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, Room 800
Washington, DC 20201

TABLE OF CONTENTS

Agenda	**1**
July 29, 2008 Meeting Minutes	**2**
Population Health/Clinical Care Connections Workgroup	**3**
AHIC Standing Committee of the Whole: Successor	**4**
Nationwide Health Information Network (NHIN) Presentation	**5**
Confidentiality, Privacy & Security Workgroup: Recommendations	**6**
Health IT Strategic Plan	**7**

American Health Information Community

September 23, 2008

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
July 29, 2008

The American Health Information Community (AHIC), a federally chartered commission formed to help advance President Bush's call for most Americans to have electronic health records (EHRs) within 10 years, held its 23rd meeting on July 29, 2008, at the Hubert H. Humphrey Building, Room 800, 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 ensure that the privacy and security of those records are protected in a smooth, market-led way. The meeting focused on: (1) the evolving landscape of products and approaches that consumers may use to "mobilize" (access, use, and share) their personal health information, from both consumer and industry perspectives; (2) an update on the AHIC successor; and (3) the supplemental priority development pathway for clinical research applications of electronic health information.

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:

Brett Baker, Director of Governmental Affairs and Public Policy, American College of Physicians (Mr. Baker represented John Tooker, Executive Vice President and CEO, American College of Physicians)

Chuck Campbell, CIO of Military Health System, Department of Defense (Mr. Campbell represented S. Ward Casscells, Assistant Secretary for Health Affairs, Department of Defense)

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 (Ms. Furlani was also represented by Bettijoyce Lide, Scientific Advisor for Health Information Technology)

Lillee Smith Gelinas, RN, MSN, FAAN, Vice President and Chief Nursing Officer of VHA, Inc.

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

John Glaser, Vice President and CIO, Partners HealthCare

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)

Scott Serota, President and CEO, Blue Cross Blue Shield Association

Rosi Sweeney, Vice President, American Academy of Family Physicians (Ms. Sweeney represented Douglas Henley, MD, Executive Vice President, American Academy of Family Physicians)

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

Charles N. (Chip) Kahn III, President of the American Federation of Hospitals

Mike Kaszynski, Policy Analyst, Office of Personnel Management (Mr. Kaszynski represented Linda Springer, Director of the Office of Personnel Management)

Robert Kolodner, MD, National Coordinator for Health Information Technology

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

Introductory Comments

Secretary Leavitt began by welcoming three new members to the Community: (1) John Glaser, Vice President and CIO of Partners HealthCare; (2) Linda Dillman, Vice President for Risk Management and Benefits at Wal-Mart; and (3) John Tooker, Executive Vice President and the CEO of the American College of Physicians. Secretary Leavitt then indicated that recently passed legislation has created another powerful way to motivate physicians to use e-prescribing. Beginning in 2009, and over the following four years, doctors will be eligible for additional payments from Medicare when they prescribe electronically. These incentives will taper off over time, and after several years, those physicians who do not e-prescribe will not be reimbursed at the highest rate. The Secretary offered three principles that should help guide future legislative efforts:

- It is important to protect the flexibility of those who have been working to invent the new health IT tools, including AHIC and all the Workgroups. Secretary Leavitt cautioned against writing legislation to bias the process in one way or another because this would slow the progress that is being made.

- Although privacy is critical regarding health IT, it is important to avoid penalizing those who have adopted health IT early.

- Respect the need for legitimate health care communication.

Mr. Weems reminded the Community that the incentives to be provided for e-prescribing will begin in January and acknowledged that the rapid pace of this program was possible due to the work that AHIC and HHS have carried out. The Centers for Medicare and Medicaid Services has to adjust only one rule to accommodate the e-prescribing initiative. In October, a conference will be held to discuss adoption of these changes. Key audiences will include physicians, pharmacists, and vendors.

Approval of June 3, 2008, Meeting Minutes

Minutes from the June 3, 2008, AHIC meeting were distributed, reviewed by Community members, and approved unanimously with no changes.

Evolving Solutions for Mobilizing Personal Health Information for a Patient-Centric Health Care System—Consumer Perspectives and Needs

Nancy Davenport-Ennis, Chair of AHIC's Consumer Empowerment Workgroup, first offered a universal definition of Personal Health Records (PHRs): a PHR is an electronic record of health-related information about an individual that conforms to nationally recognized interoperability standards, and that can be drawn from multiple sources while being managed, shared, and controlled by the individual. This definition was presented to the Community and adopted by consensus at the June 2008 meeting. The definition is also consistent with the principles that the Consumer Empowerment Workgroup (CEWG) has worked with for the past two years. Ms. Davenport-Ennis pointed to some specifics regarding the principles of this definition.

First, the CEWG believes that individuals should be guaranteed the right to access their own health information and that individuals should be able to access their personally identifiable health information, both conveniently and affordably. They believe that individuals should know how their personally identifiable health information may be used and who has access to it, and that individuals should have control over whether and how their personally identifiable health information is shared. Great strides have been made in securing personal health information, and as AHIC 2.0 moves forward, there will be an even closer scrutiny on the issue of privacy. Systems for electronic health data exchange must protect the integrity, the security, the privacy and the confidentiality of an individual's information. The governance and administration of electronic health information networks should be transparent and publicly accountable.

PHRs are a part of a very dynamic market. Today, there are more than 200 different PHR solutions offered in the United States. Some are offered in independent systems; others are offered through providers, insurers, and employers. Still others are consumer-controlled interoperable PHRs. This is a great step forward from the state of the market when AHIC was formed.

Managing Personal Health Information: Current Tools and Products

John Moore, founder and Managing Director of the health care industry analyst firm Chilmark Research, present an overview of the current tools and products in the marketplace. He began by describing the three dominant personal health information (PHI) modalities that currently exist. The most common likely is paper records stored in a shoebox or a filing cabinet. Next is desktop software, with information entered manually into a computer, and then stored possibly on a USB device. The last modality are those solutions that are on the Internet today, hosted via the Internet, that a consumer can use either on their

own or through an organization sponsoring that PHR for their use. Those have, Mr. Moore believes, the highest value in conductivity, and that is where he feels the market is headed.

Chilmark Research recently conducted a report that included asking PHR vendors about their target markets. It was found that vendors were no longer going directly to the consumer. They are going to the consumer via business, who is then buying the solution as a proxy, so to speak, for their constituents, whether it is providers buying it for their patients, employers buying it for their employees, or health plans buying it for their members. Chilmark found relatively high barriers to entry for PHR vendors in the provider market as most of the provider solutions in use today are based on existing electronic medical record (EMR) systems with a patient portal. Employer and health plan markets are quite similar in that both of these entities are looking to lower medical loss ratios and control health care costs through behavioral change.

Mr. Moore then showed a series of tables that illustrate the qualities of stand-alone consumer PHR applications and compared them to employer- and health plan-sponsored platforms. He also compared these to provider-sponsored platforms which, because they are typically using the EMR as a patient portal, are the gold standard when it comes to providing rich information that a physician can use. Unfortunately, this information tends not to be readily shared across the longitudinal record or the number of care givers that an individual consumer may be using. Mr. Moore also discussed the utility service model (e.g., Dossia, Google Health, or Microsoft HealthVault). He likened this model to creating an ecosystem, drawing in data from virtually any pertinent data source, moving that data into a secure data repository, and then allowing the consumer to invoke that data to be served up into various personal health applications of which PHRs would be a subset.

The visibility and interest in personal health information platforms has accelerated tremendously. Now that Google and Microsoft are developing products, the press mentions have increased dramatically. All of the major PHR vendors are reporting strong double-digit growth and expect this trend to continue. The danger is that with this growth, consumer expectations may move ahead of what is currently available with current technology.

Mr. Moore noted that today's solutions are still very rudimentary in many ways. One important area in which the government can play a role is moving digitized clinical data into PHRs, in terms of establishing incentives to create that data, compile it, access it and share it. He suggested that the government could lead by example here, and actually start doing this work. Mr. Moore also commented that PHR platforms are evolving rapidly, and it is far too early for prescriptive definitions and requirements.

Connecting for Health: A Common Framework for Networked Personal Health Information

Dr. Carol Diamond, Health Program Managing Director at the Markle Foundation, reviewed the privacy principles related to mobilizing PHI from a consumer perspective and discussed privacy issues important to the consumer. She explained that surveys conducted by the Markle Foundation year after year have demonstrated that the public appreciates the potential value of PHR types of services, but also expresses significant concern about the privacy of their PHI.

Dr. Diamond used a health care consumer, Millie, as an example to represent how health information moves today without significant consumer participation. Although there is significant flow of information about Millie's health care moving from doctor to laboratory to pharmacy, etc., Millie largely sits outside of this flow. New services are emerging today that propose to help Millie get her information from all the places that hold it. These consumer access services may provide PHRs or other personal health services. Consumer access services sit between Millie and all of her data sources, enabling her to get her information back. As this space evolves, consumers may use lots of different applications to

manage their health and health care, depending on their specific needs. The role of the consumer access service can be played by technology companies, provider organizations, and/or health plans. The application or service does not necessarily have to be the data source. The critical point is the flexibility to be able to use different tools and still manage and collect all of the information that is important to Millie. The Internet enables these connections, but what will the rules be to facilitate trust on the network?

The Markle surveys show that Americans believe PHRs can improve their health, but almost nine of 10 survey respondents indicate that privacy practices are a factor in their decision to sign up for a PHR. Dr. Diamond noted that most respondents also indicated that they believed PHRs would improve their abilities to: check for errors or mistakes in health records (87%), track health-related expenses (87%), avoid duplicated tests or procedures (86%), keep doctors informed of user's health status (86%), more easily move from doctor to doctor (86%), manage the health of family members (82%), get treatments tailored to user's health status (81%), and manage user's own health and lifestyle (79%).

Dr. Diamond also commented that Markle Foundation data indicate that almost one-half of the American public is interested in joining a free online PHR system, with 13.5 percent indicating that they are "very interested." More than half of those respondents not interested in joining a PHR cited worries about privacy and confidentiality. The Markle data indicate that the public is quite knowledgeable about the different kinds of privacy practices that matter to them in deciding to select one of these services.

When asked how important a set of privacy and information practices would be in their decision whether to sign up for an online PHR service, large majorities said the following would either be "essential" or "a factor" in making their decision:

- Affected people would be notified if their information falls into unauthorized hands in a way that could compromise their identity or expose their health information.

- An individual would be able to review who has had access to their personal health information.

- Individuals would have a clear process to request corrections or dispute the way their information is handled.

- Individuals would not be denied care or penalized financially based on whether they decided to provide certain medical information to an Internet-based service.

- Having individuals control what information from their medical records is made available to others (e.g., an individual with a sensitive medical condition could decide not to include information about treatment for that condition).

- Individuals could make informed choices about how their information is collected and used.

In terms of enforcement, Markle also asked respondents how effective they thought the following would be to ensure that PHR suppliers abide by privacy protections regarding personal health information:

- Having an independent organization audit the PHR organization and provide a seal of approval to certify it is following good practices (80% indicated their belief that it would be effective).

- The Federal Trade Commission or state attorneys general enforcing existing consumer protection laws, by finding any PHR that does not follow its own policies is engaging in false and misleading practices (80%).

- Market forces (i.e., consumers choosing the products and brands they trust and not using others that do not follow good privacy practices) (76%).

- Congress passing a new health privacy law to cover the special features of online PHR services (76%).

Dr. Diamond summarized the Markle Foundation's key survey findings: (1) four in five believe that online PHRs would be beneficial in managing their health and health care; (2) nearly half the public expresses some interest in using a PHR; (3) among those not interested, concern for privacy is the most frequently cited reason; (4) the majority indicate that six key privacy practices are factors in their decision to use an online PHR; (5) more than 90 percent report that their expressed agreement should be required for each use of their online health information; and (6) more than 75 percent indicated that each of four possible policy enforcement mechanisms would be effective. Key implications suggested by these findings are that among the many possible keys to stimulate broader public adoption of online PHRs and related services, a majority of the public sees a comprehensive set of privacy practices to be essential, and they support the effectiveness of a variety of possible enforcement mechanisms.

Dr. Diamond then turned to a discussion focusing on a common framework. Several years ago, Connecting for Health laid out a common framework that had three basic elements: (1) a set of core privacy principles, (2) an element called "sound network design" (making technology choices that support privacy protection, and (3) accountability and oversight. She explained that the current iteration of the common framework represents an attempt at defining how these three elements translate into the new consumer access space. This work is a set of consensus policy practices and a set of consensus technology practices. Community members were provided with an outline of the policy and technology practices and a summary of the consumer's view of these practices.

Dr. Diamond explained that the Connecting for Health Common Framework for Networked Personal Health Information is a positive step that industry can take now towards increasing trust. All PHRs and supporting services, whether covered by the Health Insurance Portability and Accountability Act (HIPAA) or not, should address each element of this common framework. She concluded her remarks with the following summary points:

- Consensus practices among health sectors and technology innovators can help Internet health information products flourish.

- A stable set of principles and practices will foster innovation and improve customer choice for these emerging services.

- This collaboration lays out specific practices that all PHRs and related services can use, whether they are covered by federal privacy rules or not, so that they can enhance public trust.

- More information is available online at www.connectingforhealth.org/phti/.

Why PHR Systems and Networks Must Be Standards Based and Interoperable

Mr. Jeff Blair, Director of Health Informatics at the Lovelace Clinic Foundation, discussed why PHR systems and networks must be standards-based and interoperable. He acknowledged that PHR systems are likely to import patient data from health care providers and health plans, and that some of these PHR systems may begin to organize that data into a virtual health record, which may eventually become some form of a lifetime health record. As this process evolves, patients will be more and more likely to ask their PHR system vendor to send part or all of that information back to the health care providers. That information also may eventually make its way to clinical research and public health organizations.

Mr. Blair explained that the same set of data can be considered from multiple perspectives (i.e., the provider, population, and personal perspectives). One of the major roles of the Nationwide Health Information Network (NHIN) is to provide interoperability within and among these health data perspectives.

There are two basic levels of interoperability. Basic interoperability is the ability to electronically communicate health data. Semantic interoperability would enable the receiving computer not only to display the text or data it has received from other systems, but to accurately interpret the meaning of the data. Many health care information systems have adopted at least some level of interoperability today. Mr. Blair commented that in the future, higher levels of interoperability will result in more accurate clinical diagnoses, in more robust clinical decision support, and in greater consistency and comprehensiveness of patient outcome measurements.

If advances are made to the point at which one can begin to measure patient outcomes better, it will enable improved clinical processes and work flows and accelerate the movement in the health care delivery system so that physicians can increasingly be rewarded for better patient outcomes. It will also provide significant improvement in the quality and cost of clinical research.

Mr. Blair noted that PHR systems/networks need to employ health information technology standards to remove barriers to the: (1) ability to import/export health care data with many different health care providers, (2) portability of PHR information between PHR vendors, and (3) communication of consumer preferences to limit access to their data. PHR systems/networks also need to connect to the NHIN to enable both patients and providers to locate patient records that may be scattered across multiple health care facilities and support electronic updates to PHRs from existing and new providers. He added that all systems within the overall health care delivery system should work together to agree upon consistent policies and services for privacy and security to enable a trust infrastructure.

Mr. Blair summarized that: (1) PHR systems/networks are an important and growing aspect of the health care delivery system and the national infrastructure for health information technology, and (2) the full benefits that flow from an interoperable national infrastructure for health information technology can only be realized if all of the systems and networks comply with common national standards for health information exchange.

Discussion Highlights

"One of my big hot buttons has been authentication, focused on how we do authentication on a consumer level. In the banking world, you may have three or four banks or organizations that you deal with, but in the health care world, you have dozens in many cases, and it can become a very cumbersome process. I notice of late it's become more on the PHR side. Is the PHR the health record, or is the EMR the health record that the physicians use? Has the PHR become a source for the physician, or…is the PHR interconnected with these EHR systems?" – Mr. Hutchinson

"I'm seeing some disintermediation from the health system that's occurring, that's being prompted by consumers, being more aggressive, and taking some personal control. And there are some creative business people out there leveraging that…I think right now it's a little bit of whatever the consumer wishes to do. There are plenty of services out there…and when I look at this market, I look at the PHR, the EMR, I almost see the EHR as being kind of the "super set" of those two, and it depends on who the entity is looking at those, and how it serves their particular purposes, whether it's the caregiver trying to help that person manage their health, or it's the consumer trying to manage their health on their own." – Mr. Blair

"The information that the consumer gathers and their personal health tool, whatever service they're using, is their copy of their information, which they control. We do not envision that it supplants the need for providers and others to have copies of that information as well…The key concept here is that in a networked world, we're really talking about copies of information. One of the really interesting appendices in here is actually how many copies of information get made each time there is an interaction with the health care system." – Dr. Diamond

"Transparency and consumer participation in health care is critical to the kinds of changes and reforms we need in health care. These tools provide an important set of opportunities to engage people in ways that they have not previously been engaged in healthcare." – Dr. Diamond

"One of the things we were very careful to do in our work is not narrowly define a PHR. We developed this consumer access service to really speak to a way that the consumer using some of their information from the record, but also other information that may be pertinent to them to manage their health…We shouldn't narrowly define "personal health record" as just the copy of the electronic medical record that the patient accesses." – Dr. Diamond

"Given that privacy is a concern, and that consumers have to have that overcome for them to adopt, and given the fact that we're making progress in being able to identify the principles around which that could flow, in your collective opinion or individual opinions, what are the one or two things we could do to accelerate their comfort?" – Secretary Leavitt

"If you look at the terms and conditions that [vendors are] signing with the various personal health applications that are going to ride on top of those secure data repositories, they're putting in very firm terms and conditions that those vendors adhere to the same level of privacy policies that they, themselves, are invoking and giving to the consumer. And if there was ever a privacy violation of the Google Health or Microsoft HealthVault, it would set them back. It would be a disaster from a market perception point of view…They have very, very strong vested interest to make sure these things stay private…So I think to some extent, the market is already looking to address that, because they have vested interest to keep these things private." – Mr. Moore

"Over a period of time, the public may grow to have greater trust in these electronic systems. But during these early years, when we have some personal health record system networks and vendors that are saying that their systems are free to health care providers and free to patients and consumers, we realize that somewhere there has to be funding for these networks. And sometimes you have to dig quite deeply to learn that it might be advertising, or that it might be de-identifying data for clinical research…I'll refer to them as secondary uses of data…It's not that the secondary uses are bad. It's that if they're hidden, and the consumers feel that they're being tricked, it could set us back." – Mr. Blair

Evolving Solutions for Mobilizing Personal Health Information for a Patient-Centric Health Care System—Industry Perspectives

Ms. Davenport Ennis introduced a set of industry expert panelists to review three evolving market solutions to mobilize PHI, including their data sources.

My Health Manager: A Personal Health Record That Works

Dr. Andrew Wiesenthal, Associate Executive Director of the Permanente Federation for Clinical Information, opened his presentation with a brief orientation to Kaiser Permanente, describing it as an integrated health care delivery system that takes care of 8.7 million people. Kaiser Permanente is the largest non-governmental purchaser of pharmaceuticals in the world. They have focused on EHRs and clinical information systems for quite some time. Dr. Wiesenthal explained that 2.2 million Kaiser Permanente members are active users of the EHR system "My Health Manager," with participation growing on a monthly basis. Approximately 60 percent of users have logged in 5 times or more in 2007. Dr. Wiesenthal indicated that Kaiser Permanente's members represent a reasonable cross section of people with health care insurance in the United States.

Dr. Wiesenthal noted that Kaiser releases all laboratory results to its members at the same time as they are released to their physicians, with very few exceptions (based on state-to-state variances) based on legal considerations. Clinical pathology results, for example, in the state of California cannot be released online. Pap smear results cannot be sent to California women online because it is against the law. Dr. Wiesenthal suggested these types of legal barriers could be a focus for this panel and AHIC in general.

Viewing laboratory results online is an exceedingly popular feature of My Health Manager. To date, Kaiser Permanente has released nearly 60 million laboratory results online. One of the most interesting features of Kaiser's EHR system is associated with physician instructions. As physicians see patients, the instructions they give the patient are documented in an after-visit summary, which would include the patient's medical problems, diagnoses from that particular visit, any prescriptions or laboratory tests that were ordered, and the instructions that the doctor has given to the member. All of this information is given to the patient at the time of the visit and is also summarized online—this is a very highly utilized and visited part of the online system.

Overall, My Health Manager offers: (1) a secure view of the shared record, (2) interaction with doctors, (3) convenient transactions, and (4) education. Members can refill prescriptions, make appointments, and act for family members (with permission). Within the Kaiser Permanente site, there are links to a host of other health information sources. Dr. Wiesenthal explained that it is not possible to e-mail doctors in an anonymized way. Members must already have a therapeutic relationship established with a health care professional before engaging in this activity. Dr. Wiesenthal noted that members come in and out of the Kaiser system, and that Kaiser must provide a way for that this to be managed smoothly. Kaiser is currently engaged with the Veteran's Health Administration in a test on the NHIN to create a system and promote standards-based interoperability.

Qchart Payer-Based Personal Health Record

Mr. Jerry Bradshaw, Executive Director of Health Information Networks at Arkansas Blue Cross and Blue Shield, noted that his organization is one of the 39 Blue plans across the country that collectively provides health insurance for more than 100 million Americans. Mr. Bradshaw explained that in the mid-90s, Arkansas Blue Cross Blue Shield developed a partnership with leading Arkansas health systems with a number of objectives, the first of which was to establish electronic medical records (EMR) systems in

physicians' offices. At that time, there were very few EMR systems in the state of Arkansas. From 1996 to the year 2000, they secured 500 licenses within the state of Arkansas directly and another 500 indirectly. The second objective was to interface hospitals, physicians, and payer systems. The final objective was to tie these components together under one of the nation's first health information exchanges. That system went live in November of 1998, with two large integrated health systems at opposite ends of the state. They were transporting laboratory reports, radiology results, and clinical documents into the EMRs in multiple physicians' offices, and communicating with multiple payers at the same time (because the system was created as an all-payer system).

In 1998-1999, it was recognized that although the system worked very well and the data were very rich, there was a hole in the record associated with all of the care that was being administered in rural communities with which the system was not interfaced. The possibility of using the coding in claims data to supplement the clinical records that were being imported was examined. In 2000, as has happened with other health information exchanges across the country, the health systems discontinued funding for the clinical part of this system, and so the clinical portion was discontinued. Mr. Bradshaw explained that the administrative and financial portions of the system continue to be enhanced, however, and today this system serves more than 95 percent of the providers in the state of Arkansas.

In 2005-2006, interest was renewed in clinical information systems. As a result, the work carried out in the late 1990s on importing claims data was revisited, and the design was completed. However, for this iteration, claims coding data were used as the primary source of information rather than having a focus on the individual venues of care delivery. The ability to import discrete clinical data, has been added and will be put into use next year. Mr. Bradshaw reported that the PHR was released to Arkansas Blue Cross Blue Shield employees in July of 2007, made available to 850,000 Arkansans effective October 2007, and then made available to their physicians 2 months later.

Mr. Bradshaw walked the Community through the system, beginning with the summary page. One of the system's features is disease management, which uses a rules engine to look for approximately 150 different chronic conditions. Once it has determined a chronic condition, the system looks through the record to determine if the evidence-based protocols for that condition are being met. If not, then it is listed as a treatment opportunity. That has been very popular with members, according to Mr. Bradshaw, and it is also popular for physicians.

There are two sources of data for medications. The primary source is the pharmacy benefits manager. Over-the-counter medications are also included (those are user-entered). Also included is a clipboard, which is a summary of all the information contained in the PHR. It may be printed or saved to external media, and it is accepted by many providers in lieu of completing a patient information form. Mr. Bradshaw noted that it is by far the most popular component of the PHR. An activity log documents all of the activity that has occurred within the member's PHR. It has specific areas to record which physicians have viewed the record, and records of who changed what, and when they changed it within the PHR.

