records (PHRs) that are easy to use, portable, longitudinal, affordable, and consumer centered.

Over the past almost three years, the CE Workgroup has heard multiple public testimonies, discussed all relevant issues, and made recommendations to advance the charges stated above. As the Department of Health and Human Services (HHS) prepares to transition the initial AHIC to its successor, the CE Workgroup has prepared the attached summary of its deliberations, recommendations, and opportunities for future work.

The WG wishes to express its gratitude for the opportunity to bring the vision of person centric health closer to reality through use of secure, reliable health information technologies. We hope that this summary will prove useful to those who will continue the outstanding effort that commenced under your leadership.

Sincerely yours,



/Rose Marie Robertson/
Rose Marie Robertson
Co-chair, Consumer Empowerment
Workgroup



/Nancy Davenport-Ennis/
Nancy Davenport-Ennis
Co-chair, Consumer Empowerment
Workgroup

WORKGROUP MEMBER LIST

Co-Chair:

Nancy Davenport-Ennis	National Patient Advocate Foundation
Rose Marie Robertson, M.D	American Heart Association

ONC Director:

Karen Bell, M.D., M.M.S	DHHS/ONC
-------------------------	----------

Members:

Jason Bonander, M.A.	Centers for Disease Control and Prevention
Jodi Daniel, J.D., M.P.H	DHHS/ONC
Lorraine Doo, MSWA, M.P.H	Centers for Medicare and Medicaid Services
Stephen Downs	The Robert Wood Johnson Foundation
Garth Graham, M.D., M.P.H	HHS/Office of Minority Health
Thomas Horan, Ph.D	Claremont Graduate University
Kevin Hutchinson	Prematics
David Lansky, Ph.D.	Markle Foundation
J.P. Little	RxHub
Ross Martin, M.D., M.H.A	Bearing Point
Susan McAndrew, J.D	DHHS/Office of Civil Rights
Col. Davette Murray	Department of Defense
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1 INTRODUCTION

1.1 VISION

Our current health care system is provider centric: patients go to multiple individual clinicians and settings for care, with no ability to integrate their care among these diverse providers nor use their health information to their own benefit. The vision for the future is one of a *patient-focused health system, enabled by consumers' ability to capture, manage, and act upon their own personal health information*. It also advances patient-centered health promotion/disease prevention and medical care delivery.

In order to realize this vision, Secretary Leavitt directed the American Health Information Community to charter a Consumer Empowerment Workgroup that would address the following broad and specific charges.

Broad Charge for the Workgroup

Make recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.

Specific Charge for the Workgroup

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.

1.2 GUIDING PRINCIPLES

The first meeting of the Consumer Empowerment Workgroup was held January 30, 2006. Prior to beginning the discussions on its charges, the Workgroup identified a set of streamlined guiding principles with respect to consumer access and use of their personal health information. Using the Markle Foundation's principles as a template, the workgroup agreed on a final list of six guiding principles grouped under the following three general headings:

1. Principles for Personal Health Records
2. Principles for Information Access and Control
3. Disclosure and Accountability Principles

The final principles included under these three categories are as follows:

- Individuals should be guaranteed the right to access their own health information.
- Individuals should be able to access their personally identifiable health information conveniently and affordably.
- Individuals should know how their personally identifiable health information may be used and who has access to it.
- Individuals should have control over whether and how their personally identifiable health information is shared.
- Systems for electronic health data exchange must protect the integrity, security, privacy, and confidentiality of an individual's information.
- The governance and administration of electronic health information networks should be transparent and publicly accountable.

2 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.

2.1 RATIONALE

The AHIC recognized that identification of a specific electronic process that could quickly bring value to a large number of health consumers was an important step towards wider acceptance and use of electronic Personal Health Information (PHI). Medication summaries and registration information (the “electronic clipboard”) not only met these criteria, but also included data that were already available in electronic format. As the Workgroup addressed the barriers and enablers to widespread availability of Medication summaries and e-clipboards, it would also uncover barriers and enablers to adoption of a wider spectrum of products and services that could enable improved personal health.

2.2 WORKGROUP DELIBERATIONS

The concept of Consumer Empowerment requires a transformation in the health information landscape. This transformation can be achieved by the creation of computer platforms that will enable patients to manage health data in personally controlled health records. The integration of data into a consumer's PHR from multiple sources requires interoperable systems that have incorporated access controls that include security and privacy features. Interoperability necessitates the development of data-standards that are

harmonized and certified for use in all PHRs and EHR products. Data-exchange standards will allow for data to be imported into a PHR or exported from the PHR into consumer accepted electronic portals.

After conducting an environmental scan (Report by Altarum, October, 2006) on tools already on the market and establishing a framework to discuss, identify, and address barriers and enablers, the following issues were identified as those needing to be addressed by this Workgroup.

1. The need to raise consumer awareness of personal health records (PHRs),
2. Confidentiality of PHRs,
3. Need for patient proxies,
4. Liability of providers,
5. State laws that act as barriers,
6. Data standards that are not yet consistent, and
7. A lack of interoperability when sharing information.

Potential populations and approaches to target early on were also discussed: the use of existing regional health information exchange with a consumer interface, PHR vendor(s) linked to one or more intermediaries to get updated registration and medication information, and payer- or employer-based portals that supply information to PHRs. Possible target populations included patients who frequently utilize the system, such as those with chronic conditions. The following populations were also to be considered: (1) pediatric population, (2) older (45+) population with high drug usage, and (3) possible local/regional geographic locations with plans/providers.

2.3 ACCOMPLISHMENTS

After extensive discussion and debate the members made recommendations in the following three categories:

1. **Interoperability**, which would include standards for the minimum dataset necessary for electronic secure and reliable exchange of registration summary and medication history between PHRs and EHRS, among PHRs, and between PHRs and health plans.
2. **Demonstrated Value**, for specific target populations which would benefit most by the specific charge. The Medicare population, where chronic conditions require the use of multiple concomitant medications, was a clear choice. The group also gave particular attention to pediatric populations, because there are opportunities to use longitudinal PHRs to follow patients over the course of their lives.
3. **Privacy and Security**, including recommendations related to HIPAA regulations and privacy, data security, consumer control, and trust. Survey data (Markle Foundation 2005, California Healthcare Foundation 2005, Westin and Harris Interactive Report,

2005) and early user experience confirm that Americans see their personal health information as highly sensitive and will demand that strong policies be in place to assure its proper management, sharing, and use. Without addressing these concerns upfront, and without promoting trust in the system through general conformance to legitimate policies and practices, users will very likely refuse to adopt and use the network suggested, undermining the mission of AHIC.

2.4 RECOMMENDATIONS MADE BY AHIC (MAY 2006) & STATUS OF RECOMMENDATIONS

The Consumer Empowerment Workgroup presented four recommendations to the Community to respond to these issues in relationship to the specific charge. [See Appendix A](#). These may be summarized as follows:

1. HITSP should identify and harmonize a core set of technical and data standards to enable interoperability of a core set of data related to medication history and medication management.
2. HHS should pilot projects to assess the value of the electronic availability of an “e-clipboard” and medication history to various populations.
3. These projects should engage the private sector in promoting patient and provider participation.
4. AHIC should charter a Confidentiality, Privacy, and Security Workgroup to address related issues identified by this workgroup and others.

All of these recommendations were forwarded to the Secretary by the AHIC and the Secretary has accepted and acted on all four. [See Appendix A](#)

3 BROAD CHARGE FOR THE WORKGROUP

Make recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered.

3.1 RATIONALE

It has been noted that the actions of our health care delivery system contribute only 10 -20% to our nation’s overall health status. Far more influential are the informed personal health choices made by each of us. Empowering consumers to take an active role in managing their health through informed use of their personal health information is the overarching goal for this Workgroup. This theme is consistent with many trends visible in the U.S. health care system today. Sixty percent of Americans support the creation of secure, online personal health records (Markle Foundation, 2005) and additional research supports the belief that consumer commitment to PHRs would result

in increased efficiencies in the health care system, lower overall costs and improved health care information access (Kaiser Permanente Institute for Health Policy Roundtable Summary Report, 2006). Patients find increased *access* to their health information and health care team to be “transformative”, potentially leading to “transformative” improvements in the quality, efficiency, and effectiveness of health care (Tang and Lansky, 2006). However, this consumer support has yet to translate into large-scale movement toward *managing* one’s own personal health information through personal health records.

3.2 WORKGROUP DELIBERATIONS (2006 – 2008)

The research and public testimony collected by the Workgroup over almost a three year period illustrated both the challenges and opportunities in meeting the goal articulated in the charge. In addition to those related to the specific charge, additional challenges include low health literacy, lack of PHR awareness, the needs of specific populations that include persons with disabilities, racial and ethnic communities and the underserved, asymmetrical state-level policies on health data sharing, lack of a clear value proposition and incentives for mass adoption, and tensions between assuring privacy while ensuring maximum flexibility to appropriately share health data and information. Based on the testimony and research, 32 recommendations were developed under four broad categories:

1. Privacy and Security -- Privacy protection and security safeguards are paramount, and timely access for all consumers and their proxies to their electronic personal health information should be ensured
2. Interoperability and Portability -- Personal health data can be exchanged among PHRs and sources of personal health information (e.g., electronic medical records, payer or pharmacy systems) under the control of the patient while preserving the meaning of the data
3. Incentives for Adoption – Establish a value proposition through appropriate incentives and enablers to encourage consumer and provider adoption of PHRs.
4. Education and Outreach -- effective messages for consumers and providers should guide broad educational efforts to engage them.

3.2.1 INTEROPERABILITY AND PORTABILITY

Most of today’s PHRs are stand-alone products that have little connectivity with other electronic data sources. Patient portals into a provider EHR have been considered “PHRs” but they do not meet the criteria of a PHR as being under the control of the patient or consumer, and the data that can be accessed through most of these portals are not portable.

Recommendations 1.1 and 1.2 ([See Appendix A – Broad Charge](#)) address this challenge by directing HITSP to harmonize interoperability standards that ensure interoperability of patient specific clinical data and information among PHRs, between PHRs and EHRs, and between PHRs and health plans for use in both the NHIN implementations and in a CCHIT certification process for PHRs and EHRs.

3.2.2 PRIVACY AND SECURITY

The Consumer Empowerment Workgroup recognized its work is expected to bring millions of new users into a nationwide health information network, raising numerous questions about privacy, data security, consumer control and trust. Survey data and early user experience confirm that Americans believe that their personal health information is highly sensitive and they demand strong protections regarding its proper management, sharing, and use. Consumers should be able to control access to the personal information in their PHRs. However, consistent, enforceable policies for release of data to PHRs, for disclosure to third parties, and for uses of data for purposes other than patient care do not exist for entities not covered by HIPAA regulations. Furthermore, such policies where they exist may not encourage the release of data in an electronic format, hindering interoperability and portability of data, and limiting use of PHRs in a treatment setting.

The National Committee on Vital and Health Statistics has since developed recommendations regarding Secondary Uses of Health Data (<http://www.ncvhs.hhs.gov/adhocwg.htm>). A number of other recommendations related to privacy and security were addressed by the Consumer Empowerment workgroup and include:

- 1 The need to identify principles and best practices with respect to privacy policies and PHRs.
- 2 Clarifications with respect to HIPAA and timely access to electronic personal health information.
- 3 Development of HIPAA compliant policies and guidelines for authorization of data release to PHRs. Consistent, enforceable policies for release of data to PHRs, disclosure of data to third parties, and secondary use of data do not exist for entities not covered by the HIPAA regulations
- 4 Addressing issues related to state variance in privacy laws as they pertain to personally controlled health information products.

These are described in detail in *Recommendations 2.1, 2.2, 2.3, 2.4* ([See Appendix A – Broad Charge](#))

3.2.3 INCENTIVES FOR ADOPTION

Adoption of any technology that is not immediately or obviously useful to the majority of consumers, is fraught with a number of challenges. First and foremost, it must be clear what the technology is and what it can do. Until recently, most PHRs have been portals into a provider's EHR or health plan portals that are populated with claims data. The data in these PHRs generally become inaccessible to patients when they change providers or health plans. Free standing PHRs, are generally a collection of personal health observations; these PHRs rarely integrate well with institutional records. Because many current PHR products are proprietary in nature, few opportunities exist to build on or customize them to meet the diverse health needs of different users.

Consensus has developed that a PHR, for purposes of certification, legislation, and fair marketing, is a collection of health data and information, interoperable when these standards are available, derived from multiple sources and stored under the control of the individual or his/her designee. Various products and services may be developed, applied to this data base, and used by the individual to access his/her information in a manageable format.

ONC contracted with Altarum to conduct an environmental scan of existing "PHRs" in September, 2006. As anticipated, there was marked variation among the products offered with respect to: functionality, privacy policies, marketing practices, definitions of PHRs, data mobility, and consumer attitudes. There is ongoing need to evaluate PHR offerings and incentives within a framework that can inform future development and adoption.

Currently, there are low utilization rates by consumers of any PHR related products. Enabling federal employees and beneficiaries to become adopters in government-sponsored PHR pilot programs could encourage adoption while providing valuable feedback and lessons learned about how to implement a PHR and about the benefits such a tool provides. The Department of Veterans Affairs, the Indian Health Service, Office of Personal Management, and CMS are all working on projects that could provide valuable information for future PHR implementations.

A survey of the needs and requirements of the underserved and special populations (limited English proficiency, cultural minorities, and the disabled) will be necessary to address their specific concerns and issues related to *adoption of PHRs*.

Lastly, health care providers (especially primary care physicians) are key partners in realizing widespread adoption of PHRs. Surveys of consumers have identified their health care providers as the most trusted sources of health data. It is important that incentives are properly aligned so that providers also realize benefits from encouraging PHR adoption among their patients and that portability of data between PHRs and EHRs is encouraged.

The following recommendations were developed to address the issues described above:

Evaluate and assess PHRs and incentives for adoption: *Recommendations 3.1, 3.2, 3.2.1, 3.2.2, 3.2.3, 3.3, 3.4* ([See Appendix A – Broad Charge](#))

Persons with Disabilities and the Underserved: *Recommendation 1.1, 1.2, 1.3, 1.4* ([See Appendix A – Under Disability](#)), *Recommendation 1.0* ([See Appendix A – Broad Charge under Certification](#)) *Recommendations 2.1, 2.2, 2.3, 2.4* ([See Appendix A – under Racial and Ethnic](#))

Provider Incentives: *Recommendation 3.5* ([See Appendix A – Broad Charge](#))

3.2.4 EDUCATION AND OUTREACH

As noted, consumer awareness and engagement in PHRs today is fairly low. Current interest in PHRs is found largely among providers, employers, health plans and software vendors, rather than among consumers. Consumer awareness and engagement could be increased through education initiatives about the benefits and value of PHRs.

A broad variety of private-sector organizations regularly provides health education to their constituents. Examples include organizations such as patient advocates, chronic disease advocates, provider associations, and umbrella entities that are trade associations composed of many consumer groups. They have established grassroots networks with proven track records for communicating information and providing education to their members.

Perhaps more important, the advent of Web 2.0 collaboration tools and the social networking revolution is making it easier for consumers to find timely, personalized health care information online. In addition, consumers are building more sophisticated virtual communities that enable them to share information about treatment, coping and building a personal network of friends using the Web 2.0 social media tools. This is a growing field and would be a good platform to use for educating the consumer on PHR use and adoption.

