The Community

American Health Information Community

September 23, 2008
8:30 a.m. - 2:00 p.m.

Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

American Health Information Community

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8:30 a.m. - 2:00 p.m. (EDT)

Hubert H. Humphrey Building, Great Hall
200 Independence Avenue, S.W.
Washington, DC 20201

8:30 a.m. **CALL TO ORDER –** *Secretary Leavitt*

8:35 a.m. **Introductory Comments** – *Secretary Leavitt*

8:40 a.m. **Comments** – *Kerry Weems, Vice-Chair and Acting Administrator, Centers for Medicare & Medicaid Services*

8:45 a.m. **Comments –** *Robert M. Kolodner National Coordinator for Health Information Technology*

8:50 a.m. **Population Health/Clinical Care Connections Workgroup**

– *John Lumpkin, Robert Wood Johnson Foundation*
– *Leslie Lenert, Centers for Disease Control & Prevention*

9:20 a.m. **BREAK**

9:35 a.m. **AHIC Standing Committee of the Whole: Successor**

– *John Glaser, Partners HealthCare*
– *Jonathan Perlin, HCA, Inc.*

10:05 a.m. **Nationwide Health Information Network (NHIN) Presentation**

Part 1: Supporting Patient Care (40 minutes)
Part 2: Supporting the Consumer (40 minutes)
Part 3: Business Application (40 minutes)

– *Robert M. Kolodner, National Coordinator for Health Information Technology*
– *Ginger Price, ONC Lead for Nationwide Health Information Network*

12:05 p.m. **BREAK**

12:45 p.m. **Confidentiality, Privacy & Security Workgroup: Recommendations**

– *Jodi Daniel, Office of the National Coordinator for Health Information Technology*
– *Deven McGraw, Center for Democracy and Technology*
– *Jill Dennis, American Health Information Management Association*

1:15 p.m. **Health IT Strategic Plan**

– Robert M. Kolodner, National Coordinator for Heath Information Technology
– Charles Friedman, Deputy National Coordinator

1:45 p.m. **Public Comment**

2:00 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 populate 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 HealtheVet 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 the 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	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 heath 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.

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