In terms of privacy and security/data access and control, this is an opt-out system. The member may opt out of participation entirely. The sensitive data in this system is automatically hidden. Approximately seven categories of data are automatically hidden. The member may go in and hide additional data if they so desire, or they may unhide data that the system has hidden, if they wish. In the next release, the system will provide even greater control to the member by allowing him or her to designate which individuals, whether that be a caregiver or one of their family members, they desire to manage their PHR for them. In terms of security, the system has a three-tiered architecture with a presentation layer, a firewall, an application server, a firewall, and a data layer.

In closing, Mr. Bradshaw commented that a PHR that uses claims data as its primary source of data is by no means perfect. But when considered within the context of the penetration of EMRs within the provider community, it offers the best method of getting at data in the short term, and offers enormous potential.

Dossia: The Employer-Driven Personally Controlled Health Record Platform

Mr. William Crawford, Director of the Informatics Solutions Group at Children's Hospital in Boston, explained that Dossia is an employer-led, non-profit organization dedicated to improving health care in the United States. It represents a collaborative effort between eight major U.S. employers, Intel, Wal-Mart, Pitney-Bows, Sanofi-Aventis, AT&T, Applied Materials, BP, and Cardinal Health. Dossia is working with Children's Hospital in Boston to develop a personally controlled health record network that can be deployed initially for the employees of these companies, and eventually, for anyone interested in making use of the system.

This unique collaboration has also been working aggressively with federal agencies including the National Library of Medicine, National institutes of Health, and Centers for Disease Control and Prevention, which have provided a tremendous amount of funding and research support for the development of the Indivo personally controlled health record software since the late 1990s. This project is a legacy involving a great deal of federal interest and investment along with commitment on the part of the employers.

Mr. Crawford explained that from an employer perspective, Dossia is very much a human resources and benefits application, driven out of a desire to provide a new service to employees at these companies to control medical loss ratios in a way that engages the individual employee and the individual consumer in the management of their own health, and gives them more tools to be directly involved. The system was very specifically designed to not allow employers to filter out particular employees based on health status issues. One of the reasons that Children's Hospital was enthusiastic about getting involved with Dossia is that from the beginning, this has been a patient-centered service that would have one specific goal: provide people more tools to manage their own health.

Unlike some of the other approaches, Dossia is a completely opt-in system. So, no employee of any Dossia founder company is required to use Dossia. But, it will be promoted to them through open enrollment for health plan benefits, and through other mechanisms varying from company to company. The use of Dossia is integrated very tightly with other kinds of disease management and outreach programs at these companies.

Dossia, as an organization, funds the development of a Web-based framework for the personally controlled health record platform. That includes funding some of the work that is being done at Children's Hospital on developing the core integral software as well as creating the infrastructure and the policies and the relationships with data sources—including Blue Cross Blue Shield of Arkansas, and also clinical data sources that are involved in actually delivering the service, based on the open source software to the employees of these different companies.

There has been some discussion about whether physicians will actually trust data within these systems when making clinical care decisions. Mr. Crawford indicated that Dossia has made a policy decision that it will bring in data from Blue Cross Blue Shield, or from a laboratory for or from a pharmacy, or from a benefits manager. And they will give the patient complete control over how those data are used—if they do not wish to share that data, they do not have to. Dossia will not allow them to misrepresent that data. If a user has been prescribed five mg of Ambien, for example, the patient cannot go back and change that

into a 10-mg prescription. They can choose to not release it at all, but they cannot represent these data as having come from a certified clinical source when it did not.

Other policies that have been implemented within Dossia have to do with information security and building up the kinds of infrastructure and hosting environments that will stand up to federal information security management policies or the other requirements that the different companies within Dossia have for the management of their own employees' data, as well as the standards that exist at Children's Hospital, which is itself a HIPAA-covered entity.

Dossia is a non-profit, employer-driven organization, focused on developing this infrastructure for the public good. Some smaller projects underway include a Massachusetts initiative that works with the school systems in Boston to take data from Children's Hospital out of Indivo and produce school medication forms and camp authorization forms, so that parents can print out their children's immunizations and other forms. That project is built on the same software platform that is being developed for Dossia, and those research results and applications will be incorporated into Dossia. Another distinctive aspect of Dossia is that it is deployed as part of health care outreach, and is a non-tethered solution (i.e., it is designed to be very portable).

Mr. Crawford then turned to the question of why employers are a catalyst for change in the health care system. Of the $2.25 trillion in health care expenditures in the United States in 2007, roughly half of that is borne in some way by employers or by employees. Health care outcomes in this country are very good, but not sufficiently better to justify the additional per capita health care spending numbers in the United States compared to other nations. Dossia, in providing the whole scope of consumer health care-driven applications, is an important aspect of trying to address this problem.

Mr. Crawford showed a slide illustrating the architecture of Dossia, which is anchored in its center with the personally controlled health record framework, built on the open source Indivo software. There is a range of personal health applications, plus a series of consumer access services (also known as PHR applications). These might be applications relating to health and wellness, or they might be what are considered PHRs that give a complete view of a patient's health care status (e.g., it could include weight loss support, disease management for diabetics, etc.).

In terms of data sources, Dossia is being built initially on top of claims data, because that is what is available for the employer populations at a large level. Project staff also are working to integrate pharmacy data, both indirectly through claims, and directly by working with pharmacies, and pushing towards laboratory data EHR data as well. The system has its origins in a clinical environment, and as such, efforts are being made to find ways to bring clinical data into the system.

In summary, Mr. Crawford commented that the U.S. health care system is breaking. Employer-provided health care is shrinking. Previous health care market efforts, governmental efforts, and private efforts have not resulted in the necessary disruptive innovation that the economic drivers within this country need to remain competitive. Health care literacy is one part of driving health care costs down and improving general health status within the United States (i.e., people can only act on what they know). Providing access to their own personal and private health care data is going to help them become better health care consumers.

Bringing Health Care Into the Internet Age

Mr. Sean Nolan, Chief Architect at Microsoft's Health Solutions Group, gave an overview of HealthVault, a product Microsoft released approximately 10 months ago. He explained that Microsoft undertook this effort because there is a huge fragmentation of data in the health care industry today, and

no individual or organization is able to see the "whole picture." This has resulted in a host of problems, ranging from the simply inconvenient to the life-threatening. Microsoft has done a lot of work trying to connect diverse sources of information in other areas, and is trying to do so in the health care field. In the company's view, the consumer is going to be the most efficient, effective, and motivated agent to connect these various information silos together in the near term.

Microsoft conducted research by placing cameras in homes with mothers—who have a deep motivation to take care of their family, particularly their children and parents. These women expressed that they felt like they did not have the control or the information they needed. They reported not understanding the privacy implications of their data. Mr. Nolan reminded Community members that health care happens in homes with home monitoring, at the gym, with nutritionists, in visits while on travel, and in ways that any purely business-focused network cannot adequately address.

In creating HealthVault, Microsoft tried to create a system that would include and incorporate all of these health care areas. HealthVault is a platform on top of which one can build the same type of personal health applications the world is talking about. Mr. Nolan noted that there are many similarities between the approach that Dossia is taking and the approach that HealthVault is taking to getting people empowered regarding their health care. HealthVault is a single online repository that consumers can use to collect their information, to share it, and to benefit from it. Mr. Nolan said he uses the analogy that Microsoft is trying to build infrastructure, plumbing and HVAC for other applications, whether they be provider portals or other applications.

HealthVault is a way of exchanging health data. Mr. Nolan said he can go to an innovative new startup, his health care provider, or a PHR application and say, "This application provides some really unique benefits to me, and I see that it's HealthVault-powered, so I understand that I can trust the privacy, I understand how my data are going to be shared, I understand what the implications of using this application are going to be."

Microsoft was guided by three principles when designing HealthVault:

- Privacy and security focused. HealthVault is unique because it puts the consumer in control of their health information. Users decide exactly what goes into their HealthVault account. They determine exactly who can see it. Microsoft has made pledges to its consumers that they will never use their data in any way without explicitly asking for their permission.

- Inclusive of industry standards. HealthVault is an open platform; it is easy to participate. HealthVault applications must accept data in every format. Microsoft has designed HealthVault to be an open platform and demonstrated early connectivity with Dossia, and potentially with Kaiser Permanente as well.

- Free for users and developers. There are no fees are charges to use the platform. Microsoft believes that creating an infrastructure that allows for online transactions in health care and allows people to take control of their health in this way will stimulate other parts of its business. Mr. Nolan explained that it is appropriate for Microsoft to contribute to a free platform that it believes does a lot of good for the world, because it will also do a lot of good for Microsoft and other commercial entities as well.

Mr. Nolan explained that today, 10 months into a launched application, there are 40 live applications on the HealthVault platform, and 50 live devices such as blood pressure monitors, glucose monitors, heart rate monitors, and pedometers. The week before this AHIC meeting, there were 300 companies at a Microsoft partner conference working to understand how they could best be a part of this initiative, and

how Microsoft could best serve their needs to bring their innovation to market. Microsoft also has donated $4.5 million to 15 organizations across the country which are building on top of HealthVault innovative solutions.

Discussion Highlights

"How do we come together as a market? We saw…earlier that the portability and interoperability at this point in time is really very low. But how do we empower our consumers to pick and choose portions from whatever target that they want? How do we use the market to move forward and make sure we have that level of normality or the sameness across all of these different applications?" – Ms. Fischetti

"What we found is that when we have been integrating with folks, the questions and the challenges is not often as much about the pure technology of connecting the two systems. It's much more what they choose to connect, and the format in which they like to do that." – Mr. Nolan

"There is a level of granularity that's provided by HealthVault and by Dossia that isn't actually encapsulated very well in the CCR. So if you're trying to make it easy for application vendors, to pick an example, who are doing a medication reconciliation application, and you get three or four different CCRs in, it's a much bigger ask for that software developer to have to take three or four CCR documents from three or four different sources, combine them, identify the different medications, find the real duplicates, find the fake duplicates, and then present that to the user in a meaningful way, than it is if the providers of that data have connected using the native HealthVault API, or the native Indivo API and put in just the medications that they're responsible for in a tightly constrained way." – Mr. Crawford

"One of the challenges is actually in the use of CCR, and coming up with ways to constrain the way data are exchanged within the existing authorized standards to make it easier for that reconciliation process to take place…One of the areas I think we can all sort of continue to work together on is how do we do these more granular data interactions in a neater, cleaner way?" – Mr. Crawford

"Our system at Kaiser Permanente, our electronic healthcare system is completely standards based, but in a much more granular level than these two gentlemen have been discussing. All of our diagnoses, procedures, medications are encoded in nationally promulgated and accepted standards…As the world matures, the job of the aggregator would be made much simpler if the data streaming out of all of these sources were standards-based." – Dr. Wiesenthal

"Decide, and then let everybody in the space understand what the decision is and how it's going to work, and even set timeframes for certain things to happen, so that by X date, certain things in electronic medical records are going to be true, certain things in personal health records, vis-à-vis data, data quality and standards use are going to be true." – Dr. Wiesenthal

"Given that there are standards, as opposed to 20 years ago, then the question is how do we, as AHIC, as HHS, help the adoption of that in a way that makes your job easy, so you're not worried about the blood pressure five years ago, but you can pick up a blood pressure now and go forward in a standardized way without having to try and kind of design or agree upon a new standard. Is there anything that we can do to make it easier?" – Dr. Kolodner

"But we then need to have regulation, and we need to have rules that make it easy for the patient to get their copy of that electronic prescription, because that, then, can become the canonical record, supported by some fill information from the pharmacy so that you know the pills were actually given out. And then we don't have to worry about figuring out the PBM data as well. So ensuring…the definitions and the

description of what the Consumer Empowerment Workgroup feels is critical for a personally controlled health record. Following that agenda is going to be the most useful thing." – Mr. Crawford

"Organizations like My Health*e*Vet are in a position to actually define, as a role model, what's going to happen in the rest of the country. A lot of people are looking at these large organizations, Kaiser being one of the very few private organizations of that type as well, that what they do, will be followed. So I think simply by setting a great example, and choosing appropriately, and discussing what is appropriate to share amongst the government agencies, will go a long way as well." – Mr. Nolan

"I just want to put a vote in for the private sector sometimes leapfrogging the government bureaucracy in the standards setting areas to try to show what can be done." – Dr. Barrett

"In healthcare, we've always had these defined workflows…And I'm just kind of curious, if you've started to see consumer-driven demand for the types of work flows and how they want to start interacting in that health care environment." – Mr. Hutchinson

"Our members now expect that physicians and nurses have health care information available at their fingertips, at all times, every day, no question. And so they expect certain behaviors. We say 'This is what I know about you. Is that still true?' That's a very different behavior than having them fill the clipboard out each time to repeat old information. And that's what they expect now. And they don't want to be filling out forms." – Dr. Wiesenthal

"We also see another segment that has been really exciting to us, which is that folks who are dealing with chronic conditions…are really looking to have a more ongoing engagement with their providers, not just when there is an emergency, or when there is a problem, but knowing that somebody is watching the trends…and that's why we think connecting all the way back to the home, and the devices, and those types of conductivity are super enabling as well." – Mr. Nolan

"This body sunsets soon. [What is] the number one thing that you recommend that we should do to make happen between now and when AHIC 1.0 sunsets? What can the AHIC 2.0 do initially to further this work in a purposeful way, because in many respects, you've made both the use case and the business case pretty clear. But I'm confused as to what this body might be able to do, and what 2.0 should initially concretely work on that would advance this agenda." – Ms. Gelinas

"I think one of the things that could be done that could be very helpful is to look at all of the different methods out there today, electronic health records, PHRs, and to begin to formulate a vision of how all those things get together. And what needs to happen in terms of those different modalities communicated with one another." – Mr. Bradshaw

"I think it would also be very valuable both for AHIC and for AHIC 2.0 to concentrate on helping the Secretary and the other operating organs within HHS to focus on ways to reassure providers and sources of data that it is okay to participate in these consumer-driven exchanges. I talk to a lot of providers. They are still concerned about HIPAA. And even though HIPAA does allow them to release information to an organization like HealthVault, like Google, like Dossia, but is operating with an authorization on behalf of an individual, there is still a lot of concern about that." – Mr. Crawford

"We found that what consumers want is not the 2-page privacy policy. They want [to know] fundamentally who gets to see it? What do they get to use it for?" – Mr. Crawford

"Population care is something that we do a great deal of, and have great, great success with. There are elements that are very useful about the personal health record, My Health Manager, that aid and abet our

population care strategies…But it's just a piece of a very much larger set of approaches and strategies…In terms of health disparities, one of the most important and up to this point, unmentioned aspects of the PHR that we have is that we can translate it. So it can appear in Spanish or Russian. We serve 40 different language groups in our population. And so pieces of our health encyclopedia, this sort of general information can be translated. And we haven't done, this, but we can translate the front end so that it is much more accessible to people. It's already in Spanish." – Dr. Wiesenthal

"Having a platform in place which you can plug other applications into creates a great opportunity for public health applications…Once we have millions of employees in Dossia, or there are millions of people using HealthVault, then it takes an outreach program; it takes some engagement. But you can get those people to flip the switch. And I think it would be worthwhile integrating that switch right into the platform so that people can choose to make that information available for broader monitor and broader public health efforts as well." – Mr. Crawford

"We've seen incredible excitement about that idea as well, the idea of citizens being able to actually participate in and contribute their information to efforts where certainly the risk and fear of privacy is paramount when people are first getting engaged in this. Once they get over a trust barrier and understand that they are in charge of releasing certain parts at certain levels of anonymization and those types of things, we see absolute excitement about the idea that there could be better clinical trials. They can come back to that personal health record years later and look at other phenotypes that might not have seemed relevant at the time but are now." – Mr. Nolan

AHIC Standing Committee of the Whole: Successor

Dr. Kolodner introduced the discussion by reminding the Community that there has been progress made in terms of moving from the concept of an AHIC successor (also known as AHIC 2.0, or A2) through to the awarding of the contract. Dr. John Glaser of Partners HealthCare Systems, serves as a co-Chair on the AHIC Sustainability Workgroup and showed a timeline that illustrated that the A2 has been incorporated. Current activities include hiring accounting and law firms to help develop bylaws and other types of necessary legal constructs. Laura Miller has been hired as the interim Executive Director; a search for the permanent CEO will begin soon. Dr. Glaser recognized and thanked members of the Governance Planning Group, Membership Planning Group, Sustainability Planning Group, Transition Planning Group, and volunteer staff.

Dr. Glaser explained that 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 health care system that supports continuously improving health care 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. The successor has the following goals:

- Accelerate the adoption of interoperable health IT by ensuring the availability of harmonized, coordinated, up-to-date standards and rigorous conformance testing through certification.

- Prioritize stakeholder requirements for health IT interoperability.

- Advance health information policies and technical approaches that promote 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.

- Oversee and facilitate the NHIN.

Dr. Glaser presented the governance recommendations, noting that A2 is recommended to exist as a public-private membership organizations of organizations. As such, it would be both funded by and run by its members. From the membership will be drawn a variety of committees (e.g., a nominating committee, a finance and audit committee, etc.) and a Board of Directors.

The Board of Directors will include 18 members who represent a blend of at-large members and specific seats (two each) that represent government and consumers (including vulnerable populations). Board tenure will term-limited with staggered elections. Of the initial Board, one-third will have a one-year term, one-third will have a two-year term, and one-third will have a three-year term; subsequent terms are for three years. All Board members will be able to serve up to two consecutive terms. Dr. Glaser noted that powers of the Board include the following: (1) defining and re-evaluating the strategies by which the organization fulfills its mission and monitoring the implementation of those strategies; (2) selecting, monitoring, evaluating, compensating and replacing the President, including contingency and succession planning; (3) reviewing and approving operational matters (e.g., financial plans, internal control systems, and audit); and (4) overseeing the execution of the organization's strategic plan.

As a means of ensuring input from specific stakeholder perspectives, standing and issues-related/*ad hoc* committees are planned. Standing committees will be chaired by a Board member and include both at-large and representative members from relevant member segments. Standing committees will be structured to require diverse member representation. Nominating, Finance and Audit, and Membership standing committees are anticipated. In terms of issues-related and *ad hoc* committees, they will be chaired by the best-qualified member, regardless of Board status and include both standing and representative members from relevant member segments. These committees also will be structured to require diverse member representation. The issues-related committees will be focused on topics and issues raised by the Board and requiring significant analysis and research. *Ad hoc* committees will be focused on short-term initiatives that require governance participation

Janet Marchibroda, of the eHealth Initiative, co-Chairs the Membership Planning Group and explained that the success of A2 requires both the input and the active engagement of many stakeholders in health care so that they can move together to take actions to support standards adoption. These stakeholders include consumers, employers, government and public health, health care providers, health informatics, research, academia, health information exchanges and regional/state-level public-private partnerships, health plans and other players, infrastructure and standards, other health entities, quality, vendors, and consultants. Ms. Marchibroda presented member outreach sub-segments for each of these stakeholder segments.

Ms. Marchibroda explained that membership interest is anticipated and is based on both short- and longer-term value propositions. The overriding value proposition for this organization and its membership is working together in a collaborative way to agree upon and drive standards for interoperability, which are absolutely necessary to facilitate the exchange of information electronically, improve quality, improve safety, reduce costs, and improve value while also addressing accessibility issues within health care. Membership in the AHIC Successor means having a seat at the table to: (1) set priorities and identify and quantify opportunities for standards identification and harmonization, (2) provide expertise on policies related to an interoperable, standards-based electronic health care system, (3) support the implementation of standards through market-driven approaches, and (4) provide technical

resources. The willingness of the market to embrace the work of the AHIC successor will be significantly enhanced if both federal and state governments actively support the work (requiring standards/certification for their procurement activities, Medicare reimbursement, etc.).

Dr. Glaser then discussed the efforts of the Sustainability Planning Group. In fiscal year 2009, which starts on October 1, A2 will largely be funded by federal contributions and grants, in an amount somewhere between $5 and $8 million. This figure obviously is subject to the processes that will unfold annually in the federal government. One of A2's core tasks in year one is to create its second stream of revenue, which is membership and membership dues. This will ensure that members have clout over the organization, because they can threaten to walk with their membership dues—an important set of tensions to have in this type of organization.

There have been discussions regarding other possible sources of revenue (e.g., conferences, publications, fees associated with contributions to the overall oversight of the NIHN, etc.). These opportunities will be explored in year one, possibly into year two, with the expectation that they will be in place by year three. The Sustainability Planning Group recommended focusing on the cost of a core set of activities to inform early budget planning. These core activities include: (1) setting priorities for standards harmonization and certification criteria development; (2) ensuring that momentum is maintained with harmonization and certification activities; and (3) providing thought leadership in the creation and use of a secure interoperable nationwide health information system to support improvements in the quality, safety, and value of accessible health care.

The group's budget formation strategy was summarized as follows:

- Develop a budget to sustain the core activities for the 2-3 years following the expiration of current grant funding.
- Obtain "fair share" of federal funding defined by federal government's role as a provider, payer, and employer.
- Obtain the remaining core funding through member dues.
- Leverage a conventional funding model.
- Adopt conservative estimates of dues revenue.
- Minimize the number of revenue streams that must be developed in the first year of operation.
- Utilize fiscal year 2009 HHS funding to explore additional revenue sources.

Based on these core activities and budget formation strategy, a fiscal year 2010 operating budget of approximately $3.2 million is anticipated, with $1.2 million in revenue expected from A2 membership and $2.o million in revenue expected from government contributions. Revenue is assumed from a tiered membership dues structure and based on an estimated 120-160 members, with a dues structure that differentiates between non-profit and for-profit organizations. A range of membership dues between $1,000 and $50,000 is recommended, with a class included for members that may not be able to pay dues or pay only a minimal amount (e.g., $100). Expenses assume 7 full-time employees including the President, contracted resources, and physical plant. The expenses also assume three working groups, a membership drive, and two existing and four new use cases.

Ms. Marchibroda described the notion of a value case, which are similar to use cases, in that they describe an opportunity for information exchange, illustrate specific scenarios for interoperability, and demonstrate a case for action based on value. Specifically, a value case presents the costs and benefits of implementing the specific scenario, and describes potential measures of actual impact on improving care. Dr. Glaser presented a roadmap showing how value cases will be developed. This process is similar to the A1 process, with the focus on value cases in this instance rather than on use cases.

Ms. Lillee Gelinas of VHA, Inc., co-chairs the Transition Planning Group, whose charge is to recommend actions and activities that need to be transferred from AHIC 1.0 to the new organization. She likened the process to a moving van, with those inside the van having to develop the road map and also build the road. This road turned out to be the screening criteria through which 1.0 activities would pass in order to be chosen as a 2.0 activity. She said the van needed a computer onboard to tie it all together, and that was the Membership Planning Group. It needed a driver, which was the Board and the Governance Planning Group, and gas, which is the ability to run (i.e., the Sustainability Group). Unlike the other three planning groups, whose work is primarily done, the Transition Planning Group is currently in high gear, Ms. Gelinas noted.

Current AHIC 1.0 initiatives fall into two major categories: (1) health IT oversight and coordination initiatives (e.g., coordination with HITSP and CCHIT, and recommendations on the NHIN); and (2) health IT advisory and convening activities. AHIC 1.0 is a Federal Advisory Committee. The Transition Planning Group has developed a framework with which to assess the seven existing AHIC Workgroups. The Transition Planning Group now believes that this framework can be used by the A2 incorporators for the screening of other AHIC functions that could potentially be transitioned to A2. In a sense, the role of the Transition Planning Group has been to determine what "gets on the moving van" and what "stays in the house." Things that "stay in the house" would be those things that are inherently governmental.

Dr. Glaser then presented the following high-level timeline for A2-related processes:

- Finalize the Board of Directors nomination process and selection criteria (June 23-July 14)
- Request nominations (July 14-August 4)
- Close the nomination process August 4 (Extended)
- Evaluate nominations (August 4-August 22)
- Develop draft initial slate of 30 candidates (August 22)
- Review draft slate of 30 candidates for conformity to agreed-upon process (August 25-September 5)
- Select the Board of Directors (September 5-September 12)
- Review the Board for conformity to the agreed-upon process (September 12-September 15)
- Finalize the Board, obtain organizational approvals (September 15-September 29)
- Announce the Board of Directors (late September).