Recommendation 4.1 ([See Appendix A – Broad Charge](#))

3.2.5 CONSUMER CONTROL OF PERSONAL HEALTH INFORMATION

As described under Privacy and Security consumers desire control over their personal health information. The Workgroup had extensive discussions over the need for developing policy and the technical capabilities for ensuring that access permissions defined by the consumer are retained with the information at all times. Three recommendations were proposed to ensure consumer control of personal health information. The recommendations refer to granular consumer control of personal health information and the need to increase technical capacity for consumer control and policy

to match, such that information cannot be shared beyond the initial recipient without permission. This is not consistent with HIPAA, which allows clinical information in a provider's medical record to be shared with other provider's for purposes of patient care. The "compromise" position that the Workgroup developed was to focus on the "aspirational nature" of such a concept and to suggest that AHIC 2.0 recognize the controversy, and act deliberately and carefully to determine how "consumer control" can be technically developed and implemented.

Recommendations: Consumer Control Personal Health Information
[\(See Appendix A – Broad Charge\)](#)

4 KEY ACCOMPLISHMENTS TO DATE: RECOMMENDATIONS AND ACTIONS

As of October 7, 2008, the Consumer Empowerment Workgroup has held 29 meetings and developed 30 recommendations. In addition, a subgroup was convened to develop recommendations for specific populations that included persons with disabilities, racial and ethnic communities and the underserved. These recommendations all fall under the following categories: privacy and security, interoperability and portability, incentives for adoption, education and outreach. There has already been significant movement on many of them, as described below.

4.1 PRIVACY

- The Centers for Medicare and Medicaid Services (CMS) and DHHS Office for Civil Rights (OCR) met this summer to discuss developing policies and guidelines for HIPAA-covered entities and business associates for authorization of data release to and from PHRs.
- The ONC Office of Policy and Research met with OCR to clarify the protections provided under HIPAA regarding the rights of consumers and their proxies to timely access to their electronic personal health information requested from covered entities.
- The State Alliance for e-Health is exploring issues relative to State privacy laws and PHRs and will share their findings with the Community and HHS.
- The Confidentiality, Privacy, and Security Workgroup was chartered and has made multiple recommendations to the AHIC to address these issues.

4.2 PHR CERTIFICATION FOR INTEROPERABILITY

- The Workgroup presented recommendations to develop certification criteria for PHRs in the areas of privacy and security and interoperability. The recommendations were accompanied by a dissent letter. Both the recommendations and the dissent letter were presented to the AHIC, and the recommendations were approved by the AHIC.

The Certification Commission for HIT is currently developing criteria for PHR certification.

4.3 PHR INCENTIVES AND OUTREACH

- CMS, AHRQ, other interested Federal agencies, and private-sector partners have piloted programs that measure and demonstrate the value of an electronic registration summary and medication history to patients with chronic disease and their clinicians.
- More recently, a new initiative was launched titled “Personal Health Records (PHR) for Medicare Beneficiaries Initiative. “ This project aims to launch a pilot in two states by the end of 2008 to provide Medicare beneficiaries with a choice of Personal Health Record platforms that will be populated with Medicare claims and other data. .

4.4 DISCUSSION

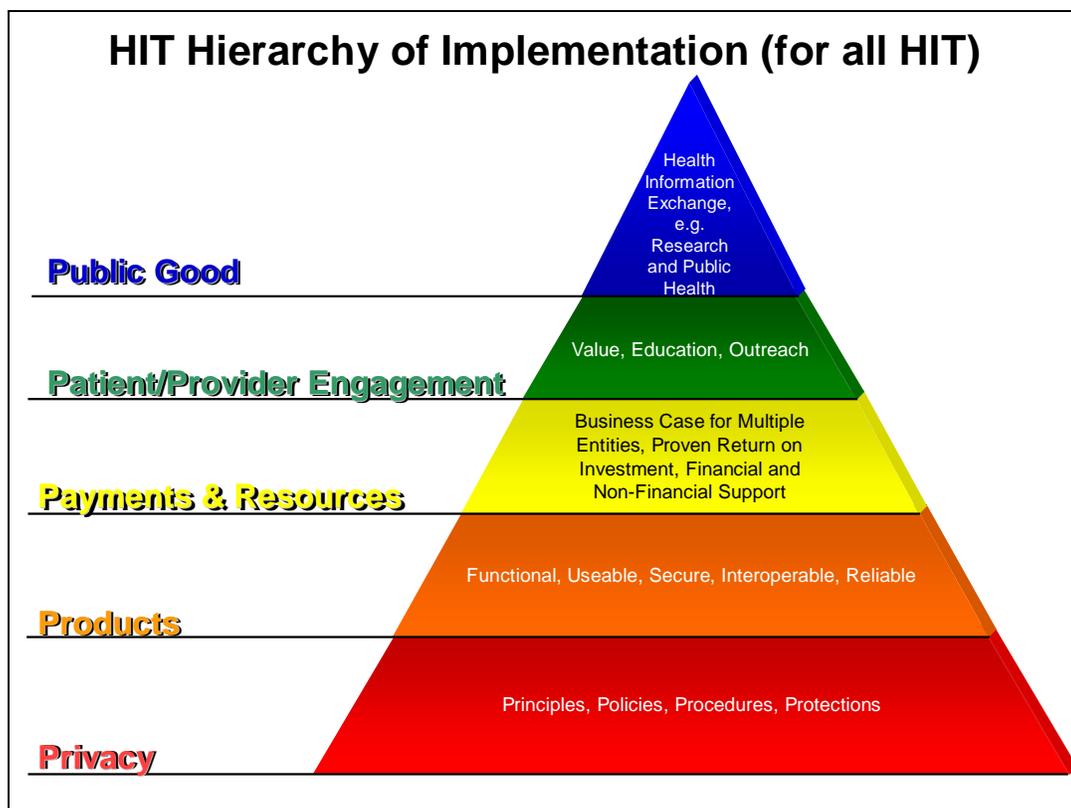
The Consumer Empowerment Workgroup members through the course of their deliberations have highlighted the positive aspects of Consumer Centric HIT and have identified a number of new policy and operational challenges to widespread adoption of products and services that will support consumer engagement in health care. These challenges must be addressed while the technology is evolving. In order to develop consumer oriented health information technology that can help consumers live healthier and fuller lives it is imperative that we understand their needs now, as we stand on the development cusp of this technology. A goal of 20% consumer engagement with HIT by 2014 will require prioritization and meeting of a number of essential elements, or milestones, with well defined interdependencies.

The major essential elements or milestones that must be met in order to reach the President’s goal for 20% consumer engagement with HIT by 2014 are outlined below.

1. Development of a Framework for Privacy Principles, Policies and Protections
2. Clear Protections from breaches of confidentiality codified
3. Consumer Survey developed to evaluate needs and desires
4. PHR Certification for Privacy, Security & Interoperability
5. Education and Outreach Program fully developed
6. Development of an architecture or platform for Health Information Exchange
7. Widespread availability of interoperable personal health information in electronic format
8. Reimbursement reform for providers of care

At its final meeting, the CE Workgroup addressed the major milestones listed above, and agreed to present them pictorially to the AHIC as their final recommendation on the interdependencies and priorities necessary to achieve consumer centric health. Applying

the example of Maslow's hierarchical pyramid of needs to HIT, helps clarify the priorities. Only when the basic needs at the bottom of the pyramid are fulfilled, can the top tier objectives be fully realized. Higher functions, such as patient/provider engagement and use of HIT for public good will not be achieved until there are adequate privacy and security protections that consumers can trust. The following depicts a hierarchy of needs relevant to the widespread adoption of all health information technology.



The CE Workgroup discussed and made recommendations on the essential elements and milestones in all five areas of the HIT hierarchical implementation pyramid with respect to the widespread use of PHRs. The following Blueprint for Consumer Engagement color codes these elements to align with the pyramid, and presents them along a timeline of priorities, based on interdependencies and planned activity. Such a blueprint allows stakeholders in both the public and private sectors to align activities for maximum synergy and success.

privacy regulations for information that travels from an EHR to PHR and PHR to EHR.

PHRs must also make their privacy commitments explicit in a published privacy notice. The notice should allow presentation of facts and policies for consumers to understand and consistently compare one health IT service provider with another and focus on the key information that may influence their decisions and choice of PHR service providers, or health record banks.

PRIVACY PROTECTIONS CODIFIED FOR CONSUMER USE OF PHI

An important adjunct to the framework is to have privacy protections in place for consumer use of PHI which ensures that consumers are protected from breaches in security. They must also know what information exists about them, the purpose of its use, who can access and use it, and where it resides.

CONSUMER SURVEY

The challenges facing this nascent industry must be identified and addressed while the technology is evolving. As the PHR field grows and new consumer access services are created the need for well designed, nationally representative, standardized surveys is clear. The goal of these surveys should be to ensure that the needs and requirements of diverse consumer populations, including racial/ethnic minorities, the underserved and the disabled are met. In addition, the surveys should provide outcome measures that evaluate improvement in care and behavioral change. It was proposed that surveys should be conducted at periodic intervals between now and 2014 to monitor adoption rates, consumer motivations, triggers and measure quality. In order to reach a wider group of consumers, surveys should use different modalities that target specific populations for instance cell phones are used extensively by certain minority groups.

WELL DEFINED EDUCATION AND OUTREACH PROGRAMS

Given the emerging array of e-health tools and the prospects for rapid innovation, well defined education and outreach programs should be implemented to assist consumers in evaluating, selecting and understanding these tools, including their privacy and security implications. These programs should also communicate the value case for HIT and HIE, and how to participate more fully in one's own health care. Implementation must also take into account the diverse needs of consumer populations, including varying levels of health literacy..

WIDESPREAD SECURE COMMUNICATIONS WITH PROVIDERS

Secure messaging has proven to be a desirable feature in health care systems that

offer this to their patients. Electronic communication between patients and physicians can reduce health plan spending and provide value to the consumer. However, for physicians to widely adopt secure communications with their patient's, *incentives and payment for care administered outside the clinical setting* must be implemented. *Reimbursement reform* is also needed for consumers and their clinicians to effectively use HIT for remote monitoring of chronic conditions, for more timely care without excessive travel, and for more patient engagement in their care.

WIDESPREAD ADOPTION OF INTEROPERABLE EHRs

Despite the benefits of interoperable EHRs, physicians and other providers have been slow to adopt. Recent data from the HIT Adoption Initiative, a survey of ambulatory physicians, found that overall physician adoption was approximately 17% for EHRs with basic functionality. However, it is predicted that EHRs will gradually increase over the next several years to spur a transformation in health care leading to more *widespread access to delivery systems data*, thus providing more consumers with the ability to easily and efficiently gain access to their personal health information. Without access to this data, adoption rates of PHRs will likely remain low.

STANDARDS AND INTEROPERABILITY

In order for consumers to access their data from multiple sources and share it as they desire, the data must exist in formats standardized for interoperability. To achieve this there is a need to establish or harmonize a set of standards for both defining specific terms and the data models for digital exchange of information that are used and incorporated by all HIT vendors. This will assure interoperability between PHRs and various other data sources such as health plans, providers, laboratories, etc.

PHR CERTIFICATION PROCESS FOR PRIVACY, SECURITY & INTEROPERABILITY

The most basic issue facing PHR adoption is consumer concern about privacy and security. *Security* is much easier to address than privacy. Security involves technological approaches to authenticating and authorizing those who access, transmit, and store electronic clinical records. CHIT is developing criteria for security, privacy, and interoperability which will assure consumers that purchase or use of a certified product will provide access to state of the art security, clear privacy policies, and the ability to exchange data with other certified PHRs and certified EHRs. These certified PHRs will be available in 2009

SHARE DATA FOR PUBLIC GOOD

As all of the elements for an interconnected health care environment come together the potential for using clinical information for improving public health through more effective personalized preventive care, disease treatments with better specificity, and innovative drug therapies can be realized.

The potential for realizing our goal of 20% Consumer Engagement with Health Self Management by 2014 will be a reality as all the essential elements are implemented and functioning together as an integrated whole. Development and widespread use of a NHIN (Nationwide Health Information Network) will provide a secure and reliable network over which certified Health Information Organizations (HIOs) can operate.

The ONC-Coordinated Federal Health Information Technology Strategic Plan: 2008 - 2012 sets forth a number of goals, objectives and strategies which outline all federal efforts in Health IT. The plan articulates strategies that describe the work needed to achieve the objectives of *Patient-focused Health Care and Population Health*. The strategies of the plan portray the totality of what is being done across the federal government to achieve an interoperable health IT infrastructure for the nation. The blue print points to the individual strategies in the Federal Plan that relate to the specific elements and milestones.

5 SUMMARY AND FUTURE OPPORTUNITIES

Throughout the course of 28 public meetings, hearing 66 public testimonies, and deliberating 32 recommendations, the CE Workgroup met both its specific and broad charges. However, the PHR landscape is rapidly evolving with new players, approaches, and applications coming to market. While privacy and security still present a significant barrier for the adoption of PHRs by consumers, there are other areas that will need careful monitoring and attention, particularly by the AHIC Successor Organization. The following were identified as opportunities for future work, development, and consideration:

PRIVACY

- Development of a framework for privacy and security that is applicable to all types of HIT.
- Policies should include penalties for non-compliance with privacy regulations and protections for consumers.

SECURITY:

- Development of technology that incorporates maximum security for consumer information and is under the control of the consumer. This should allow consumers flexibility and a high level of control over the information they choose to share with care providers and family members. Rather than resorting to a PHR that grants blanket access to personal information, consumers should be able to segment sensitive information and maintain control over who can access their electronic personal health data; this control should also include the secondary use of PHI.
- Technology should be developed based on certification of the identifier products that include authentication and authorization through a patient identifier.

PURCHASER PROTECTION

- Ongoing certification process to assure that privacy, security and interoperability standards and criteria are incorporated into certified PHRs. Certification of interoperability should assure that information can flow from EHR to PHR and PHR to EHR.

PERSONAL HEALTH DATA MOBILITY AND SECONDARY USES

- Consumer protection must be ensured while fulfilling the need for secondary uses of data for the benefit of the population. Technical capability to maintain consumer anonymity should be maximized and built into products and the Health Information Exchange (HIE) process.

APPLICATIONS

- As new applications are developed for personal use an oversight mechanism will be necessary to assure that consumer protections are in place.

HEALTH EDUCATION/HEALTH COMMUNICATIONS

- A mechanism should be in place to ensure that products clearly state their privacy and security policies. Consumers should be educated on the benefits and risks of using PHRs and EHRs.

APPENDIX A
Recommendations from the Consumer Empowerment Workgroup

1 SPECIFIC CHARGE

1.1 RECOMMENDATION 1.0

The Health Information Technology Standards Panel (HITSP) should identify the technical and data standards to enable the availability of a core registration dataset and medication history (with comprehensive review of recommendations for registration and medication history provided to HITSP by the Workgroup), including vocabularies, messaging, authentication, security standards, and appropriate documentation, by 9/30/06.

AHIC Accepted (5/16/2006)

Status/Progress Notes: Complete

1.2 RECOMMENDATION 2.0

The U.S. Department of Health and Human Services (HHS), through the Centers for Medicare & Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), other interested Federal agencies, and private-sector partners, should pilot programs that measure and demonstrate the value of an electronic registration summary and medication history to patients with chronic disease and their clinicians. The sponsoring organizations should strive to implement pilot programs that meet all the objectives identified by the Workgroup no later than 12/31/06, and an evaluation of the initial results should be reported to the Community by 6/30/07.

AHIC Accepted (5/16/2006)

Status/Progress Notes: CMS PHR pilot is in progress. Proposed scope of work to demonstrate the value of electronic registration. ONC provided \$1M to AHRQ for evaluation. A pilot of this nature must be longitudinal in order to capture data of relevance; therefore, high level reporting will be quarterly, and the final report will be ready in November, 2008.