In closing, Dr. Glaser commented that it is important that the A2 Board of Directors adopt the principles of the National Technology Transfer Act of openness, and balance, and accountability. He anticipates a conversation among Board members, once finalized, about how to adhere and live up to those guidelines.

Discussion Highlights

"What can this body do best to help you now? Are there obstacles that need to be moved? What are the things that AHIC can do to ensure a smooth transition with just the little time that this body has remaining?" – Mr. Weems

"One is…constant discussion with A1, because there is a lot of experience, and a lot of smart people here." – Dr. Glaser

"What's the relationship or how will the strategic plan…from ONC relate to the AHIC business agenda, and which agenda drives the boat? For the last two and a half years, we have been fortunate in that they have been integrated. And suddenly I see the potential for a splintering, and with a new administration, priorities could be radically different, or they could be the same. How will that integration work? I thought I had heard some discussion about difficulties with the government serving on the board of a private entity and how that could work, and I'm wondering how that has been resolved." – Mr. Serota

"I have been involved in a number of these IT startup kind of coalition groups, and they always start out with a real pure agenda, and they always end up lobbying groups. And the last thing we need, as an enterprise today, is yet another group to lobby for yet another set of something. So my plea would be, let's do whatever we have to do on the front end, and continually remind ourselves that we're supposed to do something, not lobby." – Mr. Serota

"I think that's a fair concern. One would expect it to contribute to ideas to the legislative and executive process, to be more of a series of expertise, rather than lobbying itself. I think we'll have to work hard, frankly, over the years to make sure it stays there. And frankly, I also think its members want something done." – Dr. Glaser

"On the other hand, now you've got a public-private [entity], and the ability of a Board and membership to say 'now we want to go in a direction a little different than the federal government.' Now, to the degree that that occurs, that will take some focused discussion between those, because you have to be mindful of the phenomenal role that the federal government plays both as a payer, and as a provider of care, but also as a protector of the social good; and to be blunt about it, they contribute $2 million a year revenue. And so we have to make sure that we are mindful, and listen to and follow federal lead, but at the same time, acknowledging that in a public-private partnership, it may very well come up with areas where it wants to take a left turn, or it thinks the country ought to take a left turn. And we'll have to make sure we have good ways of handling those issues as they come along…I don't doubt that we'll have a moment or two in the years ahead where that will be a challenge." – Dr. Glaser

"I think that was the other reason for having consumer seats also guaranteed, that it's important that this organization be something that doesn't violate the public good. And even when the government's $2 million gets dwarfed by whatever the value cases are, and the funds that are brought in, part of the way of organizing the bylaws is to make sure that some set of values, and the values that we had set forth previously for the target are ones that do serve as the guideposts for the boundaries in going forward." – Dr. Kolodner

"The size of the truck depends on the amount of money coming in. [Part of] the last conversation we had about this was the expectation was that everything that AHIC 1 is working on will transition to AHIC 2.

And when you've got a $6 million funding mechanism in the current AHIC 1, you're talking about $2 million or whatever the initial amount of money is that goes into it, the size of that truck, whether it's a Volkswagen or whether it's an 18-wheeler, and how much you can pack into that will depend upon how much funding [there is]." – Mr. Hutchinson

"I think this notion of extra funding is really dangerous, because there is a probability that that extra funding, particularly if it's episodic, will be a priority stealer. The body has to set the priority, and the dues are never going to cover the potential for the organization. Now, if the extra funding comes from some ongoing function, some kind of function in terms of standards setting and fees [associated with it], that's different. But I think in terms of outside groups needing things, and coming in with different amounts of money to get their help with getting things certified, I think that's tremendously problematic. And at the end of the day, we're going reach the same kind of frustration that the National Quality Forum did, that it's very hard to sustain that, and at the same time, have your own priority set." – Mr. Kahn

"If the CEO of the organization is thinking, every morning when they get up, not about how they assure a better HIT system in the country, but how they're going to raise money to keep the thing going, I think it's doomed." – Mr. Kahn

"It's going to be a tricky working out the funding on this. On the other hand, you want to have a national strategy. You want to be responsive to industry. So if a set of industry folks show up and say 'we need standards here,' okay. It may or may not be on the plan, or at this time in the plan, but if the industry says we need it now or are willing to help, we ought to respond to that kind of stuff." – Dr. Glaser

"As many of us who work in the city know, there is currently some degree of controversy that has now positioned itself around AHIC 2.0. As you continue your work, I would urge that we be very deliberative in delivering a strategy for dealing with that current conversation, and making it the positive that it needs to be…and that we engage a very broad list of stakeholders to help with that message."
– Ms. Davenport-Ennis

"As you determine what is going into the back of the moving truck…almost without fail from any group, the issue of privacy and security has, indeed, been presented at all levels. There are many ways to address that. But we're hopeful that the first box that goes in the back of the truck for consumers is going to have that issue in it." – Ms. Davenport-Ennis

Supplemental Priority Development Pathway for Clinical Research Applications of Electronic Health Information

Dr. Kolodner reminded the Community that at the last meeting, there was some interest in having a group explore whether additional resources in the area of clinical research might be brought into the process for the standards harmonization for HITSP, and whether there was a potential for extra capacity if certain interests and resources could be brought to bear. Since the last meeting, a group has been actively taking that charge from the AHIC.

Dr. Greg Downing, representing the Office of the National Coordinator, explained that this group of panelists represents experts who have been examining how prioritization processes, use case development, and standards harmonization between electronic health information exchange and clinical research activities overall can be augmented within the capacity of the national agenda for health IT interoperability. Dr. Downing explained that clinical research was originally identified as a priority by AHIC, but was not selected for use case development. At its June 3, 2008, meeting, AHIC recommended

that the ONC explore options for a "supplemental" process to support use case development, standards harmonization, and consideration in the rest of the national health IT agenda activities. The needs for EHRs to support clinical research have been increasingly recognized and the clinical research community has the capacity, infrastructure, and interest to join the national health IT agenda activities. The supplemental pathway broadens bandwidth of standards harmonization without compromising existing processes, and could help establish a partial support model for advancement of standards harmonization when it moves to the private sector.

Dr. Downing then discussed why clinical research is relevant to health information standards and interoperability. He explained that as EHR adoption increases, there will be new opportunities for health information exchange to support clinical research activities. The clinical research community is developing standards to improve reliability and reproducibility of research data, regulatory reporting, data analysis, and accountability. This activity will: (1) avoid the emergence of separate standards in health care and clinical research environments thereby creating impediments to the utility of patient data; (2) provide the opportunity for considering policy applications for informed consent, disclosures and authorizations, privacy and security, auditing, etc.; and (3) improve patient/human research subject safety.

Dr. Downing acknowledged that the proposed supplemental pathway may also represent some new challenges for the standards community and the health IT agenda nationally. For example, it establishes an additional pathway for standards harmonization during the AHIC transition, raises the possibility of another specialization category for certification as it is unlikely that all EHR systems will need to support clinical research, and requires a prioritization process for the scope of use case development given that clinical research is a broad area. Some of the exploratory work carried out since the last AHIC meeting has included the following: (1) identified early stakeholder community to ensure support and agreement on the concept, (2) discussed possible pathways with HITSP, (3) conducted a preliminary environmental scan of existing standards and potential priority areas for use case development, and (4) presented the concept to AHIC and AHIC successor transition team/incorporators

Dr. Downing pointed out that this is not a Workgroup recommendation, but rather a response to the charge that was leveled at the June 3 discussions around use case prioritization. The group continues to develop this pathway in connection with the AHIC transition to its new successor organization, and believes that a number of the members working on the transition team, as well as the incorporators, are quite familiar with some of the work in the clinical research areas, and that expertise at the management and senior leadership levels as the successor evolves has been spoken to in a number of areas.

The group feels it is important to report the progress through AHIC, via an existing Workgroup until the successor work formats have been established. Dr. Downing has had a number of discussions with the Electronic Health Records Workgroup, and the Personalized Healthcare Workgroup; leadership from both of these bodies is represented within the group. The group proposes the following:

- AHIC to authorize exploration of a "supplemental" pathway to use case development, standards harmonization, and support interoperability of electronic health information to support clinical research information needs.

- Continue development of this pathway in connection with AHIC's transition to the new AHIC successor.

- Report progress through AHIC via an existing workgroup until the AHIC successor work formats are established.

Dr. Downing indicated that this work would proceed through the following process: (1) a multi-stakeholder working group sets priorities inside of the research domain, (2) stakeholders provide support for HITSP's process, (3) stakeholders ensure that volunteers staff HITSP working groups, (4) standards will be advanced through the national health ITT agenda as with the primary pathway, and (5) recommendations will be provided to HHS for the recognition of standards. Dr. Downing also identified a series of next steps, which include establishing a workgroup and formalize arrangements with HITSP, identifying stakeholder support, researching priorities, drawing on volunteer expertise, obtaining financial support, prioritizing areas of work, making recommendations for use case development to HITSP, identifying issues and potential solutions to facilitate EHR interoperability with research data systems, and reporting to AHIC or its successor.

Dr. Rebecca Kush, Executive Director of the Clinical Data Interchange Standards Consortia (CDISC), described the Consortia as a global open non-profit standards development organization that focuses on clinical research standards (the group's standards are openly available). The Consortia began as a completely volunteer group in 1997 and incorporated in 2000; the CDISC now has more than 230 organizational members that include biopharmaceutical companies, technology providers, contract research organizations, academic research centers, and technology providers. There are active CDISC committees in the United States, Europe, Japan, and China. CDISC standards are used in more than 40 countries.

The CDISC began a new mission in 2004, one that emphasizes the interoperability between systems that work for health care and those that work for clinical research, through a number of collaborations. Dr. Kush described the value of CDISC standards, explaining that CDISC standards were shown to save approximately 60 percent of the time and cost compared to benchmark data. If CDISC standards are used at the start-up stage when the data collection fields are created, they can save anywhere from 70 to 90 percent of the non-patient participation time of a clinical study.

Ds. Kush then described the non-quantitative value of data interchange standards, which include: (1) increasing data quality; (2) enabling data integration into "knowledge warehouses" to improve science, marketing, and safety surveillance; (3) facilitating the review of regulatory submissions; (4) facilitating data interchange among partners; (5) improving communication among project teams; and (6) enabling efficient exchange of information among a variety of tools and technologies. To highlight these points, Dr. Kush quoted a member of the President's Information Technology Advisory Committee as follows: "The same EHR systems critical for improving patient care can also help accelerate clinical research and its impact on practice and improve pharmaceutical safety or pharmacovigilance, and biosurveillance for public health, dual use of EHR systems that could reduce total system cost."

Dr. Kush explained that medical research is too significant to allow it to remain a disconnected entity from health care, especially when research informs health care decisions and clinical care informs research. She noted that the United States spends approximately $100 billion on medical research per year, and the data requirements for research and for clinical care overlap substantially, especially with respect to clinical quality, safety, and efficacy use cases. These two worlds need to be connected; this harmonization would help to aggregate sufficient information across partners so that it can improve health care decisions, allow for timely safety surveillance on a global basis, help link biomarkers (including an individual's genetic markers) to population characteristics and outcomes, and facilitate research for clinicians concurrent with clinical care.

In discussing progress related to medical research standards, Dr. Kush explained that the CDISC established global medical research standards to support clinical studies. Standards support study registration, conduct, and reporting, and are referenced in FDA Final Guidance, encouraging the use of CDISC standards for eSubmissions (this is a proposed rule/regulation). In addition, Pharmacogenomics

data standards have been developed through the HL7-CDISC Clinical Genomics Work Group. Dr. Kush also noted that the FDA, HL7, NCI, and CDISC are collaboratively developing terminology/vocabulary (value sets) for core 16 domains (e.g., demographics, medical history, medications, vital signs, physical exam, etc.) that will be maintained via NCI Enterprise Vocabulary Services. The CDISC is ensuring that research standards are harmonized with each other and with HL7 standards for health care via the BRIDG Model. This model was developed and is governed by four key stakeholders: CDISC, HL7, FDA, NCI. This work is moving toward the ISO standard. Dr. Kush also noted that CDASH V1.0, a new CDISC data collection standard, will be released in the third quarter of 2008. This effort is a collaboration with FDA, biopharmaceutical companies, NIH, academic centers, and others, and is based on the CDISC eSubmission standard for FDA. The new data collection standard provides EHR companies a core standard dataset for research and is being mapped to the HITSP Continuity of Care Document.

Dr. Kush also presented information about two efforts that have been made to link EHRs with health care through research. One initiative is a technology solution to capture research data in a form within the EHR environment that supports data entered once for research and care, regulations, and subject de-identification. The other project is an HL7 EHR Functional Profile standard modified to meet core requirements for regulated clinical research.

In closing, Dr. Kush emphasized that harmonization is needed now to avoid divergent and disparate standards that will severely inhibit the use of EHRs for research and clinical decision support. It is critical that these efforts include leveraging what has already been done for clinical/medical research standards. Dr. Kush asked for AHIC's commitment for a pathway that will ensure convergence of clinical research and health care standards.

Dr. Ken Buetow, NCI's Associate Director for Health Information and Bioinformatics, noted that biomedical research is as fragmented as the rest of the health care sector. Although the research community has unquestionably embraced information technology, different and more effective approaches to exchanging information are needed. The NCI has been working with the broader cancer community to implement an alternative approach that utilizes information technology to join research "islands" into a community. NCI designated cancer centers are part of a broader experimentation component, a network of 63 different NCI designated primary research activities. In the early phases, the NCI explored how to bring this community together, along with a variety of the other stakeholders in the biomedical enterprise. They are working with more than 190 different organizations that include consumer groups, IT companies, and health care delivery groups; and have brought together individuals, organizations, and institutions joined by an internationally standards-based, computable, semantically interoperable infrastructure. The NCI is attempting to bring these disparate organizations and communities together, in a unified, interconnected, computable semantically interoperable infrastructure (the Cancer Biomedical Informatics Grid, or caBIG).

Dr. Buetow acknowledged that the NCI is not alone in pioneering these activities, and pointed to other activities underway at the NIH and its National Center for Research Resources. For example, Clinical and Translational Science Awards are now in place at 38 centers across 23 states with the primary goal of being able to bring in design and improved clinical research informatics, and to forge new partnerships with private and public health care organizations.

During these activities, the NCI recognized early on that there is an artificial distinction at times between research and health care delivery, and that to deliver on the promise of modern molecular-based personalized medicine, it is essential to join these together. As an example, Dr. Buetow discussed the success seen in the exploration and use of clinical information in a research setting for the treatment of childhood cancer. Over the last 30 years, there has been a tremendous change in the portfolio of mortality and survival in childhood cancer, with an overall reduction of cancer mortality by more than 50 percent

since the mid-1970. The use of molecular information has been embraced in this field from the very start (e.g., karyotypes—system-wide genomics profiles that were used and are continuing to be used to direct care). Childhood cancer is unique in that almost 70 percent of patients are seen in and/or enrolled in a clinical trial setting. Dr. Buetow compared this with adult cancer, in which less than 5 percent of the patients are interacting in a clinical research setting. As a consequence of blending these universes together, researchers and practitioners in the childhood cancer field are able to correlate experimental laboratory data with clinical data that are utilized to continuously evaluate outcomes. Researchers develop and refine evidence-based strategies at an individualized level at a rate that is not possible under the current publication/meeting-based information exchange approach.

The NCI is now working to connect its designated research centers with community cancer centers and community oncology programs in a manner that allows the Institute to meaningfully connect patient encounters associated with cancer with the research environment, and more importantly, allow for the research findings to be transmitted electronically and instantaneously to the community settings. A set of established computable, semantic interoperability standards are needed to facilitate these activities; work in this regard has been started at the NCI, but unanimity has not been reached on what the path of those standards and the collection of those standards should be, which international standards should be applied, and under what circumstances they should be applied. This is critical, Dr. Buetow noted, because there is an emerging infrastructure that needs to be validated against those standards as well as tested and certified as being part of and connected to those individual standards. In the absence of a uniform set of standards, a new generation of electronic infrastructure with disconnected electronic standards will result.

Dr. Buetow explained the value proposition associated with joining clinical practice and clinical research. There is value in sharing infrastructure and standards development, but more importantly, these activities will help lead to the development of the molecular medicine paradigm and standards to deal with next-generation therapeutics. By blending clinical practice and clinical research, as standards are developed, they can be easily migrated into the electronic health records and into the health information technology portfolio so that the benefits can be realized by all stakeholders across this continuum.

Mr. Greg Simon, President of FasterCures, explained that his organization's mission is to save lives by saving time in the way cures for diseases are discovered, developed, and deployed. FasterCures is a non-profit organization that does not fund research; rather, it looks at approaches for changing the current system. FasterCures does not accept funding from the pharmaceutical industry, the biotech industry, or the device industry, and is a member of the Milken Institute (an economic think tank based in Santa Monica, CA). In the interest of full disclosure, Mr. Simon noted that he is a paid adviser to the Google Health Advisory Committee and to Navigenics (a genetic testing company), and an unpaid advisor to Price Waterhouse Coopers Montage Group, which is focused on healthcare reform and innovation.

Mr. Simon explained that when a person goes to a doctor, three people/groups know what happened—the patient, the doctor, and the insurance company. None of those has the job of curing the patient by finding the next treatment. So, if the only people who know what happened to the patient at the doctor's office are not in charge of developing the next cure, how can the patient expect to accelerate the development of cures for whatever ails him or her? Only one of the people/groups involved in that interchange even has the job of tracking what is going on in the research community. If doctors had to read all of the medical journals that were available, and they did so full-time, at the end of the year they would be several years behind. Mr. Simon explained that it is not possible for to accelerate cures based on the care system that is in place today.

Mr. Simon added that we live in a world in which research into cures is not connected to treating patients for their illnesses. One goal of the American Medical Association a few years ago was to save 100,000 lives by having doctors follow the same treatment for strokes in every hospital, based on what was known

about best clinical practice. Quality of care depends on a patient's zip code, and even within a zip code, a patient may live or die from a heart attack, based on which hospital he or she goes to within a given zip code. Mr. Simon explained that FasterCures has been working to integrate what should already be integrated—the care community and the cure community? Working with the Markle Foundation, FasterCures conducted a study on how to accelerate research through the NHIN. The following guiding principles were identified: (1) bi-directional data exchange, (2) optimum use of patient data, (3) collaborative research, (4) common data standards, (5) federated networks, (6) technology and content flexibility, and (7) privacy protections. Mr. Simon explained that what unites these principles is that they are patient-centered and based on a collaboration model for integrating research into a nationwide health information network.

FasterCures then conducted a review of all of the groups in the country that are using EMRs for research as well as the models being created for integrating care and cure (and how they could serve as a model for what needs to be done at the national level). With support from the Agency for Healthcare Research and Quality and in conjunction with the National Clinical Research Resource Center, FasterCures developed a list of four activities that could be done immediately to benefit patients:

- Pursue a "Connecting for Clinical Research" program.
- Develop a post-marketing surveillance capability.
- Develop strategies for conducting broad-based population health surveillance using EHR data.
- Create an effort that uses EHRs to improve subject recruitment and enrollment into clinical studies.

Mr. Simon explained that the research community, embodied in the NIH system (which, he noted, is the world's preeminent research enterprise), is organized around the principle of studying human biology. To be successful in that system, one needs to get a grant. And to get a grant, one cannot be too ambitious and one cannot be too young. The average age of first grant receipt is 42; the average age at which people conduct Nobel Prize-winning work is 33. The research community is based on the academy model of tenure, slow publication, and the protection of intellectual property as though it were a "lottery ticket" instead of a "mutual fund" that could benefit many more people. Most researchers, Mr. Simon said, have never met people with the diseases they're studying.

Mr. Simon then explained that those in the medical community are not paid, supported in any way, or even encouraged to interact with the research community, unless they are at a major academic health center. (most people do not get treated at major academic health centers).

The question becomes: How do we get the research community and the medical community to care for each other? Mr. Simon emphasized that they must be connected in such a way that daily care is visible to the research community, and the research community feels an obligation to report their findings in a timely manner back to the medical community. Integrating new models of personalized medicine into medical care must be done more effectively.

Ms. Amy Miller, Director of Public Policy at the Personalized Medicine Coalition (PMC), noted that the Coalition represents a broad spectrum of academic, industrial, patient provider, and payer communities, and seeks to advance the understanding and adoption of personalized medicine concepts and products for the benefit of patients. The Coalition advocates for an advanced health IT infrastructure that facilities the interoperable exchange of digital biomedical information. She noted that the case for greater investment in health information technology has not developed as the Coalition wishes it would.

To address this challenge, and in conjunction with IBM, Siemens, and other members, the PMC is drafting a white paper to identify how health IT will bring new personalized medicine breakthroughs more quickly into practice. This paper will draw from leaders across the health care system representing all stakeholder groups in personalized medicine. The PMC first announced its support of health IT by adopting the following policy position:

- The Personalized Medicine Coalition actively supports the creation of a national health information network that enables the interoperable exchange of digital biomedical information securely between a diverse set of stakeholders in the healthcare ecosystem. Improved health outcomes and increased efficiency will result from evidence based practice in a quality centered healthcare center that is empowered by interoperable exchange of health information technology.

Ms. Miller commented that systems need to be developed for personalized medicine that take into consideration both clinical care and the research settings. Those systems must be interoperable so that patients' records can be aggregated and outcomes better understood. The PMC is prepared to support the activities of the AHIC regarding clinical research and the electronic health information exchange infrastructure necessary to accomplish this vision.

The PMC may be able to contribute to these efforts. The PMC can help garner the support necessary from both public and private investors to see that this effort takes off and moves forward. Its membership has the expertise to support the work of the AHIC, and its members can help identify and prioritize the specific areas for standards development.

Discussion Highlights

"The AHIC would like to hear what you mean by an auxiliary pathway and have that cleared up a little bit more; how independent is this pathway? Does this create a second or a third AHIC that we go through, and then how [will] it all really be harmonized, or how does it move forward?" – Dr. Lenert

"The process…isn't creating necessarily a new pathway or a new bodies in which to do that work, but ways to augment the processes which, to this point, have been entirely federal government supported, meaning from a financial standpoint, as well the assignment of Workgroups and activities that lead to HITSP certification process…We went through quite an elaborate process of use case prioritizations, of which this area rose very high and was recognized by a number of members as having utility, and we were asked to provide pathways for which the existing use case development and harmonization efforts could be broadened." – Dr. Downing

"The primary needs in that capacity are three. One is some programmatic and technical capabilities of bringing consensus groups together to bring priorities forward for use case development. The second is the financial resources of which to support both the contract work that HITSP through ANSI is required to do, in terms of formulating the processes and getting the standards developed and harmonized. And third is the technical expertise required to do that." – Dr. Downing

"Is this exclusive, and does this bypass the processes? The answer is no. It provides an attempt, if you will, to broaden the bandwidth around which health standards can be harmonized and recognized. And I think the alternative to that is to say that there is a limited pinhole by which the standards processes can ultimately be brought together and harmonized. And so this is in parallel and consummate with some of the goals for which the privatization efforts behind AHIC is about." – Dr. Downing

"What I wouldn't mind doing, and with the approval and blessing of this group, is to use this example, which I think is a terrific example, as a first case for A2, frankly. I think a couple of attributes, one is obviously on any national priority map you'd find this…the second is that there is a broad group of folks from the industry, academic, public, private, et cetera, to say 'we're here to work together on this stuff, and we're also willing to bring together sweat equity and dollars in a to be determined amount to further this work here.' So it need not be dollars, per se, that roll into A2. It's just effort. It's the resources required to pull it off in effect here." – Dr. Glaser

"So what I wouldn't mind doing, and I can work with Greg on this one, is to sort of rough out a process by which this would occur, and in the context of an A2 process, where there is a group of folks representing an important area, willing to step forward to work on it, and [determine] how would it work" – Dr. Glaser

"When you look at a lot of the research the data needs, they build on everything that we have. So it isn't that it's separate from the things we've done, but there are additional things that may help it to really integrate into the clinical research arena so that it serves both purposes in addition to the ones that have been advanced previously. And that there is a business need that will, in fact, provide that pull into systems, because of the benefits that are seen by individuals who are using those systems now." – Dr. Kolodner

"I think there is continued need for stakeholder engagement and information in finding out what the prioritization in these areas is going to be, a very important process to go forward. What we would like to do is continue to do some engagement in this process of finding out where the standards exist, where the organizations are, and finding out where the potential stakeholders are beyond this group that's here." – Dr. Downing

"We've never had any intention for any of this to be separate from AHIC or these other standards process…We clearly want this to be part of this greater whole, but the plea I want to make is timeliness. We're actually quite worried that in the absence of timeliness, we will lose a window of opportunity here. And if this drags on for another 6, 12, 18, 24 months, groups that are well down the path of building these infrastructures and actually are required through terms of award, and other things to be building research infrastructures, will find themselves not being able to be compliant with a process we'll create." – Dr. Buetow

"As the head of FasterCures, I'm duty bound to say let's move as quickly as possible on this…I was originally invited to testify to this group a year ago and that meeting was postponed. So I've been on the edge of my seat now for a year to make the points I made today. I would have made the same points a year ago. I'd like to make very different ones six months from now. And I think that obviously, this will go into the A2 process. But setting the foundation and really starting the momentum to make it inevitable and indispensable, I think is the key." – Mr. Simon

"I'd like to reiterate the importance of getting this done and quickly. At the Personalized Medicine Coalition, we work to solve problems, policy, business, and others around evidence to support the adoption of personalized medicine, and very often the conversation comes to who's got the data, how can we use it, and how can we use it to prove the case, be it for a business model or a policy issue? And so we've been having this conversation for a very long time, and I would like to reiterate the need for speed." – Ms. Miller

Public Comment

Speaker Number 1—Dr. Bill Hersch, Professor and Chair of the Department of Medical Informatics in Clinical Epidemiology at Oregon Health and Science University, agreed with the speakers in the last panel regarding the importance of clinical research and electronic health information, that this is an important potential use case. Dr. Hersch indicated that he was in Washington to attend this AHIC meeting and also to participate in an Institute of Medicine (IOM) meeting on building the infrastructure and the workforce for comparative effectiveness research, which will provide data on head-to-head competitions of treatments and tests. He commented that the individuals at this IOM-sponsored meeting, and also groups such as the American Medical Informatics Association (which has gone on the record advocating reuse of clinical data from EHR systems), could contribute to these efforts. He noted that the primary value of the use case, beyond the obvious importance that the panelists highlighted, will be for the AHIC process, which is largely focused on clinical care, to engage the clinical research community. There are stakeholders interested in making sure that the growth of data and EHR systems can be used for research purposes. To get there, they need most of the same standards that AHIC has been discussing for the last several years. Dr. Hersch encouraged the Community to consider this use case.

Ms. Robin Rafer commented on behalf of the HITSP Education Committee and indicated that her group is conducting a series of webinars (www.hitsp.org/webinars) intended in part to reach out to the consumer and the health care provider who do not know about HITSP or about AHIC and their work. The webinars have all been recorded, and weaved into them is “Steve’s Story,” which applies HITSP efforts to a real-world example.

Closing Remarks

Before adjourning the 23rd meeting of the Community, Dr. Kolodner thanked the Community members, speakers, and participants for their attendance and participation.

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

American Health Information Community

Population Health and Clinical Care Connections Transition Report

John R. Lumpkin, M.D., M.P.H.

Robert Wood Johnson Foundation

Leslie Lenert, M.D., M.S.

Centers for Disease Control and Prevention

September 23, 2008

PH/CCC Workgroup Member List

- **Co-Chairs:**
  - John R. Lumpkin — The Robert Wood Johnson Foundation
  - Julie Gerberding — CDC
    - Leslie Lenert - Alternate — CDC
- **Members:**
  - Cheryl Austein-Casnoff — Health Resources and Services Administration (HRSA)
  - Michael Barr — ACP
  - Scott Becker — APHL
  - Larry Biggio — State of WY
  - Theresa Cullen — IHS
  - Art Davidson — Denver Public Health Dept. (NACCHO)
  - Lisa Dwyer — CSTE
  - Jon Einbinder — Partners Healthcare
  - Thomas Frieden — NYC Dept. of Health and Mental Hygiene (NACCHO)
  - Angela Fix — ASTHO
  - Shawn Fultz — Dept. of VA
  - Shaun Grannis — Regenstrief
  - Vincent Fonseca — Texas Dept of State Health Services
  - Amy Helwig — AHRQ
  - Brian Keaton — ACEP
  - Martin LaVenture — MN Dept of Health (ASTHO)
  - John Loonsk — ONC
  - Robert Martin — CDC/COGH/OD
  - Richard L. Haberberger — Dept of Defense
  - Dave Ross — PHII
  - Lisa Rovin — FDA
  - Edward Sondik — CDC
- **Office of the National Coordinator:**
  - Kelly Cronin — ONC WG Director
  - Laura Conn — Senior Advisor
  - Shu McGarvey — Lead Staff, NG – Contractor to ONC
  - Paula Soper — Contractor to ONC

I. History and Background

- AHIC approves Biosurveillance Workgroup- November, 2005.

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

- HHS Health Information Technology Policy Council presents gap in population health needs at October 2006 AHIC Meeting.

- AHIC asks Biosurveillance Workgroup to expand scope.

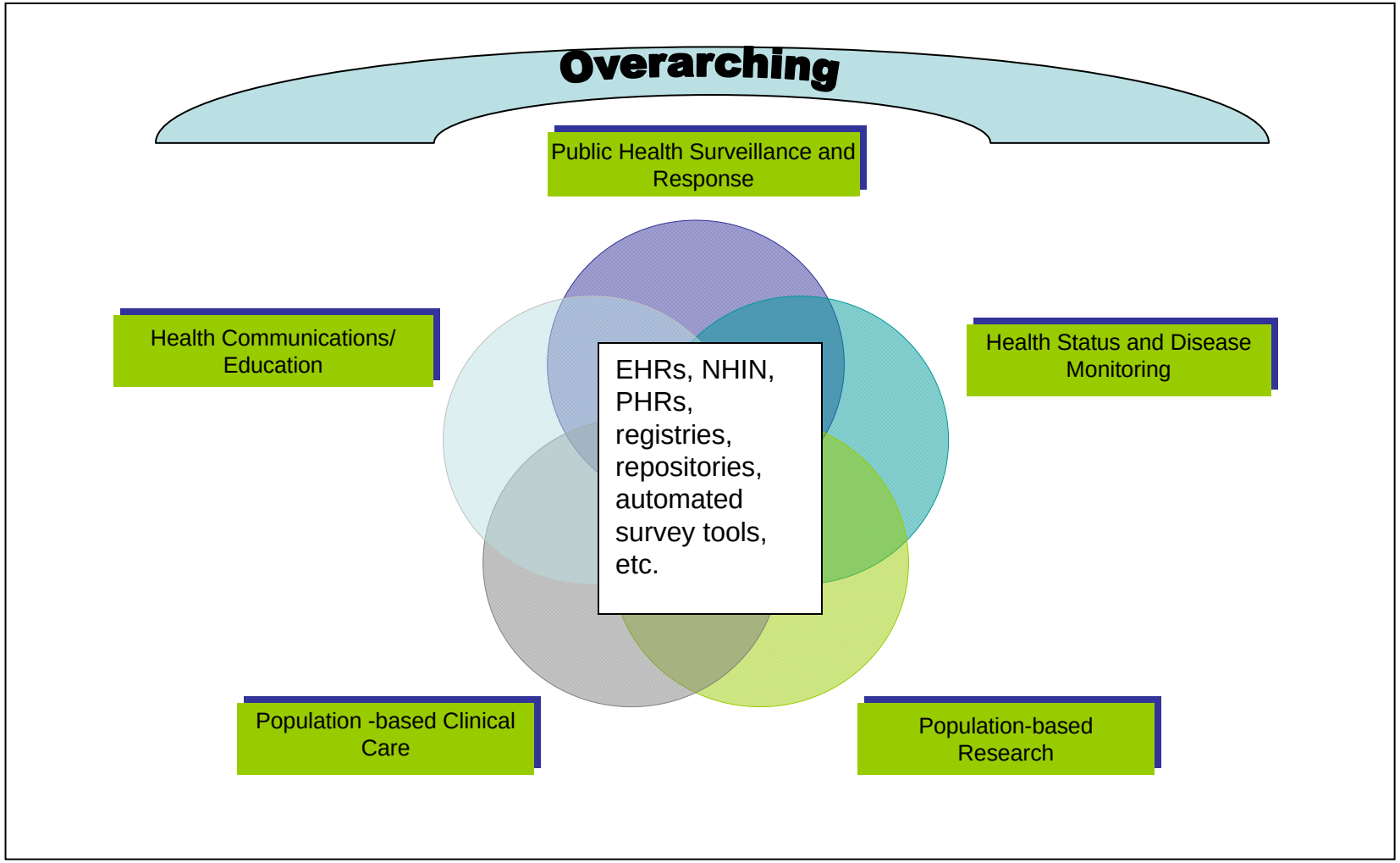
II. VISION: Expanded Charge for Population Health

- Scope for Population Health is expanded in Jan 2007

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

- Population Health constructs are developed as a framework to organize work.

Population Health Constructs



III. Overview of Challenges

Need to:

- Modernize Population Health infrastructure.
- 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.

Overview of Challenges - continued

Need to:

- Articulate and communicate the value to clinical care for including public health as an integral partner in health information technology (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.

Overview of Challenges - continued

Challenges:

- Finding community-level data sources to support population-based clinical care.
- Manual data collection methods hamper health status and disease monitoring efforts.
- Inadequate integration between Population-based Registries and EHRs.

IV. Key Accomplishments

- Biosurveillance use case developed as a result of prioritizing biosurveillance as an AHIC breakthrough area.
- Minimum dataset for biosurveillance defined and standards harmonized by the Healthcare Information Technology Standards Panel (HITSP).
- Two additional Population Health use cases advanced:
  - Public Health Case Reporting
  - Immunizations and Response Management

  Standards harmonization for these is on track for Dec 2008.
- General Lab Orders identified as an extension to the Electronic Health Record (EHR) Lab Reporting use case and is slated for 2009.
- Consumer Adverse Events Reporting identified as a 2009 extensions/gap.

Key Accomplishments – continued

- Centers for Disease Control and Prevention (CDC) Solicitation: Accelerating Public Health Situational Awareness through HIE, awarded in spring 2008, is expected to address a number of the PHCCC recommendations accepted by the Community in March 2007.

- CDC and the Council of State and Territorial Epidemiologists (CSTE) have created a process to define a common list of nationally notifiable conditions to be reported by all levels of public health.
  - Initial list of nationally-notifiable conditions, along with standardized criteria for case identification, targeted for completion by fall 2008.
  - Fundamental steps toward enabling decision support triggers for case recognition and case reporting through EHRs.

Key Accomplishments – continued

Most notable contribution of the 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.

V. Priority Activities for the Future

- 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:
  - 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.

Priority Activities for the Future - continued

- 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 labs.
  - Include veterinary and environmental data
  - Unambiguous linking of lab 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.

Priority Activities for the Future - continued

- Provide health promotion and health education materials to patients, clinical care and public health through EHRs, Personal Health Records (PHRs), websites and other associated pathways.

- Establish and manage an authoritative website to share recognized standards and implementation guidelines.
  - Include a collaborative space for the sharing of standards and implementation guides that are under development.

Priority Activities for the Future - continued

- 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

Questions?

Population Health and Clinical Care Connections
Transition Report

9/23/08

Workgroup of the
American Health Information Community

PHCCC Transition Document

Table of contents

I. Executive Summary 4

II. Background and History 8

III. Population Health Constructs 10

Descriptions of Constructs 11

Overarching Concepts 13

Public Health Surveillance and Response 13

Health Status and Disease Monitoring 14

Health Communications/Education 16

Population-Based Research 16

Population-Based Clinical Care 17

A. Population Health - Current State, Future State, Near-term and Intermediate-term Priorities 18

Overarching (OA) 18

Public Health Surveillance and Response (SR) 29

Health Status and Disease Monitoring (HS) 40

Health Communications/Education (HC) 45

Population-Based Research (RE) 48

Population-Based Clinical Care (CC) 51

Appendix I – Cross-reference of population-health construct to recommendations 54

Appendix II - PHCCC and Biosurveillance Recommendations' Status 54

Appendix III – Maternal and Child Health 54

Appendix IV – Patient Safety Events 54

Appendix V – List of Examples National, State and Local Surveys 54

I. Executive Summary

The American Health Information Community (AHIC, the Community) Population Health and Clinical Care Connection (PHCCC) Workgroup was established after the Biosurveillance workgroup completed its specific charge for biosurveillance. The PHCCC Workgroup broadened the limited biosurveillance perspective and organized around 5 basic population health constructs 1) Public Health Surveillance and Response 2) Health Status and Disease Monitoring, 3) Health Communications/Education, 4) Population-based Clinical Care and 5)Population-based Research. In addition, overarching concepts and inter-related concepts were identified that cross the 5 domains.

Progress in one domain of Population Health is interdependent on progress and success in other areas of population health. Surveillance and health status data, as well as bidirectional health communications messages are required to support population-based clinical care. Data from clinical care supports population based research, surveillance and health status and disease monitoring. While the PHCCC Workgroup identified these five specific domains, all domains need to be developed simultaneously (in parallel) to assure all components for population health advancement are addressed.

As the PHCCC Workgroup conducted its deliberations, several challenges were identified that are dependent on health information technology (HIT) and health information exchange (HIE) for a solution. The current public health infrastructure (despite recent investments for preparedness and response) is critically under-supported and in need of significant modernization. All levels of government (i.e., local, state and federal) require transformation and innovation in the information technology arena. Current funding mechanisms are highly specific to individual programs that may or may not contribute to the development of a common informatics infrastructure. A clear definition of that common informatics infrastructure is missing; certifiable interoperability criteria, including functional, non-functional and security elements must be established to support the flexible information system needs across the various levels of government and with the private sector.

Current investments and advancements in the clinical health information technology arena must be leveraged for population health. Current HIT development focuses on clinical applications that are used in direct patient care, without defining the value and the synergies that may be achieved through collaboration with public health in product design and implementation. Monitoring the health status of populations must be a specific bidirectional output of these investments. These outputs would ensure public health data reporting is not the tedious, labor-intensive manual process that is repeatedly conducted throughout

all jurisdictions in the United States. Providing the public health message to patients and clinicians at a teachable clinical moment must be supported by HIT systems that can effectively share information across the personal and public health care environments.

At a system level, efforts are at best weak to monitor costs, implications of policies and conduct health services research. Despite the best intentions of public and personal healthcare practitioners and systems, our current state does not demonstrate efficiencies and quality improvement cycles that leverage the significant past, current and future investments in health information technology to address many of these issues. While the obstacles facing public health are considerable, they are not insurmountable and considerable progress has been made over the last two years to forge a bridge between clinical care and public health. In that time, the PHCCC workgroup has made recommendations to AHIC that have initiated activities that help integrate public health as a partner in HIT.

The advancement of biosurveillance as an AHIC priority resulted in development of the biosurveillance use case. The Biosurveillance workgroup defined a minimum dataset for biosurveillance, standards for which were harmonized by the Healthcare Information Technology Standards Panel (HITSP). Two additional population health use cases have been advanced based on workgroup recommendations; these include a Case Reporting use case and an Immunizations and Response Management use case. Standards harmonization for these is currently in-progress. General Lab Orders has been identified as an extension to the Electronic Health Record (EHR) Lab Reporting use case and is slated for 2009. The Centers for Disease Control and Prevention (CDC) Solicitation: Accelerating Public Health Situational Awareness through HIE, awarded in spring 2008, is expected to address a number of the PHCCC recommendations accepted by the Community in March 2007. CDC and the Council of State and Territorial Epidemiologists (CSTE) have collaboratively drafted a process to define a common list of nationally notifiable conditions to be reported by all levels of public health. The initial list of nationally-notifiable conditions, along with standardized criteria for case identification, is targeted for completion by fall 2008. Both the process and the criteria are fundamental steps toward enabling decision support triggers for case recognition and case reporting through EHRs. As the domain tackled first, most of the progress has been made in population health surveillance and response. However, the most notable contribution of the 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 improve the health of the population. The workgroup believes that the priority activities bulleted below will continue the momentum that has been started. Some activities would be facilitated by the AHIC Successor, others by government, and still others deliberated by a Federal Advisory Committee. Each priority activity is described in more detail in the body of this document.

Priority Activities

- Develop the infrastructure and architecture for role-based, unambiguous unique identification of medical service providers in association with the Nationwide Health Information Network (NHIN) initiative to support appropriate and secure access to data and information that supports practitioners' capacity to offer comprehensive personal and public health services.
- Develop a business case for data/information exchange between public health and clinical care; include the business case for bi-directional communications (e.g., automated electronic case reporting from EHRs and automated alerts and decision support tools from public health providers to clinicians)
- Ensure that HITSP harmonization of standards for Population Health use cases is completed and followed by development of certification criteria by the Certification Commission for Healthcare Information Technology (CCHIT) to incorporate needed functionality into EHRs. These certification criteria need to be tested, validated and improved through a series of demonstration project to support implementation guides and broader and more deployment.
- Use case development should include additional themes beyond those already developed for population health(e.g., maternal and child health, population-based research, population-based clinical care). Existing population health use cases should be refined and extend the Case Reporting, Response Management & Immunization Registries, Bi-directional communications (e.g.. alerting standards and directory exchange standards), and Laboratory Test Orders to more fully include Outbreak and Event Investigation, as well as Countermeasure Allocation, Tracking, Distribution, and Administration.
- 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 (with input and participation from all levels of public health).
- Prioritize development of a Population-based Research use case and interoperability specifications to link population-based research standards to data available from electronic health records. In conjunction with Clinical Research activities, ensure that population-based research standards are included for standards harmonization.
- Prioritize development of a Population-based Clinical Care use case and interoperability specifications to include decision support triggers for patient care into EHRs that are based on community-level assessments of a population and that facilitate bidirectional sharing of pertinent clinical information.

- Establish and manage an authoritative website to share recognized standards and implementation guidelines. This would include a collaborative space for the sharing of standards and implementation guides being tested or used that are not yet recognized.
- Collaboratively 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 labs, coding public health conditions in the HITSP lab message, including veterinary and environmental data in result reporting and unambiguously linking lab data to clinical and public health records
- Collaborate with Personalized Healthcare (PHC) workgroup successor activities to provide health promotion and health education materials to patients, clinical care and public health through appropriate pathways (e.g. EHRs, Personal Health Records (PHRs), and websites).
- Evaluate population health domains to determine future priorities for use case development. These may be new use cases or extensions to existing population health use cases.
- Conduct gap analysis between data elements needed to support population health and data elements that are currently available in EHRs.
- Evaluate current measures that can be used to assess population health. This work should result in a set of recommended population health measures that are maintained and updated on a routine bases. These updates should include detailed logic, as well as audit guidance for data sets. Development of measures should follow a defined and endorsed iterative process.
- Support efforts to enhance the number of professionals with informatics training who are in public health practice. This includes professionals who will become informaticians/scientists, those who will not be informaticians but would like to increase their understanding of public health informatics, as well as continuing education in informatics for existing public health practitioners.

The opportunities for improved population health to result from current and proposed health information technology and exchange investments are great. The PHCCC Workgroup believes that this work can drastically shape the methods and approaches that any AHIC successor community undertakes.

Our work is summarized in more detail in the following pages. We have organized for the AHIC successor community, our assessment of the current state, and proposed a series of potential next steps to move toward an envisioned future state. We believe that health status improvements require a population health focus in health information technology. This work will

inform and enhance the value of the many innovations in health information technology that our country will develop over the next several years.

II. Background and History

The Population Health and Clinical Care Connections workgroup was first founded as the Biosurveillance workgroup in November of 2005 and then expanded to include population health in Oct of 2006. The history and general background of the workgroup are described in this section.

At the November 29, 2005, American Health Information Community meeting the Community recommended the formation of a workgroup on biosurveillance. This recommendation highlighted the importance of public health as an integral partner in Health IT and recognized the importance of medical preparedness to detect and contain events that threaten the health of large populations. It was recognized that steps needed to be taken to prepare for and contain the effects of a catastrophic health event, such as a terrorist attack with a weapon of mass destruction (WMD), a naturally-occurring pandemic, or the emergence of a new disease like Severe Acute Respiratory Syndrome that could cause tens or hundreds of thousands of casualties or more, weaken our economy, damage public morale and confidence, and threaten our national security.

Biosurveillance was the first step and would be enabled by data exchange among public health and clinical care to both improve the detection of outbreaks and events, as well as support situational awareness. The Biosurveillance workgroup operated under a broad charge and a specific charge:

> **Broad Charge -** make recommendations to the Community to implement the informational tools and business operation to support real-time nationwide public health event monitoring and rapid response management across public health and care delivery communities and other authorized government agencies.
>
> **Specific Charge -** make recommendations to the Community so that within one year, essential ambulatory care and emergency department visit, utilization, and lab result data from electronically enabled health care delivery and public health systems can be transmitted in standardized and anonymized format to authorized public health agencies within 24 hours.

At the Oct 31, 2006 AHIC meeting, the Interagency Health IT Policy Council recommended that the scope of the Biosurveillance workgroup be expanded to cover the broader area of Population Health[i]. Federal partners pointed out that population health was contained in many of the activities already being discussed by AHIC in the use cases and priority areas, and the benefits to the population's health of leveraging HIT were to:

- Facilitate identification of at-risk patients/populations.
- Facilitate monitoring of population health status and population health prevention and improvement.
- Enable information exchange between appropriate partners.
- Identify HIT requirements needed for population health management.
- Increase effectiveness and efficiencies of population health management in federal and private sectors.

The committee accepted the recommendation to expand the workgroup to cover population health.

At the January 23, 2007, Community meeting, the Biosurveillance Workgroup was renamed to the Population Health and Clinical Care Connections Workgroup (PHCCC). At the same time, the broad charge was expanded to meet the goals of the restructured workgroup:

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

The Community further recommended that this workgroup develop a plan to realize a specific charge (transmitting certain data from health care providers to public health systems) within one year, which is visible to the American public and works towards a broader charge (facilitating the bidirectional flow of reliable health information among population health and clinical care systems to protect and improve the public's health) over time.

The expanded scope was supported by a background document that described a working division of population health into 5 constructs:

1. Public Health Surveillance and Response
2. Health Status and Disease Monitoring
3. Health Communications and Education
4. Population-based Clinical Care

5. Population-based Research

These five constructs were seen to be overlapping and interdependent, but were selected as a way of organizing and conceptualizing a very broad field. To date, the workgroup has made recommendations in the first 3 constructs, with the greatest focus being on Public Health Surveillance and Response as a natural outgrowth of Biosurveillance. The population health constructs are used to organize the main body of this document.

III. Population Health Constructs

Population Health is an approach to health that aims to improve the health of an entire population. Population health moves beyond the individual-level focus of mainstream medicine by addressing a broad range of factors that impact health on a population level, such as environment, social structure, resource distribution, and health care access. Understanding the status and determinants of health in a population is needed to plan, implement, and evaluate efforts to improve the health of a defined population.

In expanding the scope from Biosurveillance to Population Health, the workgroup refined the benefits expressed during the Oct 2006 AHIC meeting in terms of HIT-enabled population health activities. HIT-enabled population health activities will target more complete, efficient, and timely: (1) surveillance, identification and management of emerging health conditions; (2) health status and disease monitoring, assessment, intervention, and evaluation of the impact interventions for at risk populations; (3) reduced disparities and improved population health status through clinical performance measurement/improvement using longitudinal health data linked with external data sources; (4) population health research; and (5) dissemination of population health information.