1.3 RECOMMENDATION 2.1

In the next 6 months, Federal agencies sponsoring pilots for an electronic registration summary and medication history should work with appropriate private-sector health organizations, such as patient advocacy organizations and medical professional societies, to promote provider and consumer participation in a breakthrough project through a targeted outreach initiative.

AHIC Accepted (5/16/2006)

Status/Progress Notes: CMS pilot was done in collaboration with AHIP and Blue Cross Blue Shield. Pilot began in June 2007 and is now complete. CMS is working with the

Office of the Assistant Secretary for Planning and Evaluation(ASPE). ASPE has funded and will oversee the Medicare Fee-for-Service(FFS) pilot, to test outreach to, and adoption of PHRs by FFS pilot evaluation.

1.4 RECOMMENDATION 3.0

The Community should create a consumer empowerment subgroup comprised of privacy, security, clinical, and technology experts from each Community Workgroup. The subgroup should frame the privacy and security policy issues relevant to all the Community charges and solicit broad public input and testimony to identify viable options or processes to address these issues that are agreeable to all key stakeholders.

The recommendations developed should establish an initial policy framework and address issues including, but not limited to:

- Methods of patient identification
- Methods of authentication
- Mechanisms to ensure data integrity
- Methods for controlling access to personal health information
- Policies for breaches of personal health information confidentiality
- Guidelines & processes to determine appropriate secondary uses of data
- A scope of work for a long-term independent advisory body on privacy and security policies.

AHIC Accepted (5/16/2006)

Status/Progress Notes: Subgroup was created.

2 BROAD CHARGE

2.1 INTEROPERABILITY AND PORTABILITY

2.1.1 RECOMMENDATION 1.1

HHS should promote consumer access to their personal health information in the trial implementations of the NHIN.

AHIC Accepted (1/23/2007)

Status/Progress Notes: Nine trial implementations are in the field, some are implementing CE use cases.

2.1.2 RECOMMENDATION 1.2

HHS should support CCHIT in identifying a pathway and timeline for certification of PHRs after adequate industry experience has been achieved in this market. Such certification should include: specifications for PHR privacy and security, interoperability between PHRs and personal health information data sources (including EHRs) consistent

with HITSP-identified standards, and PHR portability. CCHIT would need to develop expertise and re-examine its charter in preparation for these activities.

AHIC Tabled (1/23/2007)

Status/Progress Notes: Tabled

2.2 PRIVACY AND SECURITY

2.2.1 RECOMMENDATION 2.1

The AHIC Confidentiality, Privacy and Security Workgroup, in collaboration with the Consumer Empowerment Workgroup, should develop principles and identify best practices for privacy policies for consumers' PHR data that are interoperable, i.e., protections that follow the consumer as his or her data moves or is shared. These recommendations should apply to all individuals and entities, including both covered and non-covered entities under HIPAA.

AHIC Accepted (1/23/2007)

Status/Progress Notes: Presented to Confidentiality, Privacy and Security Workgroup for consideration. Currently, being sequenced into the larger privacy and security policy initiative.

2.2.2 RECOMMENDATION 2.2

The HHS Office for Civil Rights should provide guidance to clarify the protections provided under HIPAA regarding the rights of consumers and their proxies to timely access to their electronic personal health information requested from covered entities.

AHIC Accepted (1/23/2007)

Status/Progress Notes: Office of Policy and Research(OPR) lead met with Office of Civil Rights (OCR). OPR needs to provide more information to OCR. Discussion initiated. Working on scope.

2.2.3 RECOMMENDATION 2.3

CMS, in collaboration with the HHS Office for Civil Rights and other interested agencies, should develop policies and guidelines for HIPAA-covered entities and business associates for authorization of data release to and from PHRs, including the development of HIPAA-compliant standardized authorization language, no later than December 28, 2007.

AHIC Accepted (1/23/2007)

Status/Progress Notes: Behind schedule

2.2.4 RECOMMENDATION 2.4

The State Alliance for e-Health should consider exploring issues relative to State privacy laws and PHRs and share their findings with the Community and HHS. The Consumer Empowerment Workgroup intends to provide the State Alliance for e-Health with background information and a detailed explanation for this request.

AHIC Accepted (1/23/2007)

Status/Progress Notes: Behind schedule

2.3 INCENTIVES FOR ADOPTION

2.3.1 RECOMMENDATION 3.1

HHS, through AHRQ, and in collaboration with the Indian Health Service, CMS, the Department of Veterans Affairs, and the Office of Personnel Management, should develop an evaluation framework that can assist in the systematic assessment of PHR offerings to federal employees and beneficiaries, by December 28, 2007. Evaluation criteria may include the effect of PHR services on health outcomes, level of consumer engagement in their health care, economic impact, data security, and other measures.

AHIC Accepted (1/23/2007)

Status/Progress Notes: AHRQ established a framework to look at PHRs in a consistent way. CMS is currently executing a pilot for PHR evaluation using four plans and is working with AHRQ and ASPE to evaluate the value of PHRs to Medicare members.

2.3.2 RECOMMENDATION 3.2

In 2007, HHS, through AHRQ when appropriate, should conduct evaluations that will provide useful information needed to develop the evaluation framework for assessing PHRs specified in 3.1. Specific study topics include the impact of data sharing through health information exchange, the comparative value of various data sources, and the impact of various architectural models.

AHIC Accepted (1/23/2007)

Status/Progress Notes: AHRQ established a framework to look at PHRs in a consistent way. CMS is currently executing a pilot for PHR evaluation using four plans and is working with AHRQ and ASPE to evaluate the value of PHRs to Medicare members.

2.3.3 RECOMMENDATION 3.2.1

HHS should assess how the sharing of personal health information with consumers through the use of PHRs impacts health care quality and patient satisfaction, including the results of private sector efforts as available.

AHIC Accepted (1/23/2007)

Status/Progress Notes: AHRQ established a framework to look at PHRs in a consistent way. CMS is currently executing a pilot for PHR evaluation using four plans and is working with AHRQ and ASPE to evaluate the value of PHRs to Medicare members.

2.3.4 RECOMMENDATION 3.2.2

HHS, through AHRQ, should conduct a study to assess the comparative value of and challenges related to using data on diagnoses and medication derived from claims, administrative, clinical, laboratory, pharmacy, and consumer-based sources to populate and maintain PHRs, including evaluations of the current availability of each source of data and of consumer and clinician reactions to and decisions based on the use of these data. Because of the low rate of EHR adoption by providers, the study should begin with an examination of experiences with currently available PHRs based on claims and administrative data as well as consumer-based sources, then move to clinical and other data over time, with interim results reported back to the Community by December 28, 2007, and final results reported back by June 30, 2008.

AHIC Accepted (1/23/2007)

Status/Progress Notes: AHRQ established a framework to look at PHRs in a consistent way. CMS is currently executing a pilot for PHR evaluation using four plans and is working with AHRQ and ASPE to evaluate the value of PHRs to Medicare members.

2.3.5 RECOMMENDATION 3.2.3

HHS, through AHRQ, should fund evaluations of the impact on health care quality and patient satisfaction of various architectural models of PHRs (e.g., stand-alone, integrated, networked) and delivery methods (e.g., web-based, compact disc, flash drive) to consumers.

AHIC Accepted (1/23/2007)

Status/Progress Notes: The need to clarify the entity being evaluated – what constitutes a PHR and its functionalities – has introduced a delay in executing this recommendation.

2.3.6 RECOMMENDATION 3.3

The Department of Veterans Affairs should conduct an evaluation of the benefits of their My HealtheVet PHR in the 2007 calendar year, and report back to the Community about the status and results to date no later than December 28, 2007. Based on the evaluation, the Department of Veterans Affairs should communicate the value of their PHR to veterans and stakeholders to encourage adoption.

AHIC Accepted (1/23/2007)

Status/Progress Notes: MyHealtheVet patient portal has been established and is actively

being used. Results were presented to the CE Workgroup in December 2007.

2.3.7 RECOMMENDATION 3.4

HHS, through the Centers for Medicare & Medicaid Services and the Indian Health Service, should develop plans to offer portable PHRs with privacy protections to their beneficiaries, and report back to the Community about their plans as available. The plans should take into account the results of the studies and best practices from 2.1 and 3.2, as they become available.

Status: *Tabled (1/23/2007)*

2.3.8 RECOMMENDATION 2.0

HHS, through the Centers for Medicare & Medicaid Services and the Indian Health Service, and in collaboration with the Office of the National Coordinator for Health IT, should develop plans to offer portable PHRs with adequate privacy protections to their beneficiaries, and HHS should report back to the Community about their plans as available. The plans should take into account the results of the studies and best practices recommended by the Consumer Empowerment Workgroup on January 23, 2007, as they become available, and should build upon work already underway at the agencies.

AHIC Accepted (3/13/2007)

Status/Progress Notes: *CMS is doing this work, number of trials are underway. IHS, is studying the best way to implement this recommendation – there is technological scarcity in the catchment areas where most of the populations they serve, reside.*

2.3.9 RECOMMENDATION 3.5

In 2007, the Consumer Empowerment Workgroup should identify a range of incentives intended to increase adoption of PHRs, and report on their findings to the Community. These incentives may include financial benefits accruing to providers or other PHR offerors, financial benefits accruing to patients and consumers, or other forms of economic benefit of established effectiveness (e.g., employee productivity, customer loyalty). The Consumer Empowerment Workgroup should include in its report any available evidence documenting the effectiveness of each type of incentive and how that incentive might best be deployed to encourage PHR adoption.

AHIC Tabled (1/23/2007)

2.4 EDUCATION AND OUTREACH

2.4.1 RECOMMENDATION 4.1

In 2007, the Consumer Empowerment Workgroup should continue to study public and private sector activities to increase consumer awareness of PHRs, including the convening of an expert panel on consumer engagement and social marketing, and report on their findings to the Community.

AHIC Accepted - did not require further clearance to implement. (1/23/2007)

2.5 CERTIFICATION OF PRIVACY, SECURITY, AND INTEROPERABILITY

2.5.1 RECOMMENDATION 1.0

HHS should support CCHIT and/or other certifying entities in identifying a pathway and timeline for voluntary certification of PHRs after adequate industry experience has been achieved in the market. Such certification should include: specifications for PHR privacy and security, interoperability between PHRs and personal health information data sources (including EHRs) consistent with HITSP-identified standards, and PHR portability. The certification criteria development process should take into account the best practices for security and privacy policies to be identified by the Consumer Empowerment Workgroup, the Confidentiality, Privacy, and Security Workgroup, and other relevant groups.

AHIC Accepted (3/13/2007)

Status/Progress Notes: CE Workgroup heard testimony on social marketing in 2006 and 2008. The recommendations are in the process of being formulated and will be presented to AHIC in July, 2008.

2.6 DISABILITY RECOMMENDATIONS

2.6.1 RECOMMENDATION 1.1

HHS should coordinate activity to ensure that PHRs *sponsored by the federal government* are consistent with statutes and regulations, including accessibility standards, in accordance with Section 503 (29 U.S.C. § 793), 504 (29 U.S.C. §794) and 508 (29 U.S.C. §794d) of the Rehabilitation Act of 1973 (Pub. L. 93-112).

Status: Accepted (4/22/2008)

with minor modification – [deleted sponsored by the federal government]

2.6.2 RECOMMENDATION 1.2

As HHS develops a use case with attendant interoperability standards specific to the needs of persons with disabilities, this use case should include the following:

- Provision for coordinated care across multiple health care encounters, providers, and caregivers.
- Access to and assimilation of information currently existing in paper format.
- The ability of authorized care and service providers, including the Social Security Administration (SSA) and other public and private entities that have purview over disability compensation, to utilize electronic authentication and electronic transmittal to obtain relevant information from the PHR on behalf of the authorizing consumer or surrogate, in accordance with the authorizing parties restrictions on what data can be seen or accessed from the PHR.
- Functional assessment for use by persons with disabilities and their providers in subsequent disability record development.

Status: Accepted (4/22/2008)

2.6.3 RECOMMENDATION 1.3

As PHRs are certified, HHS should coordinate efforts to ensure that relevant electronic health information in these PHRs is interoperable with that in CCHIT certified Electronic Health Records.

AHIC Accepted (4/22/2008)

2.6.4 RECOMMENDATION 1.4

Any PHR **offered directly or sponsored by HHS** should be developed to accommodate technological applications that can be used by persons with disabilities, and can address accessibility issues that include differences in language, the broad range of racial and cultural diversity, and differences in family and community practice.

AHIC Accepted (4/22/2008) – with minor modification [~~deleted “offered directly or sponsored by HHS”~~]

2.7 RACIAL AND ETHNIC COMMUNITIES/UNDERSERVED

2.7.1 RECOMMENDATION 2.1

HHS should increase access for racial and ethnic minorities, persons with disabilities, and the underserved to health care delivery systems which are supported by health IT by

specifying language referencing the inclusion of racial and ethnic minorities, persons with disabilities, and the underserved in relevant contracts, grants, cooperative agreements, demonstration projects, and pilots which support the adoption of health IT within the delivery system.

AHIC Accepted (4/22/2008)

2.7.2 RECOMMENDATION 2.2

HHS, through the Office of Minority Health (OMH), shall lead the process of conducting an environmental scan on health IT use by medically underserved populations.

AHIC Accepted (4/22/2008)

Status/Progress Notes: The Office of the Assistant Secretary for Planning and Evaluation (ASPE) as a member of the new HHS HIT and Underserved Populations Workgroup(co-chaired by the Office of Minority Health and the HRSA office of Health Information Technology) is currently, conducting an environmental scan. The final white paper is expected to be completed by November 2008.

2.7.3 RECOMMENDATION 2.3

HHS should pursue partnerships with private sector leadership to foster better communication between patients and providers in underserved areas via secure messaging, telehealth/telemedicine, and remote monitoring in multiple settings.

AHIC Accepted (4/22/2008)

2.7.4 RECOMMENDATION 2.4

The Office of Minority Health (OMH) should work with ONC to leverage support for public/private and non-profit partnerships in efforts to market, educate, and increase usage of information technologies by racial and ethnic minorities to reduce health disparities. OMH, working with ONC, should take leadership in communicating about PHRs, their applications, and their benefits to community-based organizations by developing an action plan, timetable and metrics for the implementation of an education outreach plan.

AHIC Accepted (4/22/2008)

Status/Progress Notes: On June 12, OMH formed a “Health IT Collaborative for the Underserved,” with a goal of ensuring that underserved populations are included as health information technologies (Health IT) are developed and deployed. The Office of the National Coordinator and AHRQ joined the federal partners in this public private partnership. The conveners were OMH, the Health Information and Management Systems Society (HIMSS); the Summit Health Institute for Research and Education, Inc. (SHIRE), and Apttis, Inc. They will be joined by additional Federal agencies and private

sector and community-based stakeholders to mount a year-long Health IT initiative. Long-range, participants will work to improve the quality of care, increase access to care and care-related services and reduce the cost of care among the underserved. Web cast available at http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=2818

2.8 CONSUMER CONTROL OF PERSONAL HEALTH INFORMATION

2.8.1 RECOMMENDATION 1

For purposes of the federal government the HHS Secretary should adopt the consensus definition of a Personal Health Record as presented in The National Alliance for Health Information Technology Report (NAHIT), "Defining Key Health Information Technology Terms" (April, 28, 2008) .