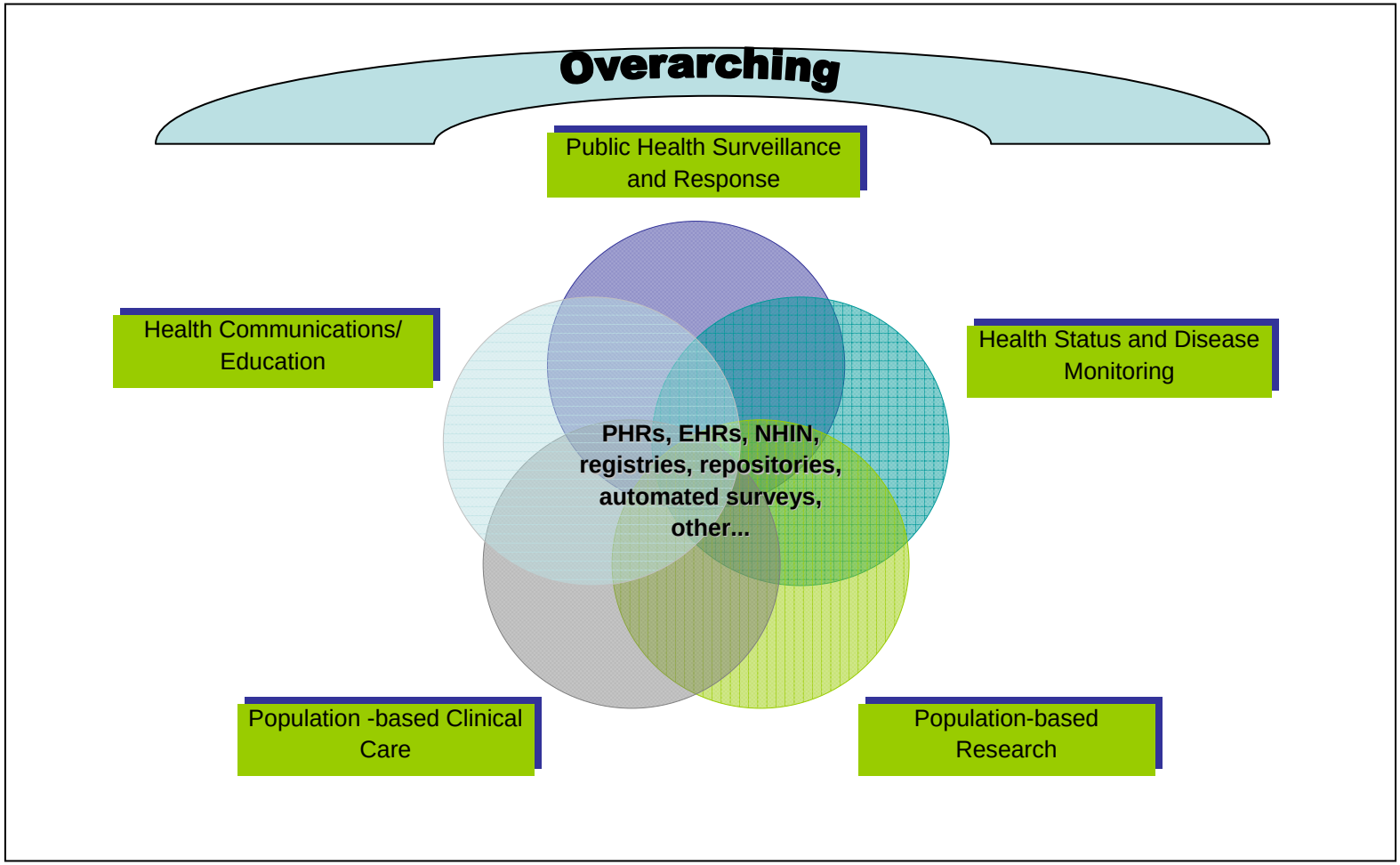
The HIT enabled population health activities listed above map to the population health constructs described below. These five constructs are not mutually exclusive but have overlaps and intersections. They are designated by the workgroup as separate constructs to assist with describing our work with sufficient detail to make recommendations to the successor Community. By definition, Population-based Clinical Care and Health Statistics and Disease Monitoring are constructs enabled through Population-based Research and Public Health Surveillance and Response. The findings for all these construct activities are communicated through Health Communications/Education.

The five central population health constructs, in addition to concepts which are overarching, are shown in figure 1.0 below. The figure illustrates the interrelated and overlapping nature of the constructs as well as their relationship with fundamental aspects of HIT such as electronic health records (EHRs), the Nationwide Health Information Network (NHIN), and personal health records (PHRs). The figure is followed by a description of each population health construct as discussed and developed within the workgroup. Descriptions are followed by a section that provides two tables for each construct. The first table is a synopsis of the current state and the envisioned future state; the second table provides workgroup assessment of priority construct areas, a suggested timeline for addressing (near-term and intermediate-term) and recommended target home transition strategy for each priority area (e.g., transition to the AHIC successor, fits under the responsibility of one or more governmental agencies or best be advanced via a Federal Advisory Committee (FACA). Delineation of identified population health priorities will help facilitate early movement and progress towards HIT-enabled population health benefits guided by the AHIC successor.

Recommendations previously accepted by AHIC are included in Appendix II. These recommendations move us closer to the benefits presented at the October 2006 AHIC meeting and the envisioned future state described under each construct. Under each section the gaps denote additional areas that still need to be addressed by AHIC, its successor, or other responsible agency in order to reach the envisioned future state and realize the resulting benefits.

Descriptions of Constructs

This section includes a brief description of each population health construct, as well as concepts that are overarching, included in figure 1, above. The descriptions provide a context and scope used during workgroup discussions on these constructs. As evidenced by the figure, these constructs overlap and the descriptions are not mutually exclusive; however, the descriptions were exemplary for the workgroup to agree to a framework and organize specific recommendations.


Overarching
Public Health Surveillance and Response
Health Communications/ Education
Health Status and Disease Monitoring
PHRs, EHRs, NHIN, registries, repositories, automated surveys, other...
Population -based Clinical Care
Population-based Research

Overarching Concepts

Overarching concepts provide the information technology foundation essential to support population health. In addition, overarching covers policy and authorization to better support population health objectives. Examples of overarching concepts are:

- An integrated public health infrastructure that supports information exchange with partners and can be used across public health program areas
- Program metrics to evaluate success and facilitate improvements
- Training in public health informatics through workforce development
- Addressing privacy concerns and reducing barriers to information exchange through policy and authorization
- Developing and disseminating business cases to articulate the benefits of automated data/information exchange between public health and clinical care
- Providing an authoritative website for population health standards
- Secure collaboration forums for clinicians and public health

Public Health Surveillance and Response

Public Health Surveillance is the on-going systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice closely integrated with the timely dissemination of these data, analysis, and interpretations to those responsible for prevention and control. Public Health Response includes the measures taken to prepare for, prevent and control disease, injury, or adverse exposure. Public Health Surveillance and Response includes:

- Notifiable condition reporting
- Situational awareness
- Active surveillance (for disease or unexplainable deaths)
- Evaluating trends in disease virulence and antimicrobial resistance, including emerging pathogenic agents
- Monitoring disease burden trends including the detection of epidemics (outbreaks) and pandemics

- Monitoring for Patient Safety Events

Data, analysis, and interpretations disseminated by a public health surveillance system can be used for immediate public health action, program planning and evaluation, and formulating research hypotheses. For example, data from a public health surveillance system can be used to:

- Guide immediate action for cases of public health importance
- Guide the response to prevent and control disease, injury, or adverse exposure
- Enable assessment of the effectiveness of control measures

Health Status and Disease Monitoring

Health status and disease monitoring involves the accurate, periodic assessment of community and patient level health status, identification of health risks (determinants of health and functional status), and determination of health service needs. Health status and disease monitoring data is used to support the three core public health functions as identified by the Institute of Medicine [ii:] assessment of community health status and needs; assurance of access to health care and population health services, and; policy development to support personal and public health goals. Examples organized by the three core public health functions are listed below, and additional examples for each health function can be found in Appendix VI:

- Assessment
  - Community and Personal Health status – collecting health status data and monitoring trends, health risks, determinants and disease within the population.
  - Disparities – Identifying and measuring health disparities, and determining needs of vulnerable populations.
  - Long term and emerging health problems – identifying disease trends, environmental hazards and risk exposures, developing disease modeling approaches.
- Assurance
  - Population health services – Including monitoring disease and responding to outbreaks and other threats and implementation of personal, community and environmental prevention activities.
  - Health care system access – Measuring available health services and gaps in service, determining trends in health services and needs and effect of changes in health practice on these needs.

- Policy Development
  - Supporting local, state and federal public policy and program decision making – Using input from community health status, assessments, program outcomes, and environmental recovery efforts to guide policy development.

Data Collection Methods - Registries and Surveys

Population-based registries and health surveys are two methods for collecting data to support health status and disease monitoring. Population-health registries fall under three main categories: disease-based registries, disease management registries and risk-based registries. Registries are used to collect and analyze data to monitor health status and individual health. Registry information is used to monitor disease trends, target individuals and communities for public health interventions, and provide decision support for exception reporting, intervention targeting and program evaluation and quality improvement.

Several national surveys are conducted annually. These provide estimates at the national, state and local levels for surveillance of health behaviors and conditions. Population-level health status assessment requires capturing relevant data in such a way that it will be generalizable to larger populations as well as usable at the individual patient level. Data collection efforts must contain enough cases for many demographic groups to allow for meaningful comparisons.

- Registries include but are not limited to: cancer, diabetes, environmental exposures, immunizations, high risk obstetrics, as well as preparedness registries for emergency volunteers and responders.

- Examples of Surveys include: Healthy People, National Ambulatory Medical Care Survey (NAMCS), National Immunization Survey (NIS), Behavioral Risk Factors Surveillance System (BFRSS), State-level Healthy People initiatives, State-level BFRSS, Local-level Healthy People initiatives. A more complete list of surveys is available in Appendix V.

Health Communications/Education

Health communication/education informs, educates and empowers providers, consumers and others about acute and chronic illnesses, injuries, and health and wellness issues. Communication tools include public websites, written materials, electronic exchanges and risk communications. Self-management by the individual and the population is promoted by providing health information, health education, and health promotion activities designed to reduce health risk, promote better health, and improve and/or maintain health and functional status. Literacy remains a critical component of effective health communications and education.

Examples include:

- Vaccination schedules, guidelines, warnings and the ability to modify immunization guidelines based on early recognition of epidemics.
- Development of case definitions, syndrome definitions, diagnostic guidelines and criteria that can be electronically integrated and tracked.
- Promotion of healthy communities and healthy behaviors through risk reduction (e.g., physical activity, nutrition, tobacco, alcohol and other drug use, unintentional pregnancy, sexually transmitted diseases, mental health, maternal and child health, and the prevention of injury and violence).
- Programs to inform and educate different audiences (e.g., general public, providers, policy leaders) through accessible health information and educational resources that promote self-management and create and support healthy communities and population health status (e.g., social marketing campaigns, media and policy advocacy, risk communications on environmental hazards and potential environmental risks).
- Partnerships with schools, faith communities, work sites, personal care providers, and others to educate and implement and reinforce health promotion programs.

Population-Based Research

Population-based research focuses on new insights and innovative solutions to health problems on a population level to ensure that all people, especially those who experience health disparities, will achieve their optimal lifespan and experience the best possible health in every stage of life. Population-based research requires adequate infrastructure, policies and internal capacity

to mount timely epidemiologic and economic analyses and conduct needed health services research. These are currently not in place, and should be the focus of on-going efforts to advance population-based research. Population-based research would also benefit from improved linkages between public health and research institutions and other institutions of higher learning.

Examples of population-based research include:

- Evaluations to determine the effectiveness of strategies and interventions on health services and systems (e.g., improvements in diabetes health indicators)
- Research to develop indicators to measure disparities in quality of care
- Evaluation of social marketing campaigns designed to influence health behaviors to identify effective communications strategies [iii]
- Strategies to evaluate the effectiveness of health services
- Research to inform the understanding of mechanisms of disease

Population-Based Clinical Care

Population-based clinical care places the care and health information of an individual patient within the context of the larger community and population which is comprised of both sick and healthy individuals. It is also known as population-based medicine or community-based medicine [iv] and it identifies defined populations, such as a patient population comprised of patients with diabetes, or a patient population that encounters barriers to personal health services, and ensures that all determinants of health (including nontraditional determinants of health disparities and inequities) are considered in the clinical care delivery model for the individual. Population-based clinical care involves four primary components: community health assessments to identify and characterize the population denominator, and identify health problems of highest priority for the population; interventions designed to improve the health of the individual and population based upon the health assessment; provision of care for individual patients, their families and the community in context of culture, health status and health needs; and assessment of the impact of interventions and care on the individual as well as the population.[v]

Some examples of population-based clinical care include:

- Prioritizing services known to decrease barriers to physical activity (e.g., sidewalks, lighting, safety measures, etc) for diabetics found within a geographical cluster in a community.
- Linking asthmatics to a service that pushes air quality alerts via electronic communication. This shows coordination between provider services and development of interventions that address identified barriers to care (e.g., culturally and linguistically appropriate staff and materials, transportation services).
- Decision support alerts for blood lead screening for child living in an zip code where many houses were built prior to 1950.
- Decision support alerts for Hepatitis A vaccine for a child living in a zip code with endemic Hepatitis A.
- Employing metabolic disease registry systems to support population-based screening, and ensure patients identified with PKU or one of the other metabolic disorders, have the appropriate diet available to them, and receive the appropriate follow-up from clinicians.

A. Population Health - Current State, Future State, Near-term and Intermediate-term Priorities

This section provides two tables for overarching concepts and each population health construct. The first table is a synopsis of the current state and the envisioned future state; the second table provides the remaining priority areas to be addressed in the near-term and intermediate-term and the recommended transition for each priority area, including whether it should be transitioned to the AHIC successor, fits under the responsibility of one or more governmental agencies or would best be advanced via a FACA.

Overarching (OA)

Overarching concepts provide the information technology foundation essential to support population health. In addition, overarching covers policy and authorization to better support population health objectives.

Overarching		
Function Ref. #	**Current State**	**Future State**
	Infrastructure	
OA_1 Capacity to meet current and emerging threats	Public health infrastructure at the local, state and federal levels is inadequate to meet current and emerging threats. Only a small proportion of public health agencies receive electronic data from clinical care or public health partners.	A modernized infrastructure supports HIEs that are integrated with public health, and support bidirectional exchange of information with public health. Through HIE, population health information is rapidly aggregated, analyzed and disseminated to community organizations. Public health has ability to track longitudinal individual patient data across care settings and effectively communicate appropriate information to public health and clinical care.
OA_2 Capacity of workforce trained in public health informatics	Public health informatics trained workforce is inadequate to support the growing need for practitioners and decision makers with this expertise.	Increased workforce trained in public health informatics is available and includes professionals who will become informaticians/scientists, those who will not be informaticians but would like to increase their understanding of public health informatics, as well as continuing education in informatics for existing public health practitioners.
	Bi-directional Communications	
OA_3 Centralized authoritative website for standards used for population health	A centralized authoritative website that manages harmonized standards and nationally accepted standards for population health is currently not available. The website needs to be administered by a neutral party, but include processes to accept input and support collaborative discussion by multiple parties with varying interests	An authoritative website is in place to share recognized standards. The website includes a collaborative space for the sharing of standards being tested or used that are not yet recognized

OA_4 Capacity for bidirectional communications	While technologies exist to support bi-directional communications, basic infrastructure to support this in an automated fashion is still under development. Unidirectional electronic communication capabilities exist through targeted Health Alert Network (e.g., e-mail) to relevant groups for safety alerts, secure web-based communication and collaboration forums, such as Epi-X, and the use of secure emails to professional organizations by relevant medical specialty, or for automated drug recalls. Standards for alerting formats and sharing of directory information exist but are not yet harmonized.	An integrated and interconnected public health and health care delivery system enables real-time, seamless, secure, and appropriate bi-directional exchange of information to meet the needs of public health and health care providers. Public health would derive information from multiple sources of data (e.g., clinical care, veterinary, environmental sources), collaborate with clinicians to assess the situation and plan a response, and send timely key summaries or alerts to clinicians to assist them in decision-making. Public health uses various communications methods (e.g., health alerts) to share investigation findings, provide case criteria updates, and promote guidelines or recommendations for the general publici. When appropriate, public health information would be shared with incident command entities to support the community mission consistent with suggested PH operational definition
	Public Health Involvement in Standards Harmonization and Certification Criteria Development	
OA_5 Capacity to clearly define interoperability standards and certification criteria to support public health	Public health has limited and only recent involvement in identifying and developing functional, security and interoperability criteria to establish the basis for developing communities with certified flexible information systems that support public health functions and activities. CDC and CCHIT have begun preliminary discussions on how to implement certification for systems that support public health. Standards for all public health jurisdictional levels are still poorly identified and defined. Some early participation in HITSP and CCHIT has helped advance HIT-enabled population health.	Certified flexible information systems that support public health functions and interoperate with clinical care systems and activities are fully implemented by public health. These systems comply with functional, security and interoperability criteria based on HITSP harmonized standards. Public health at all jurisdictional levels continues to inform vendors regarding criteria to build systems that support population health. Metrics and rigorous program evaluations are developed to inform recommendations for new programs, on-going programs and the broader charge.
	Policy and Authority	

OA_6 Regulatory capacity to promote population health while respecting the rights of individuals	Public health has been given permission to conduct operations for supporting surveillance and interventions. Uncertain capacities and regulatory barriers exist to support population-based care and research to improve the health status of populations. The Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) create confusion on how to improve health care and status for school-based efforts	Clear and consistent use cases have clarified the scope and authority of HIPAA, and public health practitioners and researchers are responsive to regulatory measures that support activities that enhance the health of the public.
OA_7 Capacity for synergy of informatics efforts across programmatic areas	Public health programs are separated from information technology support in most states and counties. This is compounded by a lack of emphasis on integrating information systems to support public health activities. Significant "silos" of data reside in both clinical and public health systems.	Language is specifically included in federal contracts, grants and cooperative agreements that ensure funds from a variety of programs mutually contribute to building informatics capacity and technical architecture. Investment supports advancing and integrating information systems and IT infrastructure.
	Business Case	
OA_8 Capacity to fully integrate clinical care partners as both a source and recipient for public health information	Limited efforts to include and value the clinical care community as an integral public health partner. Public health is only recently joining in health information exchange (HIE) and has limited presence in most communities. No clear clinical community HIE business case as yet been defined. Value of public health in the HIE has been minimally explored regarding improved clinical care and decision making. Recent CDC HIE and NHIN Trial Implementation contracts include components to integrate HIEs with public health	The business case has already been established for mutual benefit and the public health jurisdictions and stakeholders see public health as an integral partner in health information exchange (HIE). Administrators and decision makers of clinical care organizations recognize the benefits of automated data/information exchange between public health and clinical care and become advocates of this capability.

Table 1: Overarching Concepts Current and Future State

Priorities Recommended for Transition

This section describes actions that should be taken to continue progress toward the future vision. For overarching, this includes areas already identified: emerging threats, bi-directional communications, synergies across public health programs, integration with HIEs, public health system certification, and a business case for the benefits of including public health as an integral partner in HIT; as well as additional areas identified by the workgroup that require action to advance HIT-enabled population health.

Each new priority activity is identified as *near-term* (within 1 year) or *intermediate-term* (2-5 years), whereas existing recommendations are identified with *follow-up* in this column. The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 1, above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix I. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	Infrastructure				
1.	Develop a program to enhance the number of professionals with informatics training who are in public	Follow-up	OA_2	Jan 08 – Rec. 1.0 (PHCCC1.0.012008)	CDC, in collaboration with academic partners,

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	health practice.				professional societies, and public health associations
2.	Evaluate population health domains to determine future priorities for use case development. These may be new use cases or extensions to existing population health use cases.	Near-term			Successor
	Bi-Directional Communications				
3.	Establish and manage an authoritative website to share recognized standards. Would include a collaborative space for the sharing of standards being tested or used that are not yet recognized.	Near-term	OA_3	Mar 07 – Rec. 1.7 (PHCCC1.7.032007)	Successor
4.	HHS needs to ensure the broader concept of bi-directional communication (included in Public Health Case Reporting use case) is on HITSP's schedule for harmonization, and that public health agencies work	Near-term			Successor

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	on specifications and implementation guides.				
5.	Standards for formatting the structure of health alerts should be harmonized and should build off prior CDC collaboration with state and local partners.	Follow-up	OA_4	Mar 07 – Rec. 3.0 (PHCCC3.0.032007)	Successor
	Standards Harmonization and Certification Criteria Development				
6.	Public health (at all jurisdictional levels) should participate in harmonizing standards for AHIC Successor population health use cases.	Follow-up	OA_5	Mar 07 – Rec. 1.1 (PHCCC1.1.032007)	HHS, along with federal, state, and local governmental public health agencies
7.	Public health should establish an open, participatory process for certification of public health information systems for functionality, security, and interoperability.	Follow-up	OA_5	Mar 07 – Rec. 1.2 (PHCCC1.2.032007)	HHS, in collaboration with state and local governmental public health agencies, and consultation with CCHIT

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
8.	Publish (in collaboration with public health agencies) certification guidance for population HIT systems, including the ability to display relevant individual clinical data based upon population based queries.	Intermediate-term	OA_5		Other, dependant on responsible party determined by #7 above
	Policy and Authority				
9.	Develop clear and consistent communications that clarify the scope and authority of HIPAA, especially regarding exceptions for public health research.	Near-term	OA_6 RE_3		Successor with input and participation from all levels of public health
10.	Follow-up with agencies to ensure that language developed to allow funding to be used toward shared or integrated informatics is included in funding documents.	Follow-up	OA_7	Jan 08 – Rec. 2.0 (PHCCC2.0.012008)	HHS should work with CDC, HRSA, CMS, SAMHSA and others
	Business Case				
11.	Develop a business case for data/information exchange between	Follow-up	OA_8	Mar 07 – Rec. 1.0 (PHCCC1.0.032007)	HHS along with local and state public

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	public health and clinical care. • Follow progress of public health involvement via CDC-HIE contracts and NHIN Trail Implementation contracts to encourage integration and show benefits.				health partners and clinical care stakeholders
12.	Include population HIT domains in local, regional and national data sharing initiatives. Develop appropriate electronic tools to assess impact of inclusion of population health data within HIT systems.	Intermediate-term			HHS
	Metrics				
13.	Evaluate current measures that can be used to assess population health. This work should result in a set of recommended population health measures that are maintained and	Follow-up	OA_7	Jan 08 – Rec. 2.0 (PHCCC2.0.012008)	HHS, in collaboration with state and local governmental public health agencies and

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	updated on a routine bases. These updates should include detailed logic, as well as audit guidance for data sets.				the clinical care community
14.	Conduct a gap analysis of data domains needed to support measurements (as defined in priority activity #13, above) This should be done in coordination with applicable successor activities of the Quality workgroup. Development of measures should follow an iterative process. • Identify priority areas for measures • Draft appropriate initial measures and a process for their development. • Use the process to develop appropriate attributes of population health measures • Include a public comment period, followed by evaluation and public reporting and subsequent	Near-term	OA_7	Jan 08 – Rec. 2.0 (PHCCC2.0.012008)	FACA

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	evaluation Proposed measure attributes include the following: 1. relevance of the measure 2. clinical evidence 3. data that is reliable, valid, accurate, reproducible and comparable 4. feasibility of the measure to assess goals and outcomes 5. ability to define data query logic 6. feasibility of electronic reporting, aggregating and bidirectional transmission of the data 7. return on investment (population health as well as fiscal returns)				
15.	Develop more precise metrics for performance measurement. Specifically, denominator definitions and database structures required to	Near-term			HHS, in collaboration with state and local governmental public health agencies and

	Overarching				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term / Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	generate flexible denominator data sets should be developed to support population health within electronic health records.				clinical care

Table 2: Overarching Concepts Priority Activities

Public Health Surveillance and Response (SR)

Public Health Surveillance is the on-going systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice closely integrated with the timely dissemination of these data, analysis, and interpretations to those responsible for prevention and control. Public Health Response includes the measures taken to prepare for, prevent and control disease, injury, or adverse exposure.