Definition of a PHR:

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from one or more sources while being managed, shared, and controlled by the individual or designee.
AHIC Presentation: 11/12/2008

2.8.2 RECOMMENDATION 2

Personal health records should aspire to possess the functional and technical capability to enable consumer control of the collection, access, use, and disclosure of their individually identifiable health information (IIHI) according to the type of information, type of provider, and purposes/circumstance of the collection, access, use, or disclosure of the IIHI as it travels through the electronic health information exchange and when it is at rest, in accordance with provisions of HIPAA. As technological capabilities evolve, PHRs should aspire to include ever more granular levels of consumer control on the data that they contain, consistent with existing statute and regulation.

This recommendation should be a priority for AHIC 2.0.

AHIC Presentation: 11/12/2008

2.8.3 RECOMMENDATION 3

Personal Health Records (PHRs), as defined previously, should aspire to meet the needs of all populations, including persons with special needs and low health literacy, with respect to information on how and when their personal health data may be disclosed. These efforts should facilitate access to electronic resources for education and decision support related to the potential consumer risks and benefits of information disclosure and information protection, including potential legal, health insurance, and other information

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domains relevant to maintenance of basic needs. These resources should be consistent with statutes and regulations, including, but not limited to, accessibility standards, in accordance with Section 503 (29 U.S.C. § 793), 504 (29 U.S.C. §794) and 508 (29 U.S.C. §794d) of the Rehabilitation Act of 1973 (Pub. L. 93-112).

AHIC Presentation: 11/12/2008

APPENDIX B
Testimony Summaries from the Consumer Empowerment Workgroup

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TESTIFYING DATE/ DATE OF PRESENTATION	TESTIFIER/PRESENTER NAME	INFORMATION SHARED/TESTIMONY
STATE OF TECHNOLOGY AND PHR DESIGN		
Jan-06	Workgroup	Discussed challenges/issues/strategies re the electronic registration summary . Lack of commonality across database formats, time constraints in addressing needs ("good enough model"), consumer collection of information, acceptance by medical community, and HIPPA regulations were discussed.
Jan-06	Davenport-Ennis	Discussed doc which focused upon workgroup charges and stakeholders, registration summary, data elements, and current federal elements. Discussed Katrina.org (way for consumers to obtain scrip info), CAQH effort to develop business rules to exchange info re eligibility and benefits (CMS supporting). Also discussed 5 fields of data to ID individuals and sources for data elements (MPI, Rx Hub, Health Plan Reps, Labs).
Feb-06	ONC	Discussed doc which contained " 25 Preliminary Guiding Principles for Wkgrp ," grouped under 4 headings - 1) Principles for PHR (9); 2) Principles for Info Access and Control (9); 3) Disclosure and Accountability Principles (4); 4) Functionality (3).
Feb-06	Dr. Lansky	Presented 12 principles for (1), 3 new - PHRs should be voluntary, should be user friendly, and should be interoperable w/ EHRs. Focused upon 3 general headings: 1) Principles for PHRs, 2) Principles for Info Access and Control, 3) Disclosure and Accountability Principles. Consumers should have ultimate control re who could access PHR info, but - once access is given, can providers add info into EHR? " Permission " needs to be clearly defined. Authentication deemed necessary. Wkgroup agreed to accept principles as working principles, Dr. Lansky will streamline. (streamlined into 6 in March)

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STATE OF TECHNOLOGY AND PHR DESIGN		
Feb-06	Dr. Mon	Discussion re 174 data elements and sources for registration summary and medication history. Workgroup discussed 1) additional data suggestions, 2) restructuring. Advance directives, radiology, adverse medication reactions, vitamins, herbal therapies, provisional categories and other info was added. SSN, immunization info, allergies, audience and geography, data sources and medications were restructured. This initiative discussed to be " Consumer Centered ," thus should select data elements. "Clipboard" discussed to standardize minimum dataset of PHR, would have 3 critical functions: 1) record clinical treatment info for reimbursement; 2) record insurance info for reimbursement; 3) record meds and any modifications to meds.
Feb-06	Cronin	Options for Breakthrough Models discussion. Options: 1) existing regional health info exchange w/ a consumer interface re registration summary and medication history, could add radiology/pathology reports in future. 2) Expanded version of Katrinahealth.org w/ registration summary linked to medication history - gives authorized providers access to patient prescription info. 3) PHR vendor(s) linked to 1 or more intermediaries to get updated registration and medication info, send/receive consumer info, interface w/ PBMs. 4) Payer or employer portal linked to PHR vendor. # 1,3,4 were agreed to be viable options by work group.
Mar-06	ONC	Workgroup agreed to have HITSP take lead on developing minimum dataset for medication history and registration summary.
Jul-06	Dr. Daniel Sands - AMIA, ACMI, Harvard Medical School, Beth Israel Deaconess Medical Center (Testimony)	Discusses definitions of both EHRs/PHRs, how to bridge the gaps while benefitting patient/health system. Discusses components of PHR, utilization of claims data (supports it). Poses many questions re who will use, how it will be funded, what will it include - lack of business case.

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STATE OF TECHNOLOGY AND PHR DESIGN		
Jul-06	Rita Agarwal, PhD, Director, CHIDS; Corey Angst, MBA, Associate Director CHIDS (Testimony)	Discussed impact of PHRs, what patients want (online refills, patient-provider secure messaging, meds lists). Further discussed the need for PHRs, addition of patient value (empowerment, ownership). Defined types of PHRs (usb/internet/paper), populations who utilize them. Will gain momentum, but data protection/privacy, linkages remain problem areas.
Jul-06	Elaine A. Blechman, PhD, U. of Colorado at Boulder, co-chair of the HITSP consumer empowerment technical committee (Testimony)	Discusses key capabilities of a PHR system, 4 types of PHR systems: 1) view PHR (not interoperable, patient enters data); 2) freestanding (similar to view); 3) tethered (info is accessible to in-network providers, interoperable); 4) consumer controller/interoperable PHR. Advocate identifying existing standards that suit consumers' business reqs. Recommend testing/R and D to design workflow of those who utilize PHRs, interoperability testing of EHR/PHR, and outcome research.
Jul-06	Donald T. Mon, PhD, Vice President, Practice Leadership, AHIMA, Co-Facilitator, HL7 PHR Work Group (Testimony)	Reviewed HL7, PHR-HER linkage group charge. Reduced # of functions from 64 in 2003 CFH PHR Functional Description to 60 in the HL7 PHR Functional Model. Developed Conformance Criteria for each functions, which are necessary for standards to exist. Developed PHR glossary. Next will develop a PHR-EHR HIE profile to be released late 06 or early 07.

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STATE OF TECHNOLOGY AND PHR DESIGN		
Jul-06	Adrian Gropper, MD, Chief Science Officer, MedCommons, Inc. (Testimony)	PHRs will be market driven, will evolve faster than the institutional components of the NHIN. Privacy and consumer security stressed. Compares "global interoperability" to ATMs and credit card networks. Most valuable features of PHR: private, up-to-date, subject to disclosure consent, authoritative, complete and accessible, emergency-ready, competitive and voluntary (should be an array of PHR providers). Supports CCR as starting point to contain most important elements. Does not advocate a particular level of health literacy. Support that the market be left alone for innovation - no minimum criteria set. Certification commissions and standards organizations are being dominated by institutional interests - certification efforts must be re-focused.
Jul-06	D. Matt Schmidt (Testimony)	More TV documentaries/programming describing scattered patient medical data would increase PHR awareness. Consumers need evidence base. Provider encounter notes found not very useful re PHR features for consumers. Minimum set of PHR elements important, but should not limit future development. Consumers should be able to download data from each provider encounter (scan) into their memory cards - provider's office would have codes to have access to PHRs. Consumers/Providers would have different passwords, encryption to protect data would be used. Market should be allowed to fulfill with its own innovation, practicing from a minimum set of expectations.
Jul-06	Lynne Brengman, RN, BSN, MBA PeaceHealth - St. Joseph Hospital, Bellingham, WA (Testimony)	Pamphlets in provider offices, clinics, hospitals would increase consumer awareness. Medications an extremely important feature of PHRs. Users should identify important features of PHRs. This system (Bellingham, WA - Whatcom County) has an electronic community record connecting provider offices, NHs, clinics, hospitals - PHRs are available to the community. Minimum criteria should be set, then vendors should compete.

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STATE OF TECHNOLOGY AND PHR DESIGN		
Oct-06	Paul Tang, Palo Alto Medical Foundation; Ross Martin, Pfizer (Discussion, facilitators)	<p>Setting the Context for the Vision about PHRs; An Initial View of the End State</p> <p>Development of the Vision</p> <ul style="list-style-type: none"> – Additions to and comments on the end state – Additions to and comments on the current state – Identification of enablers and barriers – Description of a feasible mid-state – Review of descriptions of each state
Nov-06	William Crawford, Centers for Medicare & Medicaid Services, and Kenneth Mandl, M.D., M.P.H., Harvard Medical School, (testimony)	Presented on the PCHRI meeting held in October. This meeting brought together leaders from government, academia, provider organizations, health plans, and industry. The focus of the meeting was on developing an infrastructure that will lead to an interoperable PHR world. The conference divided participants into three tracts: a business model approach, an ethical and societal approach, and a technology and standards approach. Emphasis was placed on a personally controlled health record (PCHR), which is more than a record with personal access.
Nov-06	Stefanie Fenton, M.B.A., M.P.H (testimony)	Presented on Intuit’s “Quicken for Healthcare” efforts. This initiative started from one person’s experience trying to manage his health care costs with Quicken software. This is illustrative of their “consumer-driven invention model”: Intuit literally watches consumers in their homes using the applications, and then they build tools that work the way the consumers work. Their goal is to create solutions that help consumers make better decisions.

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STATE OF TECHNOLOGY AND PHR DESIGN		
Nov-06	Stanley Chin, M.A., Altarum Institute (testimony)	Initial results from an environmental scan of the personal health record (PHR) market. Beginning in September, they contacted as many vendors as possible as part of the AHIC invitation for public participation. Then, in order to gather more structured data, three specialty subgroups were asked specific, targeted questions. Mr. Chin emphasized that this is a market scan and not a scientific study. Out of the initial 89 vendors identified, 13 are no longer in the PHR business; 24 out of the 76 active PHR vendors participated in the scan.
Sep-07	Elaine Blechman, U. of Colorado-Boulder (testimony)	Presented on the emerging PHR types, how these PHR models meet consumer needs, and how they add value from the perspective of different stakeholders. Types of PHRs: 1) Tethered: Patient portal to parent EHR; 2) Networked: PHR exchanges data with EHR network participants; 3) Unbound: PHR account in system with capabilities of fully interoperable EHR system; consumer authorizes and audits access instead of EHR system administrator.
Sep-07	Kim M. Nazi, FACHE; Veterans Administration (testimony/update)	Presented on the VA's experience with PHR development, adoption, and benefits within the context of this large health care delivery system. MyHealthVet is now being used extensively.
Dec-07	Lorraine Doo, Centers for Medicare & Medicaid Services (CMS) (Update)	Presented on the history and progress of the PHR pilot projects and evaluation.
Feb-08	Karen Bell, ONC	PHR paradigm: presented a PHR model revised according to the discussion from the prior workgroup meeting. The changes included adding the consumer to the box scheme of the model, as well as indicating opportunities for consumer control along the lines of information flow. The intermediary aggregators, indicated by the central box on this model, are becoming the construct for a PHR, because PHRs are most likely to be comprehensive repositories of information in a secure, reliable format. This record will include not only information created by the health care system but also information that is added by and important to the individual.

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17-Jun-08	John Moore, Managing Director, Chilmark Research, John@ChilmarkResearch.com	Evolving PHR markets: • What is Market Structure Today• How will Market Evolve - 4 Generations; • Trajectory: Drivers Challenges, What to Watch
17-Jun-08	Wes Rishel, Vice-President and Distinguished Analyst, Gartner Group, Inc	The Megavendor, Ecosystem Approach to the PHR: • These preliminary Microsoft and Google efforts are currently focused in the U.S., but the vendors will reach out to other countries. • The vendors are now focusing on developing partners — health IT system developers and healthcare institutions. They will focus more strongly on enrolling consumers later. • The competition between Google and Microsoft on healthcare information is not necessarily "to the death." Both products could thrive for many years. • These programs conform to privacy policy requirements or sidestep important policy obstacles by being consumer-controlled. • These efforts ultimately will succeed based on consumer perception of a suitable risk-to-reward balance for sharing their data.
17-Jun-08	Chris Muir, ONC	Health Information Exchange and PHRs: • Overview of health information exchange • Describe RHIOs/HIOs • Discuss RHIOs/HIOs involvement with consumer services • Discuss NHIN and PHR/consumer services

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PRIVACY AND SECURITY		
Mar-06	McAndrew	<p>HIPPA regs - only apply to "covered entities," i.e. health plans, healthcare clearinghouses, providers which engage in electronic transactions for which HIPPA standards have been adopted. Employers, certain types of insurers, and providers that do not engage in electronic transactions are not subject to HIPPA regs. HIPPA privacy rule covers info that is individually identifiable - protected in oral, written, electronic form. De-identified info is not covered by HIPPA rule. Health info can flow w/out individual consent among covered entities for treatment, payment, healthcare operations. Once health info is disclosed to an entity not subject to HIPPA, HIPPA places no further restraints on that entity's use of the info.</p>
Jan-07	Stanley Chin, M.A., Altarum Institute (testimony)	<p>Presented on a review of 30 posted privacy policies for Web-based, stand-alone PHR vendors. Scoring was based on eight major categories containing 31 criteria, including communication between the vendor and user, readability, collecting and sharing user data, and definition of terminology. Of the 31 criteria, one policy covered 18 and the rest covered 15 or fewer. In conclusion, several questions remain, including the appropriate role of government, enforcement mechanisms, and privacy policy disclosure for PHRs that are not stand-alone.</p>
Mar-07	Stanley Chin, M.A., Altarum Institute (testimony)	<p>Testimony on Additional Privacy Policy Research from Environmental Scan; Conclusion: Existing policies are incomplete and there are no consensus privacy requirements; HIPAA-covered entities did not all state their protection of consumer PHI data; Privacy of PHR data should have a commonly-understood meaning among all vendors, providers, payers and users.</p>

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Jun-07	Ross Martin and Deven McGraw, CE-CPS Subgroup Co-Chairs (update)	The Subgroup held several meetings and developed the draft of essential public health record (PHR) privacy policy components. The privacy policy components convey high level principles, which would then be used by a certifying organization such as the Certification Commission for Health Information Technology (CCHIT) to establish measurable certification criteria. CCHIT has provided feedback that the components are at an appropriate level to be used by a certifying body to develop three or four more granular criteria for each component.

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Feb-06	Cronin	Barriers to implementation identified: 1) lack of interoperability; 2) Need for proxies; 3) Protection of personal health info in PHRs; 4) How to address inaccurate info v. liability issues; 5) Lack of consumer awareness; 6) Lack of a patient identifier (matching patients to records). Wrkgp agreed all barriers identified.
Feb-06	Burstin	Discussed pros/cons, options for target populations and geographic scope in regards to measurement of breakthrough model's efficiency. Options for populations included pediatric patients, patients w/ chronic diseases, state Medicaid/Medicare benefits, uninsured, and caregivers for elderly. Options for geographic scope included states with infrastructure and organizational capacity, regions w/ large employers and/or plans, regions w/ operational HINs. Workgroup agreed upon pediatric patients and chronic disease population, and one geographic area for pilot breakthrough model.
Mar-06	Lansky/J. Daniel/Maritin/OCR rep	Volunteered to develop further recommendations for privacy mechanisms outside of those not covered by HIPPA.