Public Health Surveillance and Response		
Function Ref. #	**Current State**	**Future State**
	Biosurveillance	
SR_1 Collection of	A Minimum Biosurveillance Data Set (MBDS) that supports crucial public health functions within and among local, state and federal jurisdictions for	All jurisdictions receive a real-time feed of data from in patient and outpatient areas that permits rapid identification of problems and supports real-time

appropriate data for event detection and situational awareness	biosurveillance has been defined, along with feasibility and filtering requirements for each element in the MBDS. The MBDS was further refined to show a specific level of feasibility for each element based on timeframe for implementation.	situational reporting.
SR_2 Federal support for real-time biosurveillance	In February 2008, the CDC awarded the Accelerating Public Health Situational Awareness through HIE contract and in Nov 2007 the NHIN Trial Implementation contracts were awarded. Both contracts promote public health integration with HIEs.	All jurisdictions have a broad on-going program for real-time biosurveillance, where public health and clinical care are both benefiting from integrated reporting.
SR_3 Standards for biosurveillance are developed to support clinical care connectivity with public health	HITSP-harmonized standards to support the Biosurveillance use case are available, as is the Interoperability Specification for Biosurveillance-Connecting to Clinical Care (HITSP/IS-02). Corresponding certification criteria are pending. Technical specifications are being developed through the NHIN Cooperative. Testing of the Technical Specifications and Interoperability Specifications is scheduled for Nov 2008 to be completed via the NHIN and CDC HIE contracts.	All jurisdictions implement standards, interoperability specifications and technical specifications to assure interoperable results for systems and enhancements.
	Surveillance	
SR_4 Integration of all surveillance systems	Surveillance currently involves a set of systems that are not integrated, do not communicate with each other, and have different levels of granularity which compound the problem of real time interpretation.	All systems are fully integrated and have the ability to share information as necessary since that function is built in from initial specification and design.
SR_5 Trained and astute practitioners (this relates to workforce development as described under	Surveillance systems remain dependent on vigilant, well-trained local medical and public health officials who are sensitive to the possibility that disease cases may constitute a growing epidemic with public health implications.	Surveillance continues to be dependent on vigilant well trained local medical and public health officials but computer systems are capable of automatically aggregating data, providing information and giving real-time feedback on trends and observations which may influence pattern recognition and increase the speed with which potential issues are identified.

Health Communications		
	Case Reporting	
SR_6 Comprehensive case reporting for all diseases and conditions based on jurisdictional requirements	Case Reporting is done at all levels of public health (local, state, and national levels), and is predominantly a passive activity that waits on physicians and laboratory staff to recognize a case and then know that it needs to be reported.	Case criteria and reporting mechanisms are integrated into EHRs. Triggered by decision support algorithms, clinicians are notified that a case fits criteria for reporting to public health and automatically prepares and sends a message. For routine notifiable conditions, clinicians are prompted to approve sending cases automatically to the appropriate local/state health departments, with anonymized case abstracts sent to the Centers for Disease Control and Prevention (CDC).
SR_7 Consistent and standardized reporting of notifiable conditions	Reportable condition lists vary in accordance with law, condition incidence, and surveillance capacity in each state/territory, and the content and required timeliness of reports also varies across states. CSTE and CDC have drafted a process to define a common list of nationally notifiable conditions where CDC has requested notification from states and territories; reporting to state/territory health agencies will be based on standardized criteria for case identification as well as common and condition-specific data elements to be reported with each case or laboratory result report. The initial list of nationally-notifiable conditions will be developed by August 31, 2008.	A process exists to establish and maintain a common list of nationally notifiable conditions where notifications are sent to CDC. The associated reporting criterion for each condition is defined and an established process is followed to update case and/or laboratory result reporting criteria as needed. These criteria are applied in public health systems and clinical care systems.
SR_8 Standardized methods for PH case reporting	A Use Case for Case Reporting has been developed and standards harmonization by HITSP is scheduled for late 2008.	Standards are fully harmonized to support fully automated case reporting from EHRs. All EHRs adhere to certification criteria defined to ensure this functionality.
	Outbreak and Event Management	

SR_9 Public health systems manage complex outbreaks across geopolitical boundaries	Systems are typically designed to manage complex outbreaks only within a specific geopolitical boundary. Information for cases, contacts and potential exposures are poorly aggregated by public health. Methods for real-time tracking of these linkages are rarely available for public health authorities to know who to investigate, manage, offer prophylaxis, isolate, quarantine, and/or treat.	Response activities are integrated with on-going monitoring and outbreak investigation Public health can electronically request and receive details to support contact tracing and investigate exposure sources.
SR_10 Computer support for interpretation of clusters and outbreaks and real-time data aggregation across multiple sources	There are few systems to support interpretation of data and determining whether an outbreak is occurring. Limited data exist for computer generated definitions of cluster of events or actual outbreak. No clear guidance on data aberrations and how to initiate action or response.	Data sources feed aggregation systems that have strong analytic capacities to interpret data based on sophisticated experience in reading these events. A reliable and valid automated, national system based on EHR data warns of dangers earlier and in a more targeted fashion.
SR_11 Computer systems support outbreak management	Several software solutions for outbreak management are in use and under development (e.g. CDC's OMS and state or commercially-developed systems) but few have been fully tested or routinely used by local and/or state jurisdictions.	Collaboratively developed software has been tested and deployed to support local, state and federal public health officials to monitor outbreaks and fully integrate and share data during an incident and across jurisdictions.
	Laboratory Response	
SR_12 Electronic laboratory reporting is a standard expectation of all clinical systems	Public health has implemented or been the recipient of electronic laboratory reporting (ELR) for laboratory confirmed notifiable diseases in a limited number of jurisdictions for relatively few healthcare providers. There are even fewer providers capable of exchanging information on test ordering	EHR systems automatically send lab orders while laboratory systems send test results back to EHR. All orders are electronically processed. Both of these systems are capable of sending orders and results to public health agencies and other authorized providers as necessary.
SR_13 Standards are	The AHIC prioritized laboratory results reporting for EHRs and the HITSP Interoperability Specification for Electronic Health Record-Laboratory Results Reporting (HITSP/IS-01) and	Fully tested, vetted and next generation standards are implemented in all EHR and laboratory information systems.

established for ELR	has been recognized by the Secretary. Technical specifications are being developed through the NHIN Cooperative. Testing of this specification is underway with the NHIN Trail Implementation contract.	
	Countermeasure Allocation, Tracking, Distribution and Administration	
SR_14 Integrated applications manage pharmaceutical stockpile, assess hospital utilization, staffing, bed availability, allocate and distribute medical supplies and drug products,	No integrated applications exist for these functions. Limited applications exist to support intervention (including isolation and quarantine), management, acquisition and allocation of supportive countermeasures (e.g., treatments, prophylaxis, and provisions) during a public health response.	Applications are implemented that adhere to harmonized standards and provide on-going awareness of supply and demand of drug products, medical personnel and hospital capacity (beds, ICU). Tracking activities monitor for shortages and apportion countermeasures during a shortage; tools support administrative management, distribute resources, and coordinate potential assets through the commercial sector supply chain.
SR_15 Standards are established and implemented for tracking hospital utilization	A number of standards and applications have been developed but are minimally implemented. Hospital Availability Exchange (HAVE) draft specification for exchange of hospital utilization data, has been proposed but no commercial systems support these standards or produce canned reports. The Biosurveillance Minimum Data Set (BMDS) includes data elements for hospital resource utilization.	All health care facilities, commercial sector supply chain and the national stockpile are fully interoperable and sharing real-time information to support interventions and response capacity. Information is aggregated from each hospital facility for bed capacity and resource monitoring at a regional and national level. Systems are integrated with on-going monitoring and outbreak investigation for a complex picture. Data can be extracted or “drilled down’ for more granular views by jurisdiction and facilities throughout an entire outbreak.
SR_16 Immunization tracking systems are readily integrated in	An Immunizations and Response Management use case has been developed and is scheduled for harmonization by late 2008. A limited number of immunization information systems (IIS) include this functionality currently. Relatively few EHRs	EHR and IIS are capable or tracking and informing clinicians and public health practitioners of individuals who need to receive countermeasures. Systems are capable of managing administration of countermeasures and have the ability to electronically exchange

jurisdiction-specific pictures for countermeasure monitoring	are fully integrated and have bidirectional information sharing with IIS.	information about populations relative to receipt of countermeasures and the exchange of resource and supply chain data among public and private sectors. EHRs are fully integrated and interoperable with immunization registries.
	Patient Safety Events (Details are provided in Appendix III)	
SR_17 Improved voluntarily reporting of patient safety events and quality of care based on standardized data collection.	The Secretary of the Department of Health and Human Services requested AHRQ to coordinate the development of common definitions and reporting formats (Common Formats) for patient safety events.	The Patient Safety Act is intended to apply to all settings of care, and AHRQ intends to promulgate Common Formats for settings beyond the hospital. AHRQ will develop Common Formats to address all four phases of the improvement cycle (initial reporting, root cause analysis, implementation of improvement action, and evaluation of effectiveness), thus supporting data aggregation, analysis, and learning throughout the cycle
	Maternal and Child Health (Details are provided in Appendix IV)	
SR_18 Improved maternal and child health surveillance	Maternal and child health systems are largely not integrated, do not receive data electronically from data providers and lack data and technical standards across systems. Data and information is typically not available to be shared electronically with clinicians.	Surveillance data, health status data and appropriate case management data on individuals from 9 months prior to birth through age 18 is electronically sent to public health agencies through HIEs in standardized formats. MCH data systems will use appropriate data standards to ensure integration of MCH public health databases. Appropriate data will be shared with clinicians, case managers and other care providers.

Table 3: Surveillance & Response Current and Future State

Remaining Priority Areas to be Addressed and Recommended Transition

The remaining priorities section describes the gaps between the current and future state, and the actions that should be taken to continue progress toward the future vision. The actions are organized by area within the applicable population health construct. For public health surveillance and response, this includes the areas that have already been identified: case reporting, outbreak and event management, laboratory response and countermeasures; as well as any additional areas that have been identified by the workgroup as requiring action to advance HIT-enabled population health.

Each priority is identified as near-term (within 1 year) or intermediate-term (2-5 years). The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 3 above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix II. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Public Health Surveillance and Response				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term/ Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	Case Reporting				
16.	Follow-up on approval of on-going process used to establish a common list of nationally notifiable conditions and delivery	Follow-up		Mar 07 – Rec. 2.0 & 2.1 (PHCCC2.0.032007 & PHCCC2.1.032007)	CSTE with CDC

	of first set of case definitions.				
17.	Complete process to harmonize standards (data, technical, and interoperability) for notifiable disease case reporting.	Follow-up		Mar 07 – Rec. 2.2 (PHCCC2.2.032007)	Successor
18.	Include certification criteria for automated case reporting of Nationally Notifiable conditions in electronic health records by 2009.	Follow-up		Mar 07 – Rec. 2.3 (PHCCC2.3.032007)	Successor
19.	Convene a meeting to determine a process for defining requirements and implementation criteria for supporting automated case reporting from electronic health records.	Follow-up		Mar 07 – Rec. 2.3 (PHCCC2.3.032007)	HHS
20.	Develop a business case for automated electronic Case Reporting.	Follow-up		Mar 07 – Rec. 2.5 (PHCCC2.5.032007)	HHS, with partners providers, and private industry
	Outbreak and Event Management				
21.	Undertake a program to gather requirements, identify standards, develop and disseminate Outbreak and Event Management Systems (OEMs) to state and local public health agencies.	Follow-up		Jan 08 – Rec. 3.0 (PHCCC3.0.012008)	CDC with state, local and lab partners
22.	Develop a nationwide network of OEMs.	Follow-up		Jan 08 – Rec. 3.1 (PHCCC3.1.012008)	CDC with state, local and lab partners

23.	Harmonize standards for integration of EHRs and NHIEs with systems that support Outbreak and Event Investigation.	Follow-up	SR_11	Jan 08 – Rec. 3.1 (PHCCC3.1.012008)	Successor
	Laboratory exchange				
24.	Undertake a national program to enable public health laboratories to exchange data with other public health laboratories, public health partners, NHIEs and CCHIT certified EHRs.	Follow-up		Jan 08 – Rec. 4.0 (PHCCC4.0.012008)	CDC with state, local and lab partners
25.	Collaboratively develop certification criteria for EHRs and NHIEs to support sending Test orders to and receiving result reports from public health labs, coding public health conditions in the HITSP lab message, including veterinary and environmental data in result reporting and unambiguously linking lab data to clinical and public health records.	Follow-up		Jan 08 – Rec. 4.0 (PHCCC4.0.012008)	Successor
26.	Develop the infrastructure and architecture for unambiguous unique identification of medical service providers in association with the Nationwide Health Information Network (NHIN) initiative.	Follow-up		Jan 08 – Rec. 4.1 (PHCCC4.1.012008)	HHS, with state and regional health information exchanges, public health and clinical laboratories

27.	Establish regional or national capabilities to receive and route public health laboratory results to all appropriate recipients simultaneously.	Follow-up		Jan 08 – Rec. 4.2 (PHCCC4.2.012008)	CDC with state, local and lab partners
	Countermeasures				
28.	Undertake a program to gather requirements, identify standards, develop and disseminate systems that support countermeasure apportionment, tracking, distribution, administration, and outcomes measurement at local, tribal, state and federal levels.	Follow-up		Jan 08 – Rec. 5.0 (PHCCC5.0.012008)	CDC with state, local and lab partners
29.	Convene a meeting to understand available resources and develop strategies to exchange information on the availability of, demand for, and uses of countermeasure related resources.	Follow-up			CDC with state and local partners, clinical care and private sector
30.	Create a nationwide network of interoperable countermeasure tracking and administration systems.	Follow-up		Jan 08 – Rec. 5.2 (PHCCC5.2.012008)	CDC with state and local partners
31.	Harmonize standards for integration of EHRs and NHIEs with systems that support Countermeasure Allocation, Tracking, Distribution and Administration.	Follow-up	SR_11	Jan 08 – Rec. 5.2 (PHCCC5.2.012008)	Successor

32.	Facilitate development of nationwide administrative or legal approaches for routine and emergency inter-state data exchange of countermeasure and immunization information.	Follow-up		Jan 08 – Rec. 5.3 (PHCCC5.3.012008)	HHS
	Maternal and Child Health				
33.	Prioritize development of a use case to implement exchange of data to improve maternal and child health, covering from 9 months before birth, through the birth event to 18 years of age.	Near-term	SR_18		Successor
34.	Consolidate or integrate the various component MCH systems currently in use at the local /state health department, and exchange of information between these systems and EHRs and HIEs.	Intermediate-term Additional activities for MCH are described in Appendix IV	SR_18		HHS with appropriate state and local partners
	Other				
35.	Annual evaluation of percentage of public health laboratories that are exchanging bidirectional data with clinical care HIT systems.	Near-term			Governmental Agency
36.	Development and Publication of logic for expanded set of public health diseases, including behavioral health conditions.	Intermediate term			CSTE with CDC

Table 4: Surveillance & Response Priority Activities

Health Status and Disease Monitoring (HS)

Health status and disease monitoring involves the accurate, periodic assessment of community and patient level health status, identification of health risks (determinants of health and functional status), and determination of health service needs.

Health Status and Disease Monitoring		
Function Ref. #	**Current State**	**Future State**
	Assessment	
HS_01 Health indicators available in EHRs	Data collection for health status monitoring is done predominantly through manual labor-intensive chart reviews or paper reporting. Data may not be available or accessible to measure certain community health issues and disparities. Public health researchers and planners often need to identify acceptable measurement indicators to serve as proxies of root causes of health problems.	Indicators that more accurately measure root causes of population health problems are available through access to standardized data in EHRs. Ability to measure HIT-facilitated and HIT-enabled indicators includes: • EHR-facilitated: Measures that while not conceptually limited to EHRs, would not otherwise be feasible to measure. • EHR-enabled: Measures that generally would not be possible outside of EHR context.
HS_02 Co-morbidity	Many of the existing systems for measuring and monitoring health status are disease and condition specific and do not take co-morbidity into account.	Co-morbidity is addressed in the surveillance of diseases and conditions, in the identification of tailored treatment recommendations, the identification of preventive measures, and a more complete understanding of the causal relationships among multiple risk factors associated with co-occurring diseases.
	Assurance	

HS_03 Using registries to provide equitable healthcare	Most population-based registries do not include a complete census of the population, but rather includes those individuals in a population who have certain inclusion criteria. Similarly, EHRs contain data on only those patients receiving care in a community. It is difficult to identify patients and communities most in need of services.	Population registries and EHRs can be used to identify individuals and communities with barriers to personal health services, and the health needs of those individuals and communities. Public health planners can use this information, together with clinicians and community leaders to identify, create, enhance and link individuals and communities to needed population and clinical health services.
	Policy Development	
HS_04 Population level information available for decision making	Public health planners at the local, state and federal level have no evidenced-based, technology-enabled means to review, monitor, compare and prioritize population health problems and interventions over time.	Population-level decision support for local, state and federal health planners is available and used to review, monitor, compare and prioritize population health problems. Evidenced-based decision support is used to by public health agencies to prioritize population health problems, develop policy and allocate funding.
	Survey ***Research and Surveillance***	
HS_05 Standardization of measures	Many existing surveys and surveillance systems gather data on the same problem using different, but equally valid, measures. Lack of standardization in measurement has lead to challenges combining data for analysis from different sources, difficulties with system integration and inaccurate conclusions.	Improved ability to compare data from different sources by standardizing EHR content and requirements for the inclusion of specific covariates, such as race and ethnicity. Standardized data collection processes for more timely and accurate data collection.
HS_06 Achieving statistical sampling	Health status data collection efforts must contain enough cases for many demographic groups to allow for meaningful comparisons. Many health surveys must oversample groups that otherwise would not be well represented in a simple random sample, allowing for comparisons of disease relevance by ethnicity group or age group, for example. Currently,	Near universal participation in EHRs removes some barriers to using EHRs to monitor health status because the population can be fully represented in the data.

	EHR data is often not a statistical sample because data are from a biased set of participants in certain health care settings.	
	Registry Development	
HS_07 Death Certificates	While progress is being made in the area of electronic death reporting, significant challenges remain including standardization of death certificates and necessary infrastructure developments.	Electronic birth and death registries are functional in every state. Births and deaths are reported electronically to public health agencies. Standards are adopted to support reporting from EHRs through HIEs.
HS_08 Standards adoption for registries	Considerable variability exists in the use of adopted standards in population-based registries. Registries such as immunization registries have made significant progress in the adoption of standards. However, many EHRs lag behind in the use of certain standards already adopted by public health. In other cases, population health registries lag behind EHRs in standards adoption.	Standards used in registries and EHRs are harmonized to allow for seamless bi-directional data exchange between public health and clinical systems.
HS_09 Integration of registries with EHRs	Registries are often stand-alone or not fully integrated into EHRs. Clinicians are now starting to use electronic health records to support disease and other registries that monitor and manage the care of individual patients within their practices, and for the essential integration of population-based medicine with delivery of individual patient health care services.	Population health registries are integrated with EHRs and support appropriate bi-directional communications and public health decision support. Additionally, information exchange is supported across same-type registries.

Table 5: Health Status & Disease Monitoring Current and Future State

Remaining Priority Areas to be Addressed and Recommended Transition

The remaining priorities section describes the gaps between the current and future state, and the actions that should be taken to continue progress toward the future vision. The actions are organized by area within the applicable population health construct. For heath status and disease monitoring, this includes the areas that have already been identified: integration with registries, and immunization registries; as well as any additional areas that have been identified by the workgroup as requiring action to advance HIT-enabled population health.

Each priority is identified as near-term (within 1 year) or intermediate-term (2-5 years). The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 5 above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix I. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Health Status and Disease Monitoring				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term/ Follow-up on existing recommendation**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
	Assessment				
37.	Guided by Health People 2010 and 2020, identify specific indicators and data elements essential to monitor population health and gaps	Near-term	HS_01		HHS, States and Locals

	in availability of this data in EHRs. Gaps should include indicators for co-morbidities used to inform surveillance methodology.				
	Policy Development				
38.	Assess business processes and develop requirements for population-based decision support that informs population health policy makers.	Near-term	HS-04		HHS, States and Local – Related
	Survey Research and Surveillance				
39.	Inclusion of population health measurement requirements in HIT systems	Intermediate-term	HS_05		Successor
	Registry Development				
40.	Harmonize standards for integration of EHRs and NHIEs with Immunization Information Systems (IIS)	Follow-up	HS_08	Jan 08 – Rec. 6.1 (PHCCC6.1.012008)	Successor
41.	Harmonize standards for integration of EHRs and NHIEs with Surveillance Registries and Disease Registries that extend beyond IIS's	Intermediate-term	HS_08		Successor
42.	Conduct gap analysis between data elements needed to support population health registries (e.g.., immunization, asthma, cancer, lead, etc.) and data elements that are currently available in EHRs.	Near-term	HS_08		Successor
43.	Develop roadmap to leverage HIT expansion for vital statistics registries including electronic	Near-term	HS_07		FACA

	reporting of death from EHRs and NHIEs.				
	Other				
44.	Describe business requirements to support health status and disease monitoring. These should include reporting requirements to generate population health reports at the local and regional levels.	Near-term			HHS with States and Locals

Table 6: Health Status & Disease Monitoring Priority Activities

Health Communications/Education (HC)

Inform, educate and empower providers, consumers and others about health and wellness issues and promote self-management by the individual and the population by providing health information, health education, and health promotion activities designed to reduce health risk, promote better health, and improve and/or maintain health and functional status using methods such as health alerts, websites, collaboration forums, and risk communications. Communications include development and dissemination of business cases to articulate the benefits of automated data/information exchange between public health and clinical care.

Health Communications/Education		
Function Ref. #	**Current State**	**Future State**
HC_1 Educate the public about the benefits of biosurveillance	Communication materials have been developed to educate the general public about the information that is used for biosurveillance including the benefits to the public's health, improved national security, and the protection of patient confidentiality.	Consumers, when given the choice, elect to include their information for use in biosurveillance; reflecting an understanding of the benefits of information sharing for biosurveillance.
HC_2 Provide individualized health education messages	Health education messages are not able to efficiently identify and deliver information to patients who could benefit from knowledge gained from community-level data.	Individualized health education messages based on community-level data are made available through EHRs, PHRs, websites and other health information systems. Health education messages help to promote self-management by the individual.
HC_3 National-level health education campaigns	Some national-level campaigns such as from CDC, Ad Council, etc. are targeted to specific at-risk populations.	Health educational campaigns exist that better targeted at-risk groups, populations or geographic regions.
HC_4 State-level health education campaigns	State-level campaigns to address state-specific population health issues: • State level systems such as immunization registries in Washington State that also produce age-specific health educational materials for parents.	Health education campaigns targeted to state-specific population health issues.
HC_5 Local-level health education campaigns	Local level campaigns to address specific health issues.	Health education campaigns targeted to issues predominant in a community.

Table 7: Health Communications/Education Current and Future State

Remaining Priority Areas to be Addressed and Recommended Transition

The remaining priorities section describes the gaps between the current and future state, and the actions that should be taken to continue progress toward the future vision. The actions are organized by area within the applicable population health construct. For health communications/education, this includes the areas that have already been identified: health communications for biosurveillance, business cases, and website for standards; as well as any additional areas that have been identified by the workgroup as requiring action to advance HIT-enabled population health.

Each priority is identified as near-term (within 1 year) or intermediate-term (2-5 years). The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 7 above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix I. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Health Communications/Education				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
45.	Collaborate with PHC workgroup successor activities to provide health promotion and health education	Near-term	HC_2		Successor

	materials to PHRs, clinical care and public health.				
46.	Prioritize development of criteria to be used .by PHRs and EHRs to provide educational materials to patients, providers and public health.	Intermediate-term	HC_2		Successor
47.	Assess and understand how to use EHRs and PHRs to conduct campaigns at the national, state and local levels designed to target predominant population health issues at each level. Campaigns help to promote self-management at the individual and population levels.	Near-term	HC_3, HC_4 & HC_5		Governmental Agencies

Table 8: Health Communications/Education Priority Activities

Population-Based Research (RE)

Population-based Research focuses on new insights and innovative solutions to health problems on a population level to ensure that all people, especially those who experience health disparities, will achieve their optimal lifespan and experience the best possible health in every stage of life.