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Mar-06	ONC	Workgroup agreed that recommendations fit into 4 categories: 1) policy review; 2) Interoperability; 3) Education, 4) Pilot/demo projects.
Apr-06	Handelman	Presented preliminary data based on market analysis conducted on 483 employees health benefits plan subscribers in 5 cities. Findings include: 1) 70% of consumers would probably or def use a PHR; 2) "smart card" preferred; 3) centralizing records in 1 location biggest deal; 4) summary of doctor visits and medications most preferred in PHR, claims history least; 5) most trusted source of info were providers, least third-party payers; 6) insurance carriers providing updates and consumers controlling access was preferred way to update/control access; 7) highest-ranked online tools included checking on drug interactions and identifying health risks.
Apr-06	Lansky	Discussed 2 yr old Markle Foundation survey from 6 online drug list services (small sample size). Results: 1) no uniform source from which data was provided (from pharmacies, claims, etc.); 2) 2 provider organizations permit online drug refill services - insurers do not; 3) minimum functionality is to list meds, while HIT vendor has most complete info (drug interactions/reminders); 4) minority of services allow consumers to add info; 5) in most cases, information could not be exported, only printed; 6) prescription refill much appreciated by consumer; 7) most services require user name/password for authentication .

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Apr-06	Interoperability Subgroup Recommendations	<p>Rec 1.0: HITSP should be charged w/ addressing initial set of technical standards through the delivery of initial standards - should also, review/consult with ongoing industry efforts to develop PHR standards (Sept 30, 2006 added to this item - decided upon).</p> <p>Rec 1.1: HHS should perform a market analysis w/ the goal of describing to AHIC various functions/features of PHRs as well as policies/procedures of vendors, sponsors, stakeholders. Should include an environmental scan to understand value/demand across population, security/privacy policies of PHR providers, studies intermediary networks/application sponsors/data suppliers policies and practices.</p> <p>Rec 1.2: HHS should determine the right balance between enforcing policies of PHR providers and certification of privacy and security reqs for PHRs, and how they can protect consumers rights. HHS, FTC, and AHLZ should develop white paper identifying PHR prov</p>
Apr-06	Policy Subgroup Recommendations	<p>Rec 2.0: AHIC should create an ad hoc policy workgroup comprised of people from all existing workgroups, to frame issues surrounding patient identification, linkage to patient info, authentication, and authorization. Detailed questions would be deferred to an independent, sustainable policy and security advisory body. (Decided upon in May)</p> <p>Rec 2.1: By Sept 30, 2006 HHS should support the independent advisory body on privacy and security policies to develop/recommend market/govt security policies so support HIE. Should be implemented no later than July 2007.</p>

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Jul-06	Dr. Alan E Zuckerman, Primary Care Pediatrician, Georgetown University Medical Center (Testimony)	Consumer awareness will increase once providers adopt technology. Privacy controls and authentication are critical. Once providers engage, market will drive universal adoption. Summaries of problems, medications, immunizations, test results, vital signs, procedures, index of providers can prevent delays. The ability to add home monitoring of chronic diseases and secure communication w/ providers to request med refills, test results, or provide monitoring data are also important. Consumer friendly terminology and multi-lingual versions of PHRs are a must. Minimal criteria should be established, though market innovation is a must. Certification is necessary for privacy/security, interoperability, functionality.
Jul-06	Russell J. Davis, D.P.A., M.A.P.T., Ruth T. Perot, M.A.T., Summit Health Institute for Research and Education (SHIRE) (Testimony)	Concerned with access of HIT re communities of color. Further describes cancer statistics for minority populations - African Americans, American Indians, Alaska Natives, Latinos, Vietnamese Americans, all have high, unique morbidity/mortality indicators depending on type of cancer. 68% of whites v. 50% of blacks have a computer at home. Approximately 1/3 of 281.5 million (2000 U.S. population) are comprised of African Americans, non-Hispanic whites, senior citizens - most of whom do not possess or are unfamiliar with HIT. Targeted educational campaigns are critical. Representatives of underserved communitites should participate to some extent in consumer empowerment workgroup discussions. Federal govt. must play a strong role in establishing certification standards, as well as protecting privacy. Community partnerships are essential in realizing a PHR.

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Jul-06	Bazelon Center for Mental Health Law, Consumers Union, Health Privacy Project, National Consumers League, National Partnership for Women and Families, Privacy Rights Clearinghouse (Testimony)	Govt efforts should focus on eliminating barriers to and aligning incentives in support of secure and appropriate info exchange. No exiting PHR model enables consumers to identify a complete set of institutions storing their health-related info, provide institutions with instructions for managing data, then viewing data. Advocates that the govt. does not "constrain" range of consumer features, as they will vary. Govt. should focus on universal needs, including: clear/complete process for establishing conditions of use; user-determined access and edit permissions; user-determined permissions for data use; internal audit functions; external audit functions; interoperability with other PHR/EHR systems; ability for user to include all data which they believe to be relevant/useful. HIPPA standards for PHRs should be mandatory, DHHS should enforce any violations.
Jul-06	Deborah Beranek Lafky, MS, Kay Center for E-Health Research, School of Information Systems and Technology, Claremont Graduate University (Testimony)	Conducted a study with senior citizens from a retirement community. Aged from 67-94, ranged in health statuses, computer skills range. Each was interviewed re their views on HIT, personal health info mgmt., privacy, security, interoperability. Areas of concern were security, having data available to them, all health data available to all providers. Conclusion: seniors are not as attuned to the issue of personal health info, including aspects of privacy and security, as we may believe. Continued, fundamental research re the real needs and desires of prospective users is recommended.

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Sep-06	Marc M. Boutin, National Health Council (Testimony)	Discuss cases where use of EPHRs would alleviate incorrect diagnoses in the ER (Alpha-1). Describes how the implementation of EPHRs will improve patient care/medical outcomes, integrate the continuum of care, involve the patient in major decisions. Discusses how "Social Marketing," awareness will increase EPHR use. Describes lit review/environmental scan re patients with chronic diseases - found overall patients are eager to have access to their records, have their providers more aware of their data, and to see a coordinated, streamlined system. Patients' security/privacy issues are critical. Patients did not like an analogy which the Council tested - comparing EPHRs to the convenience of ATMs/banking. Patients thought the comparison was meant to reduce human contact with providers. Currently, the Council is involved in a pilot program with CA and MA re America's Health Insurance Plans to advocate using EPHRs.
Sep-06	Michael Leu, MD, MS, Robert Wood Johnson Clinical Scholar, Yale University (Testimony)	Describes how health literacy applies to e-tools, recommends future e-health literacy efforts. Low health literacy has been linked to increased cost/utilization (2005, Howard). Clinicians may need to be trained in principles of clear health communication (lay language), and respecting patients socio-cultural responsibilities, e-tools can be designed to incorporate these considerations. Tools can make certain patients understand important questions. To improve the consumer experience: create tools to assess ability of user, HHS should support the development of standard measures to assess health literacy, tech literacy. HHS should fund demos to include tools that have been developed using patient-focused design processes. HHS should also standardize minimum data and display standards for health-related electronic content. HHS should also evaluate PHR systems in regards to their utilization by cognitively impaired, older patients. Lastly, HHS should study and evaluate PHR systems and factors contributing

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Sep-06	William Crawford (Testimony)	Discusses the role of the fed in encouraging PHR adoption and establishing criteria for evaluating incentives, policy levers, and specific programs, in regards to HHS agencies. Evidence base development includes the need to establish value and determine mechanisms to integrate PHR into clinical care, study how PHRs, with EHRs, are used for disease mgmt, and implement a linked EHR/PHR system in Community Health Centers and fund initiatives through faith-based networks that support underserved/uninsured populations. The govt. should sponsor standards development, and the adoption of PHR related standards through CMS and FEHBP-sponsored PHRs. In regards to health literacy, the govt. should develop and disseminate a consumer education campaign about the benefits of PHRs and help define the PHR for the public, establish standards for and contribute science-based health information, and establish standards for content and presentation to improve the user experience. The fed should also develop data standards for
Sep-06	Linda Mills, FL Governor's Working Group on the Americans with Disabilities Act (Testimony)	Stresses persons with disabilities (approx 47 million) are being left behind with limited or no access to HIT systems or portals. Many systems are not accessible to these citizens most likely and in critical need to use them. Many states have endorsed Section 508 of the Rehabilitation Act technical standards that define this area of Accessible Electronic and Information Technology (A-eIT). On July 1, 2006, FL implemented the FL A-eIT Act requiring FL govt. to procure, develop, and maintain A-eIT to Section 508 technical standards. Persons with disabilities must be included in the framework/strategy of the development and deployment of HIT.

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Mar-06	Davenport-Ennis/Green	<p>"Regions of Interest" document discussion, identifies several regions in the country where PHR programs exist. 6 AHRQ funded state initiatives 12 NHIN contract related entities, other regions. Matrix identifies (where available) 1) data source for registration summary; 2) data source for medication history; 3) existing PHR or organization sponsor; 4) size and population served by PHR program. Info does NOT focus on interoperability. Could CAHP survey help collect info on program/consumer experiences?</p>
Jul-06	Dr. Marc Pierson, Whatcom County, WA (Testimony)	<p>Reporting on findings from a 5-year Robert Wood Johnson Foundation study, "Pursuing Perfection," in Whatcom County, WA. Worked w/ CHF/diabetes patients, "Shared Care Plan." AHRQ worked to connect EMR medication list to PHR medication list. Paper documents (care plan) are used during physician/care team visits. PHRs - community effort; patients interested in them, especially those w/ chronic illnesses. 3/4 or more participating in this study reported high effectiveness in communicating w/ healthcare professionals, keeping track of into, understanding what meds do, feeling more confident re interactions w/ healthcare system. Discussed Shared Care Plan features, content, lack of consumer awareness. Advocated initiating PHRs prior to EMRs, providing high-speed internet access to those who lack it.</p>

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Jul-06	Jana L. Skewes, President and CEO, Shared Health Inc. (Testimony)	Subsidiary of BCBD of TN, working w/ state's Medicaid program (TennCare). Aggregates payer claims, medications and lab data into an electronic record that is accessed by providers at no charge. Info includes patient demographics, medical encounter data, medication histories, lab results, immunization records, allergies. Providers are able to electronically prescribe meds, which are automatically checked for drug-to-drug and drug-allergy interactions during process. 600,000 patients in this system today, plans to add remaining 600,000. Working w/ CMS to test feasibility of pre-populating PHRecords w/ Medicare claims data. Consumers in TN not fully aware of HIT alternatives, nor provider utilization. Education needs to improve. Connecting consumers/clinicians to health information derived from a common data source is where the ultimate value lies.
Jul-06	Dr. Jane F. Barlow, MD, MPH, MBA, Well-Being Director Global Well-Being Services and Health Benefits - IBM Corp. (Testimony)	Over 65,000 employees have created PHRs, set up from 2 data sources - the employee and their claims set. Employees set-up with personal info, then it imports medical and prescription claims history. Records contain over 1.4 million data points. System translates medical voca, i.e. - angina=heart pain. Demonstrated a reduction in both ER visits and hospitalizations, resulting in an overall 16% reduction in medical/pharm costs adjusted for medical trend over a 2 yr. period. Employees offered a financial incentive to complete a health risk appraisal, develop a personal preventive care action plan and identify quality hospitals in their area.

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Jul-06	Greg Heaslip, Vice President, Benefits, PepsiCo (Testimony)	Implemented "HealthRoads," focused upon 1) personal insights and info; 2) emphasis on wellness and prevention; 3) fitness and nutrition programs; 4) local worksite programs. Approximately 20,000 employees use PHRs. Employees are accountable for entering data/maintaining PHRs. System provides immunization reminders, checks allergic reactions, and provides info on some chronic conditions to employees applicable. New PHR will include monthly imports of medical and prescription claims data into PHR. Employee education campaign re PHR utilization will be launched.
Jul-06	Kathleen Krantz, VP Technical and Human Resources, Greater Omaha Packing Company (Testimony)	Has a wellness structure which includes a wellness committee, on-site physicals and health fairs, free preventive screenings, bi-lingual comprehensive risk appraisals, electronic education for PHRs. Use "SimplyWell" insurance program, for employees to track wellness, individual action plan, etc. 566 employees use (majority).
Jul-06	Kathleen Angel, Director of Global Benefits, Dell Inc. (Testimony)	An unidentified % of employees keep PHRs (of 60k). Enhanced PHR securely imports claims data into PHRs. Patients able to manage diagnoses, test results, medications from multiple sources. Utilizes "laymen's" terms. Participation in program voluntary (less than 50% do). PHRs alert employees of potential drug interactions, remind them of preventive service appts., provide links to educational content.
Jul-06	Carmella Bocchino, Executive Vice President, America's Health Insurance Plans (Testimony)	Discussed industry definitions of PHRs, consumers needs. Providers interested, but question accuracy of data entered by consumers. AHIP/BCBSA project will begin shortly - PHRs will contain 13 data categories, will pilot test this model with 10 health plans in different geographic regions. PHRs will contain a core set of info (no matter what vendor is used) - registration and medication history, as well as other categories will be included/updated.

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Jul-06	Nathan Solomon, CIO and Co-founder, FollowMe (Testimony)	Discussed personal example of her son diagnosed w/ hydrocephalus, that portable info is critical. FollowMe went live in 2001. MiVIA - PHR which serves migrant workers. Patients own the PHR, not interoperable. Advocate consumer ownership of PHR, control by consumer, more publicity surrounding PHR usage. Advocate features such as self mgmt plans, current meds, allergies, access to accurate medical info, emergency information card. Govt. should establish minimum criteria for privacy/security. Govt. should play a role in determining interoperability.
Jul-06	Dr. Phillip Marshall, Vice President, Product Strategy, WebMD (Testimony)	Supports consumer education re personal health history, providers possessing essential health history to make clinical decisions, and consumer mobility across the healthcare continuum. Consumers should control data. The NHIN and RHIOs must discuss the potential of consumers using their own systems to connect onto the NHIN. Validation of users is necessary, and data portability is critical to future system developments. Discusses increasing consumer awareness through financial incentives, encouragement from providers, importation of med/lab/immunization data, educational material. Further discussed valuable patient features of PHRs (lab results, immunizations/preventive services, medication history, condition history). Supports CCR document and HL7 standard.
Jul-06	Dr. Edward Fotsch, CEO, Medem Inc. (Testimony)	Supports P4P programs tied to "replacing clipboards," HHS can motivate providers quickly. PHRs adoption will lead to EHR adoption. Providers should offer PHR services. Consumer authentication standards need to be adopted. PHR network may want to be considered re emergency preparedness. Consumer Empowerment and the Chronic Care Wrkgrp should be combined.