Population-Based Research		
Function Ref. #	**Current State**	**Future State**
RE_1 Support for population-based research	Support for operational public health practice research is minimal.	The benefits to care derived from population-based research are recognized and supported.
RE_2 Collaboration between organizations supporting Population-based Research	Limited linkages exist between public health and research institutions and other institutions of higher learning.	Public health, research institutions, and academic institutions share information and work collaboratively to advance population-based research.
RE_3 Infrastructure to support research	Infrastructure, policies and internal capacity for epidemiologic, economic analyses and health services research is disorganized and poorly supported.	Population-based research agenda is enabled by EHR's and health information exchanges.
RE_4 Strategy to use HIEs	No effective strategy is in place to use HIE to support evaluation of health service effectiveness.	Strategy is developed and implemented to support evaluation of health service effectiveness.
RE_5 Access to data	Limited access to data exists to perform research that informs the understanding of mechanisms of disease.	Policies and authorizations are in place to support usage of clinical data for population-based research.
RE_6 Harmonization of standards	A number of standards activities in health care information and in clinical research practices have been independently advancing but there has been little organizational effort to coordinate these efforts.	Standards are harmonized: • To aggregate sufficient information across partners such that research findings lead to informed healthcare decisions

		• For timely safety surveillance on a global scale • To link biomarkers (including an individual's genetic markers) to population characteristics and outcomes

Table 9: Population-based Research Current and Future State

Remaining Priority Areas to be Addressed and Recommended Transition

The remaining priorities section describes the gaps between the current and future state, and the actions that should be taken to continue progress toward the future vision. The actions are organized by area within the applicable population health construct.

Each priority is identified as near-term (within 1 year) or intermediate-term (2-5 years). The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 9 above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix I. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Population-Based Research				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term**	**Cross-refer. from Current State /Future**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**

			State	Tracking #	
48.	Define the scope of how health information technology can be used to advance population-based research; and prioritize development of the associated use case.	Near-term	RE_3		Governmental Agency
49.	Collaborate with the Clinical Research activity to ensure that population-based research standards are included for standards harmonization.	Near-term	RE_6		Successor

Table 10: Population-based Research Priority Activities

Population-Based Clinical Care (CC)

Population-based clinical care places the care and health information of an individual patient within the context of the larger community and population which is comprised of both sick and healthy individuals.

Population-Based Clinical Care		
Function Ref. #	**Current State**	**Future State**
CC_1 Fully functional population-based clinical care system	Clinicians, clinical practices and health systems who want to implement population-based clinical care using community-level data are challenged to find data sources. Local level data for population estimates on issues such as immunization rates, communicable disease, diabetes, or coronary artery disease is often not available or difficult to obtain. Identifying issues of highest priority in a community may also be difficult.	Supported by a modernized infrastructure and bi-directional communications, population-level data flows bi-directionally between public health and clinical care settings and between public health and the patient (e.g. air quality alerts). Public health is able to collect patient-level data, perform analysis, and return population-level information on community health status. In turn, this information is incorporated into the clinical decision support system to allow clinicians, within their workflow, access to the right information about the population at the right

		time.
CC_2 Population-based information available at the time of care	Clinicians practicing population-based medicine often focus on the population served within their practices but may know little about patients outside of their practices, especially the medically underserved and populations suffering from health disparities.	Access to on the fly population-based queries enables clinicians to include information about communities and populations within the EHR clinical data display. This information ensures that providers are aware of population based factors affecting their patients on a daily basis, such as high levels of arsenic in drinking water in their communities.
CC_3 Health assessments done as part of routine care to benefit public health	Population health assessment, priority setting and tracking is the cornerstone to population-based clinical care. These activities occur at all jurisdictional levels, often with governmental public health as the lead organization. Through the Healthy People Process at the national level, priorities and goals are set at the beginning of each decade and national funding and policy efforts are focused on achieving those goals. Most, if not all, states conduct a similar process. Many states and local communities use Healthy People as a starting point and modify the priorities and goals as appropriate for their populations.	Measurement of Healthy People indicators, widely used by all jurisdictional levels, is supported by EHRs and HIEs. Data necessary for measuring each indicator is contained in a standard format in all EHRs. Anonymized data is transmitted to appropriate public health authorities or other appropriate entities automatically for ongoing measurement of trends.
CC_4 Current public health information and alerts available at time of care	Current electronic health records provide information that is patient and provider centric. This inability to provide population based data at the point of care impedes clinicians' abilities for quality of care evaluation, as well as early situational awareness of potential disease threats to populations.	Public health and EHR systems are integrated to provide timely public health alerts from public health to providers at the point of care, such as an alert about a foodborne outbreak that includes signs and symptoms, recommended laboratory tests and recommended treatment quality

Table 11: Population-based Clinical Care Current and Future State

Remaining Priority Areas to be Addressed and Recommended Transition

The remaining priorities section describes the gaps between the current and future state, and the actions that should be taken to continue progress toward the future vision. The actions are organized by area within the applicable population health construct.

Each priority is identified as near-term (within 1 year) or intermediate-term (2-5 years). The *Cross-Reference from Current State/Future State* column shows if the priority aligns with a line item in the Current State/Future State Table 11 above. The *Cross-Reference to AHIC PHCCC Recommendation Letter and Status Tracking #* column is used if the priority is related to a recommendation made by the PHCCC workgroup to AHIC. This column includes both the date the recommendation letter was accepted by AHIC as well as the recommendation number that links the recommendation to its status in Appendix I. The recommended Responsible Party for each priority indicates if this work would be assumed by the AHIC successor, governmental agencies, or a FACA committee.

	Population-Based Clinical Care				
	Priority Areas to be Addressed and Recommended Transition				
	Activity	**Near-Term / Intermediate-term**	**Cross-refer. from Current State /Future State**	**Cross-Refer. To AHIC PHCCC Recs. Letter and Status Tracking #**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
50.	Define scope of information resulting from analysis of community health status and surveillance, to be integrated into the clinical electronic health record to support improved delivery of patient care for members of that community.	Near-term	CC_3		Governmental Agency
51.	Prioritize development of a Population-based Clinical Care use case and interoperability specifications to include decision	Near-term	CC_1,CC_2 CC_3,CC_4		Successor

	support triggers for patient care into EHRs that are based on community-level assessments of a population.				

Table 12: Population-based Clinical Care Priority Activities

Appendix I – Cross-reference of population-health construct to recommendations

Appendix II - PHCCC and Biosurveillance Recommendations' Status

Appendix III – Maternal and Child Health

Appendix IV – Patient Safety Events

Appendix V – List of Examples National, State and Local Surveys

---

[i] Overview Population Health and HIT, Terry Cullen, *Indian Health Service*, http://www.hhs.gov/healthit/documents/AHICBinder103106.pdf

[ii] *Committee for the Study of the Future of Public Health; Division of Health Care Services. The Future of Public Health*, 1988.

[iii] Minnesota eHealth. *Population Health and the Public Health Information Systems Work Group Definitions, Conceptual Model, and Principles Working Approach. Minneapolis, MN: Minnesota eHealth. 2008, May, 2: 4.*

[iv] Weiss K. Part I. A look at population-based medical care. *Dis Mon.* 1998 August; 44(8):353-69.

[v] Association of Medical Colleges. *AAMC contemporary issues in medicine: medical informatics and population health; medical school objectives report II.* Washington, DC: Association of American Medical Colleges, 1998; June.

Appendix I

Cross-reference from constructs to existing PHCCC recommendations

Overarching AHIC Recommendations made to promote progress toward future state

Recommendations that are overarching for population health were accepted by AHIC in March 2007. These covered the areas of bi-directional communication, a business case for including public health as an integral partner in health information technology activities, an authoritative website for standards, public health support for HITSP, public health system certification, and integration with HIEs. A recommendation was also accepted in January 2008 that provides clarification for, and endorses use of, preparedness and other funds for building infrastructure in public health agencies and laboratories. The recommendation included development of program metrics to assess the ability of public health information systems to interoperate and support public health investigation and response.

A cross-reference to the numbering schema used in the Current Status Spreadsheet found in Appendix II is provided below in Table 1.

Date of Letter / *Subarea*	**March 2007**	**January 2008**
Workforce Development		PHCCC1.0.012008
Program Metrics & Infrastructure Development		PHCCC2.0.012008
Bi-directional Communications	PHCCC1.5.032007 PHCCC1.6.032007 PHCCC3.0.032007 PHCCC3.1.032007 PHCCC3.2.032007	
Public Health support for HITSP	PHCCC1.1.032007	
Public Health system certification	PHCCC1.2.032007	
Integration with HIEs	PHCCC1.3.032007 PHCCC1.4.032007	

Business Cases **Website for Standards**	PHCCC1.0.032007 PHCCC1.7.032007	

Table 1- Cross-reference of Overarching Recommendations to Current Status Spreadsheet

Public Health Surveillance and Response AHIC Recommendations made to promote progress toward future state

AHIC accepted recommendations for biosurveillance in May 2006. The May 2006 set included a recommendation to form a Biosurveillance Data Steering Committee. Recommendations from the Biosurveillance Data Steering Committee were submitted to and approved by AHIC in October 2006. In March of 2007, AHIC approved recommendation for Case Reporting. Following this, the workgroup focused on response management recommendations which were initially presented in September 2007. At this time AHIC made a request that the workgroup reconvene to define a more tactical timeline for implementation of the broad visionary recommendations for response management. Updated response management recommendations, along with a roadmap developed by the CDC, were presented and accepted by AHIC in Jan 2008.

A cross-reference to the numbering schema used in the Current Status Spreadsheet found in Appendix II is provided below in Table 2.

Date of Letter / *Subarea*	**May 2006**	**October 2006**	**March 2007**	**January 2008**
Biosurveillance	BSV1.0.052006 BSV1.1.052006 BSV1.2.052006 BSV2.0.052006 BSV3.0.052006 BSV4.0.052006	BDSG1.0.102006 BDSG1.1.102006 BDSG1.2.102006 BDSG2.0.102006 BDSG3.0.102006		
Case Reporting			PHCCC2.0.032007 PHCCC2.1.032007 PHCCC2.2.032007 PHCCC2.3.032007	
Outbreak and Event Management **Laboratory Response**				PHCCC3.0.012008 PHCCC3.1.012008 PHCCC4.0.012008 PHCCC4.1.012008 PHCCC4.2.012008
Countermeasures				PHCCC5.0.012008

				PHCCC5.1.012008 PHCCC5.2.012008 PHCCC5.3.012008

Table 2 -Cross-reference of Public Health Surveillance and Response Recommendations to Current Status Spreadsheet

Health Status and Disease Monitoring AHIC Recommendations made to promote progress toward future state

Recommendations for Integration with Registries and Immunization Registries were a component of the response management recommendations initially presented in September 2007. At this time AHIC made a request that the workgroup reconvene to define a more tactical timeline for implementation of the broad visionary recommendations for response management. Updated response management recommendations, along with a roadmap developed by the CDC, were presented and accepted by AHIC in Jan 2008.

A cross-reference to the numbering schema used in the Current Status Spreadsheet found in Appendix II is provided below in Table 3.

Date of Letter / ***Subarea***	**January 2008**
Integration with Registries	PHCCC6.0.012008
Immunization Registries	PHCCC6.1.012008

Table 3: Cross-reference of Health Status and Disease Monitoring Recommendations to Current Status Spreadsheet

Health Communications and Education AHIC Recommendations made to promote progress toward future state

A recommendation to educate the general public about the information that is used for biosurveillance including the benefits to the public's health, improved national security, and the protection of patient confidentiality was accepted by AHIC in May 2006. The March 2007 AHIC letter contained an important

recommendation for developing a business case for data/information exchange between public health and clinical care as well as develop a communications plan to improve the understanding of the need for this exchange. The March letter also recommended development of a Website for Standards. The need for workforce development was articulated in the Jan 2008, which has been accepted by AHIC.

A cross-reference to the numbering schema used in the Current Status Spreadsheet found in Appendix II is provided below in Table 4.

Date of Letter / ***Subarea***	**May 2006**	**March 2007**	**January 2008**
Health Communications for Biosurveillance	BSV3.1.052006		

Table 4: Cross-reference of Health Communications/Education Recommendations to Current Status Spreadsheet

Appendix III - Patient Safety Events

Background and History

The PHCCC workgroup received testimony on Adverse Events at the February 2007 workgroup meeting. An Adverse Events subgroup was formed and after considerable deliberations determined that the recommendations considered by the workgroup would cause potential overlap with AHRQ's implementation of the Patient Safety and Quality Improvement Act and coordination of common definitions and reporting formats for patient safety events. This document provides an summary of the current state, future state and next step activities to advance automated integrated reporting of Patient Safety Events.

Current State

The Patient Safety and Quality Improvement Act of 2005 (Patient Safety Act) establishes a framework by which doctors, hospitals, and other health care providers may voluntarily report information on a privileged and confidential basis regarding patient safety events and quality of care. The Patient Safety Act provides for voluntary formation of Patient Safety Organizations (PSOs), which can be public or private organizations, that collect, aggregate, and analyze information regarding the quality and safety of care delivered in any healthcare setting.

In order to allow standardized data collection, the Secretary of the Department of Health and Human Services requested AHRQ to coordinate the development of common definitions and reporting formats (Common Formats) for patient safety events. AHRQ began the development process in 2005 and AHRQ plans to issue the Common Formats in August, 2008 as version 0.1 Beta, pertaining to acute care hospitals. This release date will allow potential PSOs and participating providers to see them in advance of the final regulation and, where appropriate, to offer comments on how they might be improved. It is anticipated that the regulations will be final by the end of calendar year 2008.

The Common Formats being released in August are based on: 1) an inventory of 64 reporting systems, public and private, which constitutes an "evidence base;" 2) an inter-governmental Patient Safety Work Group comprising AHRQ, CDC, CMS, FDA, HRSA, HIS, ONC, NIH, and the DoD and VA; and 3) two separate pilot tests in DoD, IHS, and VA facilities, with revisions to the Formats made after each test.

The Common Formats delineate definitional and reporting specifications that allow healthcare providers to collect and submit standardized information regarding patient safety events. Use of the Common Formats is voluntary, in recognition that reporting patient safety work product to a PSO in a standardized manner may not be initially practicable for certain providers or in certain circumstances.

The Common Formats will be released as paper forms that can be used by providers and PSOs as is, although AHRQ realizes that, over time, computer programs (developed in the private sector) will make use of the Formats more efficient. While AHRQ plans to issue new versions of the Formats annually in the form of guidance, the Agency is prepared to release the second version in less time (perhaps after 6-9 months), depending on the volume and nature of comments received from users and others.

AHRQ's Common Formats include:

- Descriptions of patient safety events and unsafe conditions to be reported
- Delineation of data to be collected for event types
- Example patient safety event reports
- An electronic metadata registry
- Paper forms to allow immediate implementation
- A user guide.

Common Formats will apply to all patient safety concerns:

- Incidents – patient safety events that reached the patient, whether or not there was harm
- Near misses (or close calls) – patient safety events that did not reach the patient
- Unsafe conditions.

The Common Formats are not an attempt to replace any current mandatory reporting system, collaborative/voluntary reporting system, research-related reporting system, or other reporting/recording system.

Envisioned Future State

The Patient Safety Act is intended to apply to all settings of care, and AHRQ intends to promulgate Common Formats for settings beyond the hospital. Such settings include:

- Nursing homes and other bedded facilities
- Ambulatory surgery centers
- Other ambulatory care settings, including community health centers, rehabilitation centers, and hemodialysis centers
- Physician and practitioner offices
- Retail establishments such as pharmacies

AHRQ's initial Common Formats addresses patient safety event reporting, the first stage in the improvement cycle. In the future, AHRQ will develop Common Formats to address all four phases of the improvement cycle(initial reporting, root cause analysis, implementation of improvement action, and evaluation of effectiveness), thus supporting data aggregation, analysis, and learning throughout the cycle:

Near Term Activities and who should be responsible for them (AHIC Successor, Government agency(ies), some other FACA)

AHRQ has issued a task order contract to the National Quality Forum (NQF) to act as a focal point for all feedback on the Common Formats. NQF will solicit public comments (including providers, professional organizations, the general public, and PSOs), triage them in terms of immediacy of importance, set priorities, and convene expert panel(s) to offer advice on updates to the formats. This process will be a continuing one, guiding periodic updates of the Common Formats.

AHRQ's Patient Safety Work Group (PSWG) will continue development of Common Formats as described above. The PSWG will provide assurance that AHRQ's formats remain in conformance with other important definitions/formats, such as CDC's definitions for healthcare associated infections and FDA's definitions for blood usage and device adverse events.

In addition, AHRQ's Common Format activities should be considered and coordinated with HITSP deliberations for Population Health TC adverse event data elements. The Common Formats address all adverse events, in particular those that are high volume and serious, with the requisite detail to meet the PHCCC standard. They provide specific definitions that have been coordinated with all other relevant agencies, provide the detail necessary for requisite analysis, and are interoperable with data that will be collected under the aegis of PSOs.

I. Contents

I. Executive Summary 2
II. Background and History 3
III. Overview of Maternal and Child Health Programs 4
A) Description of Areas of Maternal and Child Health Programs and Information Systems 4
(i) Enabling Legislation and Funding 4
(ii) Publicly Funded Insurance Programs 5
(iii) Screening and Surveillance Programs 5
(iv) Clinical and Support Services 5
(v) Programs Supporting Maternal and Child Health 5
(vi) Information Systems Supporting Maternal and Child Health 5
B) Current State, Future State, Near-term and Immediate-term Priorities 7

I. Executive Summary

The AHIC Population Health and Clinical Care Connection (PH/CCC) Workgroup was established after the Biosurveillance workgroup completed its specific charge for Biosurveillance. The PH/CCC Workgroup broadened the limited biosurveillance perspective and organized around 5 basic population health constructs 1) Public Health Surveillance and Response 2) Health Status and Disease Monitoring, 3) Health Communications and Education, 4) Population-based Clinical Care and 5)Population-based Research. In addition, overarching concepts were identified that cross the 5 domains.

The Workgroup identified four priority focus areas for 2008: bidirectional communications; registries; maternal and child health (MCH); and integration with health information exchanges (HIEs). As these four areas are broad and complex, each could encompass a full year of work. To move all four areas forward, the workgroup held several hearings with a focus on MCH with emphasis on bidirectional communications, registries and integrations with HIEs within the MCH domain

Through PH/CCC Workgroup hearings, several challenges were identified that must be addressed to ensure progress in the exchange of MCH data between clinical care and population health domains. These challenges fall into four areas: 1) Integration of MCH information systems; privacy and data sharing; funding and infrastructure support, and; standards development.

Priority activities:

1. Develop a national level agreement that could be adopted by local and state health departments to support bidirectional sharing of school health and WIC information;
2. Leverage Immunization Information System (IIS) infrastructure as a platform for integration of childe health information systems within public health, a portal to child health records for health care providers, health plans, schools, and for real-time, bi-directional sharing of child health information with provider EHRs and HIES.
3. Identify key elements of a pediatric and obstetric HER for public health, including a common core list of data elements and to identify existing standards and gaps in standards. Identified standards should be included in CCHIT certification of pediatric EHRs.

Information gathered from hearings and opportunities for progress are outlines in the following pages. The opportunity for Maternal and Child Health to benefit from advances in health information technology is great. While some work has been undertaken in this area, there is opportunity to leverage existing work and new advances to make great strides in the near-term.

II. Background and History

The Population Health and Clinical Care Connections workgroup was first founded as the Biosurveillance workgroup in November of 2005 and then expanded to include population health in Oct of 2006.

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

The Community further recommended that this workgroup develop a plan to realize a specific charge (transmitting certain data from health care providers to public health systems) within one year, which is visible to the American public and works towards a broader charge (facilitating the flow of reliable health information among population health and clinical care systems to protect and improve the public's health) over time.

The expanded scope was supported by a background document that described a working division of population health into 5 constructs:

1. Public Health Surveillance and Response
2. Health Status and Disease Monitoring
3. Health Communications and Education
4. Population-based Clinical Care
5. Population-based Research

These five constructs were seen to be overlapping and interdependent, but were selected as a way of organizing and conceptualizing a very broad field. To date, the workgroup has made recommendations in the first 3 constructs, with the greatest focus being on Public health Surveillance and Response as a natural outgrowth of Biosurveillance.

The Workgroup identified four priority focus areas for 2008: bidirectional communications; registries; maternal and child health (MCH); and integration with health information exchanges (HIEs). As these four areas are broad and complex, each could encompass a full year of work. To move all four areas forward, the workgroup held several hearings with a focus on MCH with emphasis on bidirectional communications, registries and integrations with HIEs within the MCH domain

Hearings held:

- March 5, 2008
  - Overview of maternal and child health (MCH) programs in US
  - Overview of Medicaid and State Children's Health Insurance Program (SCHIP) data needs
  - Maternal Child Health and Immunization Data Exchange Initiative Within HIS
  - Overview of MCH data needs at the Health Resources and Services Administration (HRSA)
- April 3, 2008
  - State and local MCH program needs and information systems
  - Long term management in MCH
  - Integration of MCH information systems
    - immunization registries
    - newborn screening
- May 7, 2008
  - School health
  - Vital records
  - Integration with HIEs

III. Overview of Maternal and Child Health Programs

Structure of MCH programs may vary from state to state, however, the funding sources, programs and services offered are typically similar. Federal and State programs for women and children are both clinically and non-clinically oriented, such as food and nutrition programs. A brief overview of MCH is provided below

A) Description of Areas of Maternal and Child Health Programs and Information Systems

(i) Enabling Legislation and Funding

Two major federal funding sources support MCH programs at the state and local level. Title V, The Maternal and Child Health Services Block Grant funds maternal and child health and services for children with special health needs; supplemental security income for children with disabilities; lead-based paint poisoning prevention programs; genetic disease programs; sudden infant death syndrome programs; hemophilia treatment centers; and adolescent pregnancy prevention

grants. The Title X Family Planning Program is the second major source of funding. This program is solely dedicated to providing comprehensive family planning and preventive service, with priority given to low income individuals.

(ii) Publicly Funded Insurance Programs

Medicaid and the State Children's Health Insurance Program (SCHIP) are important programs for ensuring low income women and children have access to health care services. Both programs are jointly financed by Federal and State governments. State MCH programs may partner with Medicaid and SCHIP on initiatives, and use Medicaid and SCHIP data for program planning and evaluation. A key component of Medicaid is the Early and Periodic Screening and Diagnostic Program.

(iii) Screening and Surveillance Programs

Several MCH screening and surveillance programs are in place to ensure the health of individual children and monitor trends in population data. These programs range from universal newborn screening and lead screening to pregnancy risk assessment fetal, child and infant death. Data from clinical providers is required for the success for all of these programs.

(iv) Clinical and Support Services

MCH clinical services are provided through a several venues including family planning clinics, well child clinics, school health clinics, and through services contracted to community providers. MCH programs also provide case management through a variety of programs including family case management through Medicaid and case management for at-risk infants. Since case management programs may have different funding sources, one individual or family may be eligible for or enrolled in more than one program simultaneously..

(v) Programs Supporting Maternal and Child Health

In addition to Medicaid, other programs are critical to MCH infrastructure. Vital records programs are important sources of data on births as well as infant and maternal deaths. Immunization programs provide funding for vaccines and most local health departments administer childhood vaccines at public health clinics. Most state immunization programs and some local health departments run immunization registries, which are an important sources of data for many MCH programs. The Women, Infants and Children (WIC) program is not funded through or administered by state and local MCH programs, but serve the same population. WIC is an important source of education and funding for nutritious food for low income women and children. MCH programs may partner with WIC programs on certain educational initiatives.

(vi) Information Systems Supporting Maternal and Child Health

There are many information systems in place to support maternal and child health programs and activities. Several information systems used by state and local MCH programs are specific to MCH, funded through and administered by the state program. Other systems, such as WIC, are specific to MCH, but may be funded and administered through programs outside of MCH programs. Still other information systems important to MCH infrastructure, such as vital records systems and immunization registries, are important information systems for many stakeholders including MCH but are not funded through or administered by MCH programs. The level of integration of MCH systems is minimal and dependent on the state and/or local initiatives in this area.