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Jul-06	Mark Wallin, ICW (Testimony)	International e-health provider (LifeSensor - their PHR). Introduced to European market in 2000, links patients to providers. Authorized physicians can view entire patient history/necessary data. Also utilizes e-card. With software, providers can update medical data directly from their database into patients' PHR, and can gather relevant info for their electronic records. Pharmacies can also be integrated into network. They promote integrating all systems. They've publicly funded tests with e-card in Germany, as well as integrating pharmacy networks, transferring insurance data, and developing a software development kit which makes it possible to link other network/info systems to the e-card. Have also led breast cancer projects - storing/transmitting dispersed patient info (OnkoPath).
Jul-06	Dr. David McCallie, Vice-President of Infomatics and Chief Scientist, Cerner Corporation (Testimony)	Describes independent health record banks (IHRBs). Argues govt. institutions, insurers, employers should populate/sponsor these accounts on behalf and under the permission of patient. Data must be under consumer control re access, security, and privacy. Have deployed community health records (CHRs) in TN and KS Medicaid populations, which are automatically populated by data feeds from payers, pharmacy benefit claims. After medical/PBM claims (pharm), likely that office encounter notes will flow into the PHR. Claims data should be the starting point for PHR/IHRB data elements. Believes CCR represents a starting point for standardization re captured clinical info. Also believe HL7 and ASTM should work together to create a single standard. ONCHIT should address PHR/IHRB use cases as well as NHIN/RHIO use cases. Offers steps to integrate PHR utilization among providers: 1) claims uploading; 2) doc/fax uploading from provider offices; 3) transparent uploading and downloading between compliant EMR and patie

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Sep-06	Mary Ellen Zipper, Director for Client Relations at CapMed (Testimony)	Offer a web-based PHR, a desk-top based PHR, and portable PHR on a USB drive. "One size fits all" does not work. Research shows users are more interested in a PHR which is capable of being populated electronically. Future of PHRs is a patient-centric model. One time employer incentives have worked (\$\$\$ for completing a health risk assessment), but oftentimes employees do not return to PHR. Clinicians should explore p4p options, as many may be in sync with required care mgmt protocols. Widespread adoption of PHRs will follow the availability of standardized electronic clinical info. Only 20% of physicians are utilizing EMRs unfortunately - an increase in this group will help drive PHR adoption. The govt. should require all EMR systems comply with and support established standards - similar for PHRs. Several e-pharmacy networks, claims data, lab and imaging systems would be a good starting point for populating a PHR. Another source of medical data - glucose meters, blood pressure monitors, cholesterol
Sep-06	Donald T. Mon, PhD, AHIMA (Testimony)	Discusses AHIMA's consumer outreach: through website (www.myPHR.com), and through a series of community-based presentations held across the country by AHIMA trained Community Education Coordinators (CEC). Primary goals were to increase public awareness of PHRs, to provide consumers with info needed to better manage their personal health info. To date, a total of 64 CECs have been trained, who've trained 486 presenters nationally. Over 4000 consumers have participated in 258 community presentations. The campaign has generated over 200 media placements reaching an estimated 10 million people. Consumers must learn what a PHR is, how to use/distinguish amongst PHR products, then training. Proposes a public/private collaborative effort re adoption of PHRs.

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Sep-06	eRisk Working Group for Healthcare's Guidelines for Online Communication (Testimony)	Suggests guidelines re e-communication. Areas of concern re online communication include: security, authentication, confidentiality, unauthorized access, informed consent, highly sensitive subject matter, emergency subject matter, doctor-patient relationship, medical records, licensing jurisdiction, authoritative information, commercial information. Areas for consideration re online fee-based consultation include pre-existing relationships, informed consent, medical records, fee disclosure, appropriate charges, identity disclosure, available information, online consultation v. online diagnosis and treatment, internet pharmacies. Re PHRs, patients must be advised re changes to patient data, patient authentication, and patient education/care mgmt.
Sep-06	Dr. Eduardo Artez, Peoplechart Corporation (Testimony)	Discusses a lack of inclusion re PHRs in regards to developing new electronic data exchange capabilities. Suggestion include: govt sponsored interoperable projects to explicitly include participation by PHRs; Provide a public list of these "capable" source system entities as part of disclosure and transparency; Review ways to promote or motivate provider source systems to leverage current EHR data exchange infrastructure with PHR; Ensure that the source systems (labs, pharmacies, hospitals, etc.) set up a patient identification code, so that the PHR can retrieve data for only that patient; Facilitate easier data access by requiring patient file upload with strong encryption be placed outside the firewall; Leverage and promote the use of off-the-shelf or open source encryption software for securing data exchange; Educate provide source systems on the importance and tangible benefits for patients in having an electronic copy of their clinical records.

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FINANCIAL		
Jul-06	Dr. James T. Canedy, SimplyWell LLC (Testimony)	Discusses financial incentives from employers: reduced premiums, HAS contributions, lower deductibles. Tax credits for businesses investing in this technology. SimplyWell - 20,000 users in 49 states that touch their record 2.4 million times/month. Application is populated through employer or insurance company eligible files. Once enrolled, person controls their PHR. Can measure identified participants cost outcomes over time - data indicates a decrease in sick days/hospital days/year, an increase re compliance w/ annual physical exams/preventive health exams. Info presented in layman's terms. Advocates early standardization of PHR elements. Health literacy can be promoted through learning modules linked to PHR. Fed should establish minimum standards re interoperability.
Sep-06	Dr. Eduardo Artez, Peoplechart Corporation (Testimony)	Works on behalf of consumers to collect, organize, and securely distribute patient medical records. Advocate standardizing photo-copying rates and processes. Assembled data from 3 study sites - 2 in Honolulu, Cleveland - studied "exorbitant" rates re photo-copying, from both medical record depts internal to the provider, and medical record companies which provide outsourced services. Found great disparity in states' laws governing fees. 30% of providers didn't charge anything, others ranged from \$7.22 - .40 per page. Average cost is .61/page, avg. medical record is 75 pages = \$46/record. Also, most providers charge up front fees, approx \$15-\$20/record. Avg. no. of days it takes Peoplechart to obtain a patient's record = 37 days. Nearly 30% of records took over 2 months to collect, due to rate(s) disputes. 2/3 of all requests required 2 verbal and written attempts. This should not be a revenue generating service - patients have a right to their information.

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FINANCIAL		
Sep-07	Paul Tang, Palo Alto Medical Foundation; (testimony)	Presented a proposed model for reimbursing providers for online care, which is recognized as a major barrier to PHR adoption. Beneficiaries of online care: Patients (convenience, access, health outcomes, lower costs); Payers (cost savings, health outcomes); Employers (productivity, employee health); Providers (efficiency of communication); Costs of online care; Providers: (HIT investment and operating costs, lack of reimbursement); Lack of reimbursement for rendering care online is significant impediment to its effective use need for public policy; Proposed E&M coding criteria are familiar, easy-to-apply and reproducible criteria for reimbursable electronic encounters; Estimated volume of visits modest and likely to replace office visits (decreasing overall costs); Proposed next steps: demonstration pilots of eVisits

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STANDARDS AND CERTIFICATION		
Feb-07	Alisa Ray, Executive Director, and Mark Leavitt, Chairman, Certification Commission for Healthcare Information Technology (CCHIT) (testimony)	Presented testimony on the potential benefits and concerns about certification of personal health records (PHRs). Markle Foundation’s survey (Dec 7, 2006) indicated the major barrier to PHR adoption was consumer concerns about identity theft, fraud, and misuse of personal data; Certification of PHRs for privacy and security could help overcome this barrier; Certification’s positive effects on accelerating adoption would outweigh any hypothetical ‘frictional’ effect of certification – especially with certification focused on security and interoperability rather than functionality.

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INTEROPERABILITY		
May-07	Stanley Chin, Altarum Institute (testimony)	<p>Results of Environmental Scan on Interoperability and Data Mobility: The full potential of PHR systems will not be realized until they are capable of widespread exchange of information with HIT sources.</p> <p>The development of high-functioning, proprietary portals attached to specific EHR or hospital information systems is one such approach. A second, more robust, model of information exchange was: open document standards (i.e., CCR, CDA) are used as a medium of exchange between source HIT systems and the PHR, and from the PHR to any other system.</p>
May-07	Steve Parente, University of Minnesota and John Casillas, The Medical Banking Project (testimony)	<p>Electronic Medical Banking: new technology platform called the integrated health card, which would integrate clinical health information with PHRs. What if interoperability is too hard? This provides a very real Plan B that could be faster and cheaper to deploy. The significance of the Medical Banking PHR new technology is its development based upon a currently accepted form of information technology, insurance payment transaction processing. It also provides a platform that links data across all sites of care without a command and control integrated delivery system.</p>
May-07	Kelly Cronin, ONC (testimony)	<p>Presented on: Health Information Exchange (HIE) – A multi-stakeholder entity that enables the movement of health-related data within state, regional or non-jurisdictional participant groups. NHIN Health Information Exchange (NHIE) – An HIE that implements the NHIN architecture (services, standards and requirements), processes and procedures, and participates in the NHIN Cooperative. The 2007 NHIN trial implementations were also discussed.</p>

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INTEROPERABILITY		
May-07	William Crawford and Kenneth Mandl, M.D., MPH, Harvard Medical School; David Lansky, Ph.D., Markle Foundation (testimony)	Role of HIE for PHRs: data intermediary services in connecting consumers to the NHIN. Key Insight #1: Confront privacy head on by exercising the individual’s rights to information; A critical issue for RHIOs, SNOs or NHINs. Key Insight #2: Make the patient the integrator of his/her own medical record; At one extreme: an opportunity for an “organic NHIN” or an “HIE of One”. The Road Ahead: Defining the policies used by entities at each link in the “chain” of data handling; Implementing the policies used by entities at each link in the “chain” of data handling; Enforcing the policies used by entities at each link in the “chain” of data handling .
May-07	Steve Downs, Robert Wood Johnson Foundation (testimony)	Emerging Technologies: presented on emerging technologies that collect “patient-sourced” data to feed into applications and other data sources.

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SECONDARY USES OF DATA		
Jul-07	Dr. Charles Safran, Harvard Medical School (testimony)	Toward a National Framework on Secondary Use of Health Data: Secondary uses of healthcare data are widespread; Patient privacy issues dominate the public trust; Technological capabilities to merge, link, re-use, and exchange data are outpacing the establishment of policies, procedures, and processes.; Need for additional attention and leadership at the national and state levels.
Jul-07	Jonathan White, AHRQ; Jason Bonander, CDC (testimony)	Jonathan White, AHRQ, presented on current activities regarding the secondary uses of data in terms of quality measurement and reporting. Jason Bonander, CDC, presented on public health data collection and Personal Health Records (PHR) data use for public health.

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SECONDARY USES OF DATA		
Sep-07	Simon P. Cohn; Chair, National Committee on Vital and Health Statistics (testimony)	Summary of testimony: As health data uses are enhanced through information technology, there is a need to weigh potential goods with potential harms (and find improved ways to reduce the risk of harm); HIPAA provides a minimum bar for data stewardship, yet there are new challenges not addressed by HIPAA and remaining confusion/lack of clarity about current uses (e.g., distinctions between quality improvement efforts and research); Large databases with enhanced data linkage capabilities, despite enhanced protection techniques, pose new challenges; Trust is fundamental. As health data uses are made further from the nexus of care, trust begins to erode. Transparency plays an important role, but may not always be sufficient; HIPAA’s safe harbor standard for de-identification may provide insufficient identity protection, especially for very small subsets of data.

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SPECIAL POPULATIONS (DISABILITY)		
Oct-07	Fred Cowell, Paralyzed Veterans of America (testimony)	Presented on the advantages of PHRs for people with disabilities, as well as the privacy and security concerns.
Oct-07	David Stapleton, Mathematica Policy Research, Inc., (testimony)	Presented on the role of PHRs in facilitating the “ disability policy transition ” from policies that focus on caretaking to empowerment policies.
Oct-07	Ron Manderscheid, Constella Group, LLC (testimony)	Presented on the science, a case study, and a business case to promote the ability of PHRs to empower people with disabilities.
Oct-07	Thomas Horan, Claremont Graduate University (testimony)	Presented on the role of PHRs to assist in the disability determination and on the development of a user taxonomy.

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SPECIAL POPULATIONS (DISABILITY)		
Mar-08	Thomas Horan, Claremont Graduate University (testimony)	Stated that eight unique needs of the disability community were identified, and the subgroup formulated recommendations to meet these needs in order to advance PHR use. Eileen Elias, subgroup co-chair, added that these recommendations have been vetted through the HHS Office of Disability. In summary, the workgroup will reorganize and streamline the recommendations into those pertaining to the use case (Recommendations 2, 4, 5, 7, 8) and the “stand alone” recommendations (1 and 3). A recommendation letter will be developed based on this discussion and circulated for workgroup feedback.

TESTIFYING DATE/ DATE OF PRESENTATION	TESTIFIER/PRESENTER NAME	INFORMATION SHARED/TESTIMONY
SPECIAL POPULATIONS (RACIAL AND ETHNIC MINORITIES)		
Dec-07	Garth Graham (Minority Health, HHS) (testimony)	Presented on how health IT, and particularly telehealth, can be used as a tool to reduce health disparities in racial, ethnic, and rural populations.
Dec-07	Ruth T. Perot (Summit Health Institute for Research and Education, Inc.) (testimony)	Presented on the promise of health IT and the risks of minority non-participation in health IT.
Dec-07	Teresa Zayas Cabán (AHRQ) (testimony)	Presented on the research efforts to reduce disparities through health IT.

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SPECIAL POPULATIONS (RACIAL AND ETHNIC MINORITIES)		
Jan-08	M. Chris Gibbons (Johns Hopkins Urban Health Institute)(testimony)	Presented on the emerging field of Populomics , which focuses on the potential role of technology to address racial and ethnic disparities. Gibbons commented that cell phone usage is high among racial and ethnic groups, and that Latinos use cell phones more than any other technology. These technologies are a new and promising field, but he cautioned not to “put the cart before the horse.” Because this field is so new, little is known about why consumers use the technology or what effect its use will have on behavior change. Dr. Weinberg recommended a recent paper on this topic to inform the discussion. He also commented that while the new models of cell phones with wireless internet abilities open a range of technology solutions, much can be done with more widely available SMS, such as appointment reminders, medication reminders, and directions to healthcare facilities. These possibilities introduce consumers to health IT.
Jan-08	Cesar Palacios (Proyecto Salud Clinic, Wheaton, MD) (testimony)	Presented on the use of electronic medical records (EMRs) at a low-income, Latino “safety net” health clinic . EMR - CHLCare challenges. Making the PHR meaningful to patients (culturally and linguistically); Improving patient health literacy; Low patient computer literacy; High implementation costs associated with a fully capable Health IT system connected to providers, patients, community clinics, hospitals, specialists, laboratories, and others; Providing timely patient education tailored to their needs; Maintaining clinic’s workforce trained and willing to invest on patients education
Jan-08	Kathy Ficco (St. Joseph Health System Sonoma County) (testimony)	Presented on technology uses to improve health care delivery to migrant agricultural workers. MiVIA is a patient “owned” electronic Personal Health Record (PHR) originally designed for Migrant Agricultural Workers and expanded to include anyone with a medical condition i.e: Homeless, Special Needs, Women, Children.