Table 1: MCH Program Areas and Information Systems

Area	**Programs** **P= Primary MCH activity** **S= Supporting MCH activity**	**Supporting Information Systems**
Policy and Funding	• Title V (P) • Title X (P)	• N/A
Publicly Funded Insurance Programs	• Medicaid (S) • SCHIP (S) • Medicaid Expansion (S)	• Medicaid Management Information System (MMIS)

Screening	• Newborn Screening (P)
	  o Metabilic Screening (P)
	  o Universal Newborn Hearing Screening (P)
	• Blood Lead Screening (P)
	• EPSDT (S)
		• Lead registries
		• Newborn screening registries
		• Newborn hearing screening registries

Surveillance Programs	• Pregnancy Assessment and Monitoring System (PRAMS) (P) • Fetal and Infant Mortality Review (FIMR) (P) • Child Death Review (CDR) (P) • Vital statistics (S) • Birth defects	• Congenital malformation registry • Electronic Birth Certificate • Electronic Death Certificate
Clinical and Support Services	• Family case management (P) • Pediatric primary care (P) • School health (S)	• Case management tracking systems • Public health clinic management systems and EHRs • School health information systems

Area	Programs P= Primary MCH activity S= Supporting MCH activity	Supporting Information Systems
	• Family planning (P) • WIC (S) • Immunization (S)	• WIC management information systems • Immunization Information Systems (IIS) (also know ask Immunization Registries)

B) Current State, Future State, Near-term and Immediate-term Priorities

This section contains information on the current state of MCH information systems and data exchange and a synopsis of the desired future state. This section also contains a number of recommended priority areas to be addressed in the immediate-term and near-term and the recommended transition for each priority area.

Ref. #	Issue / Current State	Future State
MCH_1 Integration of MCH Information Systems	Some states are integrating data from early childhood programs such as WIC, early intervention programs, and Medicaid. Very few places have integrated information systems for more than two or three program areas. The most common registry system that is integrated starts with an Immunization Information System (IIS).	The integrated information systems are capable of producing a consolidated record, The exchange of health information is bi-directional. The information needed is available to authorized recipients in “real time”, i.e. at the point of service provision versus retrospectively. This functionality of the information systems is “seamless” regardless of the hardware and software of each user.
MCH_ 2 Privacy and Data Sharing	Data exchanges with schools remains problematic for public health agencies. Schools in many locales have gained access to immunization registries but FERPA presents barriers to public health and healthcare providers gaining access to school-based health records	Barriers in FERPA to sharing necessary data between schools, public health and clinicians are removed, allowing for continuity of care regardless of the service setting, and access to aggregate data for public health analysis.

Ref. #	Issue / Current State	Future State
	FERPA can be more of a barrier than HIPAA in the exchange of information. In local jurisdictions, data exchange agreements or memorandums of agreement are developed that addresses some of these issues.	
MCH_3 Funding and Infrastructure Support	Lack of dedicated funding for integration of data systems – Maternal and child health programs will require additional financial support to convert to a new generation of standards-based systems. Many of the existing systems are antiquated and unable to be modified to reside in an integration environment and cannot be made to interpret standards-based messages. Without additional funding, a reduction in direct services will result.	Developing an integrated data exchange system between public programs long term financial savings will result through reduction in duplication in effort and a streamlined approach to care delivery.
MCH_4 Standards Development for Pediatric EHR to Support Population Health	CCHIT has released guidance for ambulatory pediatric HIT systems in 2008. however, there has been little additional work completed regarding traditional "standards development" for integrated child health information systems (ICHIS). Because of the variation in the ways maternal and child health programs are organized within public health agencies, there remains some confusion over exactly what "MCH systems" includes. Initial work has been completed on the contents of the public health pediatric medical conception through 5 years of age.[i]	A fully defined public health pediatric EHR specification is developed, with appropriate standards identified. These standards will be included as a certification requirement for pediatric EHR products.

Priority Areas to be Addressed and Recommended Transition

Activity	**Near-Term / Intermediate-term**	**Cross-refer. from Current State /Future State**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
Overarching			
Ensure relevant Federal Enterprise Architectures meet MCH needs (e.g. new Medicaid MITA is able to meet needs of public health)	Near-term	MCH_1	Government
Develop a national level agreement that could be adopted by local and state health departments to support bi-directional sharing of school health and WIC information.	Near-term	MCH_1 MCH_2	Government
Identify a mechanisms for sustained funding of MCH information technology that encourages development of integrated systems and discourages development of stovepiped systems.	Near-term	MCH_3	Government (federal, state and local)
Infrastructure – Support for Bi-directional Communication and Integrated MCH Systems			
Leverage Immunization Information System (IIS) infrastructure as a platform for integration of child health information systems within public health (MCI), a portal to child health records for health care providers, health plans, schools (Online Registry), and for real-time, bi-directional sharing of child health information with provider EHRs, HIEs (Web services)	Near-term	MCH-1	Government
HHS in collaboration with HRSA/MCHB, relevant CDC programs and the Association of Maternal and Child Health Programs (AMCHP), should define which functions and responsibilities fall within the MCH reference and, based on this definition, which aspects of automation of those functions should be considered targets for integration.	Immediate-term	MCH_4	Government Other

Activity	**Near-Term / Intermediate-term**	**Cross-refer. from Current State /Future State**	**Responsible Party** • **Successor** • **Governmental Agency** • **FACA** • **Other**
Integration with EHRs and HIEs			
Identify key elements of a pediatric and obstetric EHR for public health, including a common core list of data elements and to identify existing standards and gaps in standards. Identified standards should be included in CCHIT certification of pediatric EHRs.	Near-term	MCH-4	Government Other (HITSP, CCHIT)
Case Management			
Identify requirements for integrated case management across MCH programs.	Immediate-term	MCH_4	Government
School Health			
Explore how to reduce barriers to exchange of pediatric data between public health, pediatric providers and public health, especially barriers created by FERPA.	Immediate-term	MCH_2	Government
Women, Infants and Children			
Explore how to reduce barriers to exchange between and Women Infants and Children (WIC) systems and other MCH systems created by WIC regulations and funding mechanisms	Immediate-term	MCH-2	Government

Partnerships

The Association of Maternal and Child Health Programs (AMCHP), the American Immunization Registry Association (AIRA), the American Academy of Pediatrics, the American Academy of Family Physicians and Birth Defects Research for Children, Inc. are all organizations that should be consulted on maternal and child health informatics. Additionally, the National Association of Chronic Disease Directors includes among its members the state directors of public health chronic disease programs, all of whom deal with aspects

of child health. All of these organizations represent leaders who must engage in the integration discussion and must help transform the information infrastructure of their public health agencies.

Close coordination with HRSA/MCHB, relevant CDC programs and the Association of Maternal and Child Health Programs (AMCHP) will be needed to define which functions and responsibilities fall within the MCH reference and, based on this definition, which aspects of automation of those functions should be considered targets for integration.

[i] *Pediatric Electronic Health Record: Public Health Perspectives.* Public Health Data Standards Consortium, 06/23/2004. .http://www.phdsc.org/about/committees/pdfs/nhin/PHDSC%20Pediatric_EHR_PH_Report_011005.pdf. Downloaded 7/21/2008.

Appendix A.

Detailed Descriptions of Areas of Maternal and Child Health

I. Policy and Funding

Title V - The Maternal and Child Health Services Block Grant has operated as a Federal-State partnership since 1935, when the Social Security Act was passed. The Federal Government, through Title V, pledged its support of State efforts to extend health and welfare services for mothers and children. When the Title V program was converted to a block grant in 1981 seven categorical programs were consolidated: maternal and child health and services for children with special health needs; supplemental security income for children with disabilities; lead-based paint poisoning prevention programs; genetic disease programs; sudden infant death syndrome programs; hemophilia treatment centers; and adolescent pregnancy prevention grants.

Title X - The Title X Family Planning program was enacted in 1970 as Title X of the Public Health Service Act. Title X is the only federal grant program dedicated solely to providing individuals with comprehensive family planning and related preventive health services. The Title X program is designed to provide access to contraceptive services, supplies and information to all who want and need them. By law, priority is given to low income individuals.

II. Publicly Funded Insurance Programs Covering Mothers and Children

Medicaid – health insurance program for low income individuals jointly financed by the Federal and State governments and administered by the States.

State Children's Health Insurance Plan (SCHIP) – Jointly financed by the Federal and State governments and administered by the States, SCHIP was created to provide health insurance to children, whose families earn too much money to be eligible for Medical Assistance but not enough to purchase private health insurance.

III. Screening and Surveillance Programs

Metabolic Screening Program –States routinely test blood spots collected from newborns for up to thirty metabolic and genetic diseases of which the four most commonly included are phenylketonuria, congenital hypothyroidism, galactosemia, and sickle cell disease. Many states are also tasked with providing follow-up to infants identified through newborn screening programs, including ensuring appropriate diagnosis, treatment, and ongoing evaluation. In many cases, education is also a program responsibility along with counseling and provision of other ancillary services.

Universal Newborn Hearing Screening - Approximately 3 out of every 1,000 infants are born with significant hearing loss, making it the most common birth defect. Technology is currently available to conduct cost-efficient, physiological screening on a universal basis prior to hospital discharge. In 1993, less than 5 percent of all infants were screened for hearing loss prior to hospital discharge. Today, more than 90 percent of newborns are screened before hospital discharge. Universal newborn hearing screening prior to hospital discharge is now the standard of care in the United States.

Lead Screening - Childhood lead poisoning surveillance programs at estimate the extent of elevated blood-lead levels among children; assess the follow-up of children with elevated blood-lead levels; and, examine potential sources of lead exposure help allocate resources for lead poisoning prevention activities. These programs may be managed at the state health department or the state department of the environment.

Pregnancy Risk Assessment Monitoring System (PRAMS) – This system was initiated in 1987 because infant mortality rates were no longer declining as rapidly as they had in prior years. The goal of the PRAMS project is to improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity, and maternal morbidity. PRAMS provides state-specific data for planning and assessing health programs and for describing maternal experiences that may contribute to maternal and infant health.

Fetal and Infant Mortality Review (FIMR)- Since 1990, MCHB has funded the National Fetal and Infant Mortality (FIMR) Resource Center. FIMR is a community-based action method that examines a fetal or infant death as a sentinel event and mobilizes community action to improve services and resources for women, infants, and their families.

Child Death Review (CDR) - The National Center for Child Death Review is a resource center for state and local CDR programs, funded by the Maternal and Child Health Bureau. It promotes, supports and enhances child death review methodology and activities at the state, community and national levels. To conduct a comprehensive, multidisciplinary review of child deaths, to better understand how and why children die, and use the findings to take action that can prevent other deaths and improve the health and safety of children.

IV. Clinical and Support Services

Family Case Management - Case management is defined by Medicaid as "an activity under which responsibilities for locating, coordinating and monitoring necessary and appropriate services for a recipient rests with a specific individual or organization." These services may include, but are

not limited to, administrative case management; outreach activities; targeted case management which provides services for individuals in a specific geographic area or a specific set of services; and, coordination of services among multiple programs.

Pediatric Primary Care – often referred to as 'well baby checks' pediatric primary care focuses on the general health and well being of children up to the age of two. The overarching goal of this care is to administer immunizations; conduct weight and height checks; monitor progression of growth and developmental milestones; and, provide anticipatory guidance to parents/caregivers. This care can be provided in a variety of settings including, but not limited to private providers, federally qualified health centers, and local health departments**.**

School Health - A coordinated school health program brings together school administrators, teachers, other staff, students, families, and community members to assess health needs; set priorities; and plan, implement, and evaluate school health program activities. These components are: health education, health services, nutrition services, health promotion for school staff, physical education, mental health and social services, healthy and safe school environments, and family/community involvement. School health programs are most effective and efficient when all of the components are addressed together in a coordinated approach supported by school health councils, collective planning, administrative support, identified leaders, parents, and community members.

The following programs support maternal and child health

Women, Infants and Children (WIC) - Established as a pilot program in 1972 and made permanent in 1974, WIC is administered at the Federal level by the Food and Nutrition Service of the U.S. Department of Agriculture. WIC is not an entitlement program, rather a federal grant program that serves low income women and children. WIC provides nutritious foods, nutrition education and referrals to health and other social services at no charge. WIC serves low-income, pregnant, postpartum and breastfeeding women, infants and children up to the age of five who are at nutritional risk.

Vital Statistics – Vital Statistics is charged with registering all births, deaths, and fetal deaths within a state; issuing certified copies of birth, death, and marriage certificates and providing divorce verifications; and compiling and analyzing vital statistics data.

Immunizations – Immunizations prevent disease in the individuals who receive them and protect those who come into contact with unvaccinated individuals. Vaccines help prevent infectious diseases and save lives. Immunization programs are monitored by state health departments with the program being implemented in the private and public health care systems.

Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. It's required in every state and is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services.

Appendix B

Detailed Description of Information Systems Supporting Maternal and Child Health

I. Information Systems Specific to MCH

Lead Registry - CDC began collecting childhood blood lead surveillance data in April 1995. The national surveillance system is composed of data from state and local health departments. Because CDC does not obtain any identifying information about the child, the identification of duplicate test results and sequential tests on a single child, blood lead test results are maintained by the state in a child-specific database. In addition to blood lead test results, state child-specific databases contain follow-up data on children with elevated blood lead levels including data on medical treatment, environmental investigations, and potential sources of lead exposure. Surveillance fields for the national database are extracted from the state child-specific database and transferred to CDC.

Title X - Title X grantees submit yearly reports to the Office of Population Affairs (OPA) where they report on the scope of services or activities that were proposed in their approved grant application and supported with Title X grant funding. Reports are submitted electronically on OPAs web-based grant management system. The reported data includes but is not limited to: family planning client demographic data, economic and social profile of family planning users, family planning method, cervical and breast cancer screening, sexually transmitted disease screening, and family planning encounters and utilization of clinical staff.

Title V – Title V grantees submit yearly report to the Maternal and Child Heatlh Bureau where they report on their activities that were proposed in their approved grant application. Reports are submitted electronically via a web based reporting system. States are required to report on eighteen (18) national performance measures which include but are not limited to: teen birth rate, newborns screened for hearing before hospital discharge, dental sealants, children with special health care needs that receive comprehensive care in a medical home, mothers who smoke during pregnancy, immunization rates for children, and obesity screening in children who participate in WIC. In addition, Congress has enacted a number of amendments to Title V adding requirements that the program work closely with and assist Medicaid in a number of activities. These activities include: coordination of EPSDT, coordination agreements with State Medicaid programs, provide a toll-free number for families seeking Title V or Medicaid providers; provide outreach and education to facilitate enrollment of Medicaid eligible children and pregnant women, share data collection responsibilities particularly related to infant mortality, provider service for children with special health care needs and disabilities not covered by Medicaid.

Pregnancy Risk Assessment Monitoring System (PRAMS) - is an ongoing state- and population-based surveillance system designed to collect information on self-reported maternal behaviors and experiences that occur around the time of pregnancy. PRAMS generates statewide estimates of perinatal health indicators among women who recently delivered a live infant. Each participating state uses a standardized data collection method developed by CDC. PRAMS staff in each state collect data with mail and telephone questionnaires. Because PRAMS data are state- and

population-based, findings are generalizable to an entire state's population of women delivering a live-born infant. PRAMS allows CDC and the states to monitor changes in maternal and child health indicators (e.g., unintended pregnancy, prenatal care, breast-feeding, smoking, drinking, infant health). PRAMS enhances information from birth certificates used to plan and review state maternal and infant health programs.

The Pregnancy Mortality Surveillance System (PMSS) - Since 1987, the CDC has conducted ongoing national surveillance of pregnancy-related mortality. The Pregnancy Mortality Surveillance System (PMSS) detects pregnancy-related deaths, analyzes factors associated with these deaths, and publishes information that may lead to state and national prevention strategies

Newborn Screening – The panel of newborn disorders screened for varies from state to state, and decisions for adding or deleting tests involve many complex social, ethical, and political issues. Usually, newborn population screening disorders are tied to issues such as disorder prevalence, detectability, treatment availability, outcome, and overall cost effectiveness. A voluntary reporting database is hosted by the National Newborn Screening and Genetics Resource Center and is designed to provide a secure, Internet based, real-time, information collection and reporting system for capturing state and territorial newborn screening information programs.

Newborn Hearing Screening - Typically, 1-3 percent of those screened require referral for diagnostic evaluation. The provision of timely and appropriate follow-up services for those infants needing further evaluation continues to be a problem in some parts of the country. Loss to follow-up rates range from less than 10 percent in States with a well developed infrastructure, to as high as 50 percent in states that do not yet have the infrastructure to track and retrieve infants and families needing further services. States with infrastructure tend to be those with a mandate to screen and report. Forty States have legislative support for the hearing screening program. There are 53 grants to states and territories supporting statewide systems of newborn hearing screening, audiologic diagnostic testing before 3 months of age and enrollment in early intervention programs before the age of 6 months, with ties to a medical home and family-to-family support services. Some of the programs are supported by state law, others are not.

Congenital Malformation Registry - Birth defects affect about one in every 33 babies born in the United States each year. They are the leading cause of infant deaths, accounting for more than 20% of all infant deaths. Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. In early 1998, Congress passed the Birth Defects Prevention Act of 1998. This bill authorized CDC to: collect, analyze, and make available data on birth defects; operate regional centers for applied epidemiologic research on the prevention of birth defects; and, inform and educate the public about the prevention of birth defects. CDC awards grants to 15 states to track major birth defects and use the data for prevention and referral of affected children to needed services. In addition CDC funds eight (8) Center for Birth Defects Research and Prevention.

II. Information Systems Related to MCH

Electronic Birth Certificate/Electronic Death Certificate – Birth and death certificates are used in the United States for administrative and public health purposes and serve as the primary source of birth and death information. While the majority of birth certificates are handled electronically, completion of death certificates vary. An electronic death registration system is expected to reduce reporting delays, improve data quality, and increase the utility of death information.

Enumeration at Birth (EAB) – the EAB program was established in 1989 as another means of improving the SSN process. This program is available in all States as well as the District of Columbia and Puerto Rico, and allows parents to indicate on the birth certificate information form whether they want an SSN assigned to their newborn child. States provide SSA with birth record information about newborns whose parents want a Social Security card for their child, and SSA then assigns an SSN and issues a card. This process greatly reduces the potential for someone to use another person's birth certificate to obtain a Social Security card..

Immunization Registries - These confidential, computerized information systems contain vaccination histories and provide immediate access to a child's current immunization status to authorized providers. As a centralized, secure site of single record storage they provide an official immunization record for school, day care, and camp entry requirements. These no-cost tools were created in conjunction with the Centers for Disease Control and Prevention and are available in every state. As families move in and out of both public and private health care systems, parents and providers can use registries as a powerful tool to ensure that the child receives timely immunizations and proper treatment. Using the registry public health departments can identify those children who are at risk in the event of a disease outbreak or other emergency such as hurricanes, earthquakes, floods or man-made disasters. They can locate communities with low coverage rates so that they can provide targeted interventions to increase coverage rates and protect more children from disease.

WIC – Since 1992 State WIC agencies have been reporting a Minimum Data Set consisting of 20 variables from their management information systems to the Food and Nutrition Service of USDA. Data collected includes: income, nutrition risks, migrant status, pregnant, breastfeeding, postpartum, infant, child, age, race, weight, height and blood measures. In addition, another 13 supplemental data set items were requested from State data systems if they had the capability and included variables such as source of healthcare, education, number in household on WIC and birth weight.

Youth Risk Behavior Survey - The Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC) and state, territorial, tribal, and local surveys conducted by state, territorial, and local education and health agencies and tribal governments. Unintentional injuries and violence, tobacco use, alcohol and other drug use, sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection, unhealthy dietary behaviors, physical inactivity

Medicaid – States submit eligibility data and claims tapes to the Centers for Medicare & Medicaid Services through the Medicaid Statistical Information System (MSIS).

EPSDT report - The CMS-416 provides basic information on participation in the Medicaid child health program. States provide CMS with the following information: the number of children provided child health screening services; the number of children referred for corrective treatment; the number of children receiving dental services; and, the State's results in attaining goals set for the state under section 1905(r) of the Act. The information is used to assess the effectiveness of State EPSDT programs in terms of the number of children (by age group and basis of Medicaid eligibility), who are provided child health screening services, are referred for corrective treatment, and the number receiving dental services. In

addition, federal rules call for coordination with Title V which include establishment of written state MCH-Medicaid agreements which provide maximum utilization of Title V supported services and reimbursement of Title V providers for services rendered, even if such service are provided free of charge to low-income uninsured families.

Indian Health Service Resource and Patient Management System (RPMS) –

- Obstetric Care Module to monitor First OB Visit, Follow up OB Visit, L&D / Consultant Visit, Post Partum
- Well Child Module has dynamically determined guidelines, dynamically customized for each specific well child visit
- Immunization Data Exchange Initiative to develop an electronic bi-directional immunization data exchange between RPMS and state Immunization Information Systems (IIS)

Appendix V

Health Status and Disease Monitoring Systems and Initiatives

National-Level Examples of Health Status and Disease Monitoring Systems and Initiatives:

- Healthy People
- The National Ambulatory Medical Care Survey (NAMCS) provides information on the provision and use of medical care services in office-based physician practices, while the National Hospital Ambulatory Medical Care Survey (NHAMCS) provides data on medical care services in hospital emergency and outpatient departments
- The National Health Interview Survey (NHIS) collects data on a broad range of illnesses, injuries, activity limitation, chronic conditions, health insurance, health care use, and select risk factors.
- The National Health and Nutrition Examination Survey (NHANES) collects data in mobile examination clinics from a nationally representative sample. Resulting data inform on the prevalence of certain chronic conditions, various physical and psychological measures, growth and development, and nutrition behaviors.
- The National Immunization Survey (NIS) is an ongoing survey monitoring vaccination coverage rates among children 19-35 months of age.
- The Behavioral Risk Factors Surveillance System (BFRSS) is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. For many states, the BRFSS is the only available source of timely, accurate data on health-related behaviors.
- The Youth Risk Behavior Survey (YRBS) monitors health risk behaviors among students in grades 9 to 12, such as tobacco use, dietary behaviors, physical activity, alcohol and other drug use, sexual behaviors, and unintentional injuries and violence.

- State Examples

    - State-level Healthy People initiatives
    - State-level BFRSS
- Local Examples
    - Local-level Healthy People initiatives
    - Community health status assessment and improvement planning
        - Examples:Mobilizing for Action through Planning and Partnerships (MAPP) - Mobilizing for Action through Planning and Partnerships (MAPP) is a community-driven strategic planning tool for improving community health. Facilitated by public health leaders, this tool helps communities apply strategic thinking to prioritize public health issues and identify resources to address them. MAPP is not an agency-focused assessment tool; rather, it is an interactive process that can improve the efficiency, effectiveness, and ultimately the performance of local public health systems.
        - State-specific processes (for funding or accreditation)

American Health Information Community Successor

Update on Status and Activities

September 23, 2008

Agenda

- Operational Update
- AHIC Successor Board of Directors
  - Design and Nomination Process
  - Announcement of Board Members
  - Inaugural Meeting Agenda
- Refining the Value Case Prioritization Process
- Transition of Workgroup Activities
- Collaboration with HITSP/CCHIT/NHIN
- AHIC Successor Membership and Outreach

Operational Accomplishments to Date

- AHIC Successor, Inc. was incorporated July 17, 2008.
- HHS grant successfully awarded to AHIC Successor, Inc. on August 29th.
- Laura Miller appointed as Interim Executive Director.
- Basic operational Infrastructure put in place.
- Board nominated and selected.
- Recruitment begun for permanent President/CEO.

The Board of Directors Design

- Comprised of 13 at-large members, plus two consumer and two federal government representatives
  - Year one includes seats for the three incorporators
  - Terms of 1, 2, and 3 years
- Board members commit to:
  - Fulfill fiduciary responsibilities
  - Ensure the organization has resources to fulfill its mission
  - Attend a minimum of four to six Board Meetings a year
  - Implement Board actions
  - Provide thought leadership on industry trends and developments
  - Participate in and/or chair periodic advisory committee meetings

Board Nomination Process

- A Nominating and Governance Committee nominated Board of Directors (