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SPECIAL POPULATIONS (RACIAL AND ETHNIC MINORITIES)		
<p>Jan-08</p>	<p>Armin Weinberg (Intercultural Cancer Council/Baylor College of Medicine) (testimony)</p>	<p>Presented the opportunities, challenges, and possible solutions on how to best implement health information technology (HIT) strategies among racial, ethnic, and underserved populations. Recommendations: 1). Focus efforts on where those with limited resources have already joined in the information technology revolution. 2). Launch an aggressive set of programs designed to engage young minority and underserved health professionals in the design and use of HIT. 3). Provide health care providers with incentives to apply technology equally to all. 4) Establish an implementation schema that cuts across all appropriate DHHS and other Federal Agencies and programs with the requirement of public and private involvement and accountability.5) Empower communities to play a role in HIT by committing funds that will support five to ten year plans that promote applications within existing social, healthcare and service sectors that first focus on consumer need rather than the system’s needs.</p>

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SOCIAL MEDIA (HOW SOCIAL MEDIA CAN INCREASE PHR ADOPTION)		
Feb-08		HIT and Consumer Attitudes: presented soon-to-be released research on consumer attitudes about healthcare and HIT - Key themes from survey results... The system is complex and not well understood: personal experiences drive attitudes and unmet needs; Unmet needs are basic: better service, personalization, value; Consumers are receptive to disruptive innovations; Most consumers are not financially prepared to take on the risk; Consumers recognize differences in pricing and quality comparing among plans and providers; Consumers want tools to customize the health services and insurance programs they use; The market is not homogenous: there are distinct segments and distinctions among key groups.
Mar-08	Jay M. Bernhardt, PhD, MPH, CDC (testimony)	Key Terms and Concepts: What is Social media?: Online technologies and practices that people use to share opinions, insights, experiences, and perspectives; New media: media created with computers that includes some aspect of interactivity for its audience and is usually in digital form; User-generated content: media content that are produced or influenced by end-users, as opposed to traditional media producers.
Mar-08	Fard Johnmar Founder, Envision Solutions, LLC (testimony)	Presented on user trends for social media technologies. Pay Attention To The “Third Screen” -Mobile is freeing Americans from their desks, giving us the ability to reach them where they live, work and play. Older Americans Avid Social Media Users - With social media new does not equal young.
Mar-08	Janice R. Nall, National Center for Health Marketing, CDC (testimony)	Provided examples of health applications in social media -YouTube – user-shared video; flickr – user-shared photos; Twitter - microblog; Organized Wisdom – social network; Digg – social bookmarking; del.ici.ous – social bookmarking

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SOCIAL MEDIA (HOW SOCIAL MEDIA CAN INCREASE PHR ADOPTION)		
Mar-08	David K. Ahern, PhD, Brigham & Women's Hospital, Harvard Medical School (testimony)	Social Media and Personal Health Record (PHR) adoption: Is there an Evidence-base? Qualitative Study of PHR Concept - Employed moderated focus groups; Purpose was to understand how people currently manage health-related information; Hear what they need and want to manage their health.
Mar-08	Grant Wedner, Daily Strength (testimony)	Presented on the experiences of an e-health social network . Market - Market: ... social revolution - 84% of internet users 30-49 have looked for health information online (Pew Internet, 2006); 136 million adults search for health info online (Harris Interactive, 2007); Online health audience = 66% of online population (Jupiter, 2006); 116 million adults used the Internet for health information in 2006 - vs. 40M five years ago.(Manhattan Research, 2007); 34% of ALL adults online consume UGC for health (Jupiter, 2006)
Apr-08	James Allen Heywood, PatientsLikeMe (testimony)	PatientsLikeMe is a patient-centered company creating new knowledge derived from the real-world disease - Our mission is to improve the lives of patients through new knowledge derived from their shared real-world experiences and outcomes
Apr-08	Patricia Flatley Brennan, RN, PhD; University of Wisconsin, Madison (testimony)	What is needed to engage patient and clinicians in healthy choices? It's not the PHR -- It's what you do with it!

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CLINICAL DECISION SUPPORT		
Apr-08	Joshua Seidman, Ph.D.; President, Center for Information Therapy (testimony)	<p>Mission: Advance practice & science prescribing & using health information to improve people’s health; Vision: A future in which every health decision is informed. Patient-Centered HIT Initiative- Key Insights—Technology: Many clinicians not asking about Web access; Many patients using email, cell phones, etc.; Use of smart cards; EHR implementation without portal access; PHR implementation missing 2 things: 1) Link between PHI & contextualizing content 2) Concerted strategy to drive adoption</p>
Apr-08	Karen Sepucha, PhD; Health Decision Research Unit; Massachussets General Hospital (testimony)	<p>Tools to Support Knowledge-Based & Patient-Centered Medical Decisions: Lessons Learned: Integrating decision aids into clinic flow: Is feasible and beneficial to both patients and providers; Helps patients make informed, values-based decisions; Helps achieve patient-centered care.</p>

American Health Information Community

Quality Workgroup Vision Roadmap

Carolyn Clancy
HHS/Agency for Healthcare Research and Quality

Richard Stephens
The Boeing Company

November 12, 2008

Quality Workgroup Members

Co-Chairs:

- Carolyn Clancy HHS/Agency for Healthcare Research and Quality
- Richard Stephens The Boeing Company

Members:

- Abby Block HHS/Centers for Medicare and Medicaid Services
- Janet Corrigan National Quality Forum
- Helen Darling National Business Group on Health
- Anne Easton U.S. Office of Personnel Management
- Nancy Foster American Hospital Association
- George Isham HealthPartners and AQA alliance
- Jane Metzger First Consulting Group
- Susan Postal Hospital Corporation of America
- Gerald Shea AFL-CIO
- Barry Straube HHS/Centers for Medicare and Medicaid Services
- Jonathan Teich Brigham & Women's Hospital
- William M. Tierney Regenstrief Institute, Inc.
- Phyllis Torda National Committee for Quality Assurance
- Reed V. Tuckson United Health Group
- Charlene Underwood Siemens Medical Solutions & HIMSS EHR Vendor Association
- Margaret VanAmringe The Joint Commission
- Josie Williams Quality and Patient Safety Initiatives

Quality Workgroup Advisors

Office of the National Coordinator for Health IT:

- Kelly Cronin, Director
- Michelle Murray, Workgroup Lead

Senior Advisors:

- Kristine Martin Anderson Booz | Allen | Hamilton
- Theresa Cullen HHS/Indian Health Service
- Tammy Czarnecki VA/Veterans Health Administration
- James Ellzy DoD/TRICARE Management Activity
- Jerry Osheroff Thomson Healthcare
- Jon White HHS/Agency for Healthcare Research and Quality

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Bottom Line

- In 2006 we *believed* health IT would enhance health care quality and value
- We have created a clear path forward
- **The devil is in the details**

4

Context: Moving to value-driven health care



- Costs increasing much faster than quality
- Payment rewards *volume*, not value
- Current focus on transparency of quality and cost, incentives to reward high performance, “hard wiring” quality
- Health IT could reduce burden and help accelerate improvement
- Needed: a clear path aligning quality and health IT

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What did the Quality Workgroup hope to accomplish?

Specific charge:

Make recommendations to the American Health Information Community that specify how certified health information technology should capture, aggregate and report data for a core set of ambulatory and inpatient quality measures.

[Addressed in the March 2007 recommendations letter to the AHIC]

Broad charge:

Make recommendations to the American Health Information Community so that health IT 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 health IT.

[Addressed in the April 2008 recommendations letter to the AHIC]

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Future Vision

- Transparent reporting of meaningful quality performance informs choices and focuses improvement efforts
- Quality information is patient-focused
- Health IT can reduce reporting burden and drive improvements in care when it is delivered
- Requirements: ONE set of priorities for quality; a clear locus of accountability

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Key themes from the vision guided the workgroup

- Patient-focused quality measurement
 - Payment changes and reforms that accelerate the pace of quality improvement
 - Importance of data exchange and aggregation
 - Alignment with national priorities for quality of care
- Proactive consideration of health IT in supporting quality measurement
- Support for use of data from multiple sources
- Adoption of EHRs and other applications
- Support for evidence-based care and quality improvement through effective use of Clinical Decision Support (CDS)

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Conceptual Roadmap for Achieving the Vision of the Quality Workgroup

Future State Components	2008	2009	2010	2011	2012	2013
Policy:						
Incentives*	Small but increasing evidence base from existing P4P/VBP programs	Payment principles established	Consensus reached on paying for value	Payment changes and reforms created and tested	Payment changes and reforms implemented	
Legal Framework for Data Sharing*	HISPC reports released (2007)		States agree on common framework		States harmonize regulations and statutes addressing privacy and security for data sharing	
Data Stewardship	Broad agreement on need	Policies & procedures developed	Sample HIE agreements developed	Stewards identified	Stewards certified & compliance w/ rules established	
Data Exchange and Aggregation	Limited aggregation (primarily claims data)	Increased aggregation for P4P (increased use of clinical data)	Scalable data model exists	Established longitudinal aggregation (multi-source patient-centric data used including clinical and claims data)		
Infrastructure:						
Clinical Decision Support	CDS use is not standardized	Pilot studies of standardized CDS implemented	Best practices for patient-centric CDS established	Best practices for patient-centric CDS incorporated into certification criteria	EHRs w/CDS and other CDS tools certified	
Measure Set Evolution*	Setting-specific metrics used; NQF exploring episodic measures	Consensus-based patient-centric quality metrics identified and field tested		Single set of patient-centric quality metrics used		
Data Element Standardization	NQF HITSP identifies data element types	Standards identified for elements needed for quality measurement on an ongoing basis		Standards for quality measurement incorporated into EHR certification process		
Quality Data Set	Preliminary efforts by CMS (CARE tool) and NQF (HITEP)	Minimum QDS established for core measures	QDS expanded for additional measures (e.g., structural, outcome)	QDS includes data elements for longitudinal, patient-centric measures		
Coding Improvements	Classification systems (e.g., ICD-9) that facilitate billing are used for quality reporting	Ongoing efforts to improve coding of diagnoses and clinical care, mapping across coding systems, and guidance		CMS regulates conversion to ICD-10		
Patient & Provider Record Matching	Multiple methods used; demos and pilots in place		Technical principles and best practices established	Accountability for matching methods established		

*Potential Accelerant

Health IT Expert Panel at National Quality Forum (2007)

- Health IT Expert Panel charged to:
 - Identify **common data types** for measures to be standardized
 - Develop an overarching quality **measure development framework** using EHR systems
- Health IT Expert Panel concluded:
 - Promote EHR problem list in place of billing data
 - Work with HITSP on data “dictionary”
 - Codify allergies, side effects and certain diagnostic tests
 - EHR development needed for pharmacy interface and discharge instructions
 - NQF endorsement should evaluate quality of data requirements

Bottom Line

- In 2006 we *believed* health IT would enhance health care quality and value
- We have created a clear path forward
- **The devil is in the details**

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Continued public and private action will be required to realize the vision

- The Quality Workgroup focused its 2008 recommendations on the infrastructure components of the Vision Roadmap because substantive progress could be made within the next year
- The work of the Quality Workgroup will be continued by government entities and private sector forums such as AHIC Successor, Inc., and the National Quality Forum
- The policy-oriented components of the Vision Roadmap will need further attention in the coming years

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Department of Health & Human Services
Office of the National Coordinator for
Health Information Technology

The AHIC Quality Workgroup Vision Roadmap:
A Path to Improved Quality Measurement and Reporting
Through Increased Automation

Executive Summary

November 12, 2008

Introduction

Health care costs continue to rise more rapidly than the rate of quality improvement, adding considerable urgency to efforts to improve the return on investment for health care. A consensus has been reached that payments should reward high-quality, high-value care rather than volume of care, and that belief has become a foundation of reform proposals. Transparency about health care quality and costs provides consumers with the necessary information and the incentives to choose health care providers and services based on value. Similarly, this information helps providers focus their efforts to improve quality. An essential requirement underlying this approach is the measurement of quality in an efficient and consistent manner while minimizing reporting burden. Health information technology (health IT) can support both ease of measurement and improvements in the quality of care. The work of the Quality Workgroup, in particular the Vision Roadmap, illustrates a path forward for quality measurement and health IT in meeting the goal of re-aligning health care around value.

The Quality Workgroup

The American Health Information Community (AHIC) formed the Quality Workgroup (QWG) in 2006 and charged the workgroup with facilitating the use of interoperable health IT to improve quality measurement, reporting and improvement. In this context, “interoperable” refers to IT systems that are able to exchange and use information.

In January 2007, the Quality Workgroup presented to the AHIC a vision of an ideal future state for quality measurement and reporting. This vision promotes the goal of consistent delivery of high quality care across settings and over time. Based on testimony and research, the Quality Workgroup then developed a roadmap that suggests a path forward for achieving the future state of the vision by 2014 through increased automation of quality measurement and reporting through the use of interoperable health IT.

Summary of the Vision of the Quality Workgroup

The AHIC Quality Workgroup envisions a future in which transparent reporting of quality performance results in better patient care. Transparent reporting means that the public is given access to quality data about clinicians and hospitals. Achieving this vision will require changes to how data about clinical care is captured to evaluate provider performance. It will radically shift the way health care information is shared among clinicians and providers, and in particular, how it is used by consumers.

Today, providers struggle with assembling a comprehensive view of a patient’s health care experience due to the way information is collected and stored. Often, information about a patient’s care exists on paper in particular health care settings (e.g., a hospital or provider’s office) yet is not shared outside of that setting. Clinicians have limited access to information that would help them effectively transition patients across settings and coordinate with other care providers when patients have multiple chronic conditions. Also, the average consumer needs

better information to make more educated choices about which providers to see and which treatments to undergo. Consumers desire information about the cost, quality and efficiency of care.

The Quality Workgroup expects that quality measurement and improvement activities will evolve from focusing on the health care setting to focusing more on the patient, regardless of the health care setting at which they seek care. This evolution will require new efforts to collect and combine data and analyze trends over time and across care settings, also known as “data aggregation.” The increased availability of aggregated, patient-centric yet secure data will enable assessment of quality over time to guide improvement for both individual patients and groups of patients. Providers are currently frustrated by the burden placed on them to manually collect data to support quality measurement. In the future, the burden placed on providers to meet reporting requirements will be reduced by ensuring that the data needed to assess care is automatically collected while administering care and that information systems allow for seamless transfer of information. Consumers will be empowered to take a more active role in their health care. Providing more information will afford consumers the opportunity to be informed when choosing clinicians or hospitals and when selecting treatments.

The following key themes emerged from the vision and are reflected in the vision roadmap:

- **Patient-centric quality measurement:** The patient’s needs should be at the center of any quality improvement efforts. Patient-centric quality measurement requires collecting and connecting data over time and across care settings to build a more complete view of the patient’s care than is currently possible.
- **Payment changes and reforms that accelerate the pace of quality improvement:** It is often said that “you get what you pay for.” Better-coordinated, higher-quality health care will require changes in how clinicians and hospitals are paid. Payment changes and reforms would also create incentives for the development of the health IT infrastructure needed for the secure exchange of health information across care settings.
- **Importance of data exchange and aggregation:** Patient-centric care requires the secure exchange of data between providers and across care settings. In order to measure the health of groups of patients over time, this data must be combined and analyzed, or aggregated.
- **Alignment with national priorities for quality of care:** Quality measurement and improvement will be most effective when it is aligned with emerging national priorities for improving the quality of care. Progress toward alignment of measurement systems with the priorities should be regularly assessed.
- **Proactive consideration of health IT in supporting quality measurement:** The role of health IT in supporting quality measurement should be proactively considered as quality measures are developed and implemented. Currently, quality measures are often developed in silos within care settings without consideration of the capabilities of information technology, resulting in delays and extra costs later on. A more proactive approach to aligning quality measurement and health information technology will increase efficiency,

lower net costs, and facilitate better quality measures. For example, because quality measures are generally based on evidence-based guidelines, coordination among quality measure developers and clinical guideline authors is essential.

- **Support for use of data from multiple sources:** Collecting data from multiple existing sources (e.g., paper-based and electronic, administrative and clinical) is currently necessary, because not all data needed for quality measurement exists in any single source. For example, determining whether care was delivered at a fair cost will always require some financial or economic data integrated with clinical data. Electronic clinical data from electronic health records (EHRs) and other sources would be integrated as it becomes available.
- **Adoption of EHRs and other applications:** Adoption of EHRs and other health IT applications will facilitate data sharing, automation of population health analysis, and clinical decision support. Consumers and clinicians will realize more value from health information when critical information is widely portable, more easily aggregated at a patient level, and available at the point of care.
- **Support for evidence-based care and quality improvement through effective use of Clinical Decision Support (CDS):** CDS interventions support clinicians and patients in making decisions at key decision points in care delivery. Priorities for development of CDS tools should be shaped by national priorities for health care quality improvement. If quality measure development, CDS development, payment policy and evaluation efforts across various stakeholders can be better aligned, system level changes to achieve a high performance health care system will be more likely to succeed.

Overview of the Quality Workgroup Vision Roadmap

The vision roadmap provides guidance for current and future quality improvement efforts of groups such as the AHIC, its successor, and various quality alliances. The vision roadmap builds upon the key themes from the vision and outlines key changes in ten areas, or components, that must occur over the next few years to realize the vision. These components are grouped into two categories: those that address policy issues and those that address infrastructure issues. Please see Figure 1 for the detailed vision roadmap diagram.

The policy components of the vision roadmap include:

- Incentives
- Legal Framework for Data Sharing
- Data Stewardship
- Data Exchange and Aggregation

The infrastructure components of the vision roadmap include:

- Clinical Decision Support (CDS)
- Measure Set Evolution
- Data Element Standardization
- Quality Data Set (QDS)
- Coding Improvements
- Patient and Provider Entity Record Matching

The Quality Workgroup considers three of these components to be particularly important for accelerating the pace of progress toward automated and patient-centric quality measurement and improvement: Incentives, Legal Framework for Data Sharing, and Measure Set Evolution. In its recommendations letter to the Secretary of the Department of Health and Human Services (HHS), dated April 22, 2008, the Quality Workgroup chose to focus on the infrastructure components as work in these areas can continue regardless of the political environment in the coming months, whereas the needed changes and reforms for the policy components are more dependent upon political forces. Consequently, the recommendations from the Quality Workgroup addressed the topics of Measure Set Evolution, Data Element Standardization, and the Quality Data Set. Clinical Decision Support remains important to the Quality Workgroup; another AHIC workgroup, the CDS Ad Hoc Planning Group, took up this topic in a recommendations letter to the Secretary also dated April 22, 2008, with input from the Quality Workgroup.

Figure 1: Conceptual Roadmap for Achieving the Vision of the Quality Workgroup

Future State Components	2008	2009	2010	2011	2012	2013
Policy:						
Incentives*	Small but increasing evidence base from existing P4P/VBP programs		Payment principles established	Consensus reached on paying for value	Payment changes and reforms created and tested	Payment changes and reforms implemented
Legal Framework for Data Sharing*	HISPC reports released (2007)		States agree on common framework			States harmonize regulations and statutes addressing privacy and security for data sharing
Data Stewardship	Broad agreement on need	Policies & procedures developed	Sample HIE agreements developed	Stewards identified	Stewards certified & compliance w/ rules established	
Data Exchange and Aggregation	Limited aggregation (primarily claims data)	Increased aggregation for P4P (increased use of clinical data)		Scalable data model exists	Established longitudinal aggregation (multi-source patient-centric data used including clinical and claims data)	
Infrastructure:						
Clinical Decision Support	CDS use is not standardized	Pilot studies of standardized CDS implemented	Best practices for patient-centric CDS established	Best practices for patient-centric CDS incorporated into certification criteria		EHRs w/CDS and other CDS tools certified
Measure Set Evolution*	Setting-specific metrics used; NQF exploring episodic measures		Consensus-based patient-centric quality metrics identified and field tested		Single set of patient-centric quality metrics used	
Data Element Standardization	NQF HITEP identifies data element types	Standards identified for elements needed for quality measurement on an ongoing basis			Standards for quality measurement incorporated into EHR certification process	
Quality Data Set	Preliminary efforts by CMS (CARE tool) and NQF (HITEP)	Minimum QDS established for core measures	QDS expanded for additional measures (e.g., structural, outcome)		QDS includes data elements for longitudinal, patient-centric measures	
Coding Improvements	Classification systems (e.g., ICD-9) that facilitate billing are used for quality		Ongoing efforts to improve coding of diagnoses and clinical care, mapping across coding systems, and guidance		CMS regulates conversion to ICD-10	
Patient & Provider Record Matching	Multiple methods used; demos and pilots in place		Technical principles and best practices established		Accountability for matching methods established	

* Potential Accelerant

American Health Information Community

Personalized Healthcare Workgroup

Douglas E. Henley, M.D.
American Academy of Family Physicians

November 12, 2008

Personalized Health Care (PHC) Workgroup Member List

- **Co-Chairs:**
 - John Glaser Partners HealthCare
 - Douglas Henley American Academy of Family Physicians
- **Staff Co-Chair:**
 - Gregory Downing Office of the Secretary, HHS
- **Members:**
 - Carolyn Clancy Agency for Healthcare Research and Quality
 - Beryl Crossley American Clinical Laboratory Association, Quest
 - Paul Cusenza Entrepreneur and Consultant
 - Andrea Ferreira-Gonzalez Virginia Commonwealth University
 - Becky Fisher Patient Advocate
 - Felix Frueh Food and Drug Administration
 - Emory Fry Department of Defense
 - Alan Guttmacher National Institutes of Health/NHGRI
 - Kathy Hudson Genetics and Public Policy Center
 - Betsy Humphreys National Institutes of Health/NLM
 - Charles Kennedy WellPoint
 - Joel Kupersmith Department of Veterans Affairs
 - Stephen Matteson Pfizer
 - Deven McGraw National Partnership for Women and Families
 - Amy McGuire Baylor College of Medicine
 - Mark Rothstein University of Louisville
 - Steve Teutsch Merck
 - Janet Warrington Consultant
 - Andrew Wiesenthal Permanente Federation
 - Dennis Williams Health Resources and Services Administration
 - Marc Williams Intermountain Healthcare

PHC Workgroup Senior Advisors

- **Senior Advisors:**

- Mary Beth Bigley Office of the U.S. Surgeon General
- Greg Feero National Institutes of Health/NHGRI
- Joseph Kelly Centers for Medicare & Medicaid Services
- Muin Khoury Centers for Disease Control and Prevention
- Katherine Kolor Centers for Disease Control and Prevention
- Michele Lloyd-Puryear Health Resources and Services Administration
- Elizabeth Mansfield Food and Drug Administration
- Clement McDonald National Institutes of Health/NLM
- Armando Oliva Food and Drug Administration
- Dina Paltoo National Institutes of Health/NHLBI
- Jonathan Perlin HCA, Inc.
- Ronald Przygodzki Department of Veterans Affairs
- Gurvaneet Randhawa Agency for Healthcare Research and Quality
- Lisa Rovin Food and Drug Administration
- Maren Scheuner RAND Corporation
- Jean Slutsky Agency for Healthcare Research and Quality
- Reed Tuckson UnitedHealth Group; SACGHS
- Mollie Ullman-Cullere Harvard Partners Center for Genetics and Genomics
- Grant Wood Intermountain Healthcare

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American Health Information Community Workgroup on Personalized Healthcare

Broad Charge for the Workgroup:

Make recommendations to the American Health Information Community for a process to foster a broad, community-based approach to establish a common pathway based on common data standards to facilitate the incorporation of interoperable, clinically useful genetic/genomic information and analytical tools into electronic health records to support clinical decision-making for the clinician and consumer.

Specific Charge for the Workgroup:

Make recommendations to the American Health Information Community to consider means to establish standards for reporting and incorporation of common medical genetic/genomic tests and family health history data into electronic health records, and provide incentives for adoption across the country including federal government agencies.

<http://www.hhs.gov/healthit/ahic/healthcare/>

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- Personalized Healthcare Recommendation Status
- Family Health History Tool Update
- Newborn Screening Recommendation Status
- Pharmacogenomics and Clinical Research Recommendation Status
- Future Work and Remaining Issues
- Personalized Healthcare Workgroup Related Publications

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Personalized Healthcare Recommendation Status

Recommendations accepted by the AHIC on July 31, 2007: Family Health History and Genetic/Genomic Tests

- Personalized Healthcare Use Case published in February 2008, and is currently with Healthcare Information Technology Standards Panel (HITSP)
- Family Health History Tool prototype under development and completion is expected in December 2008
- Exploring demonstration pilots via Nationwide Health Information Network (NHIN) and other networks

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Family Health History Tool Update

- Tool is based on My Family Health Portrait, a collaborative effort of Centers for Disease Control and Prevention (CDC), Office of the Surgeon General (OSG), and National Institutes of Health (NIH) in 2001
- Collaboration with Department of Veterans Affairs (VA)-led Family Health History Multi-Stakeholder workgroup to make the application openly available for download, installation and customization
- Interoperability and portability demonstration on 25th November 2008
- Deployment of tool anticipated for December 2008

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Newborn Screening Recommendation Status

Recommendations accepted by the AHIC on February 22, 2008: Newborn Screening

- Newborn Screening (NBS) Use Case completed public review; following reconciliation of comments will be passed to HITSP
- Newborn Screening Resource Database prototype under development
- HHS Implementation Committee
- Transfer of interfaces and implementation sharing with NBS community via Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDGDNC) and others
- Exploring demonstration pilots via Nationwide Health Information Network (NHIN) and other networks

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Pharmacogenomics and Clinical Research Recommendation Status

Recommendations presented to the AHIC on June 3, 2008: Pharmacogenomics/Clinical Research

- Clarification of National Institute of Standards and Technology (NIST) standards activities for Pharmacogenomics data
- Electronic health record (EHR) use to support clinical research
- Identification of a core set of data elements that need to be captured in EHRs to investigate the outcomes of Pharmacogenomics-based clinical interventions

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Future Work and Remaining Issues

- Implementation of Newborn Screening Resource Database
 - National Library of Medicine (NLM) will house database
 - Health Resources and Services Administration (HRSA) will provide ongoing maintenance of content
- Privacy and security issues associated with newborn screening
- Formation of EHR/Clinical Research Value Case Workgroup
 - Public Private Partnership operating through ANSI/HITSP
 - Function in a similar process (HITSP, CCHIT)
 - Kick-off meeting on November 10, 2008
 - Plan value case recommendation by February 2009

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Personalized Healthcare Workgroup Related Publications

- **Advancing Personalized Health Care through Health Information Technology: An Update from the American Health Information Community's Personalized Health Care (JAMIA 2008)**

John Glaser, Douglas E. Henley, Gregory Downing, Kristin M. Brinner, Personalized Health Care Workgroup of the American Health Information Community

<http://www.jamia.org/cgi/reprint/15/4/391>

- **New Standards and Enhanced Utility for Family Health History Information in the Electronic Health Record: An Update from the American Health Information Community's Family Health History Multi-Stakeholder Workgroup (JAMIA 2008)**

W. Gregory Feero MD, PhD, Mary Beth Bigley DrPH, MSN, ANP, Kristin M. Brinner PhD, and the Family Health History Multi-Stakeholder Workgroup of the American Health Information Community

<http://www.jamia.org/cgi/content/abstract/M2793v1>

- **Confidentiality, privacy, and security of genetic and genomic test information in electronic health records: points to consider (Genetics in Medicine 2008)**

Amy L. McGuire, JD, PhD; Rebecca Fisher, MLIS; Paul Cusenza, MBA; Kathy Hudson, PhD; Mark A. Rothstein, JD; Deven McGraw, JD, MPH; Stephen Matteson, BS; John Glaser, PhD; Douglas E. Henley, MD

<http://www.geneticsinmedicine.org/pt/re/gim/abstract.00125817-200807000-00002.htm?jsessionid=L1NLTVB2INTVyJgmtFzPwBqFn1h61mX8yXwTwxJzhmNQ4k1G2fCl-815685239181195629180911-1>

<http://www.jamia.org/cgi/content/abstract/M2793v1>

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Personalized Healthcare Workgroup Related Publications

- **Toward a Future of Personalized Cancer Care (Cancer 2008)**

Michael O. Leavitt and Gregory J. Downing, DO, PhD

<http://www3.interscience.wiley.com/cgi-bin/fulltext/121411697/PDFSTART>

- **Advancing Patient-centric Pediatric Care through Health Information Exchange: An Update from the American Health Information Community's Personalized Health Care Workgroup (Pediatrics 2009 in press)**

Kristin A. Brinner, PhD and Gregory J. Downing, DO, PhD

- **Information Management to Support Personalized Decision-Making in Health Care (Med Decis Making 2008 in press)**

Gregory J. Downing, DO, PhD; Scott Boyle, PhD; Kristin M. Brinner, PhD; Brandon M. Welch, MS; Jerome A. Osheroff, MD

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American Health Information Community

Review of Clinical Decision Support Activities Under the Community

Charles Friedman, PhD
Deputy National Coordinator
Office of the National Coordinator for Health IT

November 12, 2008

Overview of Clinical Decision Support

- CDS is inherently cross-cutting, and engaged several AHIC Workgroups.
- CDS provides individuals involved in care decisions with scientific and person-specific information, intelligently filtered, at appropriate times to enhance health and care.
- CDS in electronic health record and other clinical information systems has great potential to improve quality and value of health care.
- Fully realizing this benefit poses challenges.

CDS Chronology

- **June 2006** – Release of CDS Roadmap. Generated by American Medical Informatics Association (AMIA) through an ONC/AHRQ contract.
- **May 2007** – Formation of CDS Ad Hoc Planning Group.
- **January – April 2008** – CDS Recommendations were drafted by the Ad Hoc Planning Group and reviewed by five AHIC Workgroups.
- **March 2008** – Formation of CDS Government Collaboratory.
- **April 2008** – Approval of CDS Recommendations by AHIC.

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CDS Recommendations Approved by AHIC

1. Drive measurable progress toward priority performance goals for health care quality improvement through effective use of CDS.
2. Explore options to establish or leverage a public-private entity to facilitate collaboration across many CDS development and deployment activities.
3. Accelerate CDS development and adoption through federal government programs and collaborations.

AHIC adopted these recommendations April 22, 2008.

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CDS Ad Hoc Planning Group Members

- **Chairs:**

- John Glaser (Emeritus) Partners HealthCare
- Paul Tang (Current) Palo Alto Medical Foundation

- **Public Participants:**

- Blackford Middleton Partners HealthCare
- Bob Greenes Arizona State University
- Don Detmer American Medical Informatics Association
- Jerry Osheroff Thomson Healthcare
- Jonathan Teich Elsevier / Harvard
- Marc Williams Intermountain Healthcare
- Norman Kahn Council of Medical Specialty Societies
- Steve Teutsch Merck

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CDS Ad Hoc Planning Group Members (cont.)

- **Government Participants:**

- Hon Pak Dept. of Defense
- Carolyn Clancy HHS/AHRQ
- Jon White HHS/AHRQ
- Les Lenert HHS/CDC
- Elizabeth Mansfield HHS/FDA
- Anthony Watson HHS/FDA
- Miles Rudd HHS/IHS
- Greg Downing HHS/OS
- Charles Friedman HHS/ONC
- Chitra Mohla HHS/ONC
- John Loonsk HHS/ONC
- Karen Bell HHS/ONC
- Kathleen Fyffe HHS/ONC
- Kelly Cronin HHS/ONC
- Michelle Murray HHS/ONC
- Rachel Nelson HHS/ONC

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CDS Government Collaboratory

- Includes ~90 representatives of multiple agencies across three federal Departments.
- Meets quarterly.
- Synergizes CDS efforts within the government.
- Currently launching several collaborative projects.
- Will promote and track implementation of activities related to advancing CDS.

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Sunset Sonata

- CDS Recommendations AHIC adopted April 22, 2008, identified needs/activities important to advancing CDS.
- Important that each activity identified has a “home.”
- Collaboratory may be able to assume some activities.
- Other groups will need to take up other activities.
- December 2008 – CDS Ad Hoc Planning Group administrative meeting to identify potential home for each activity.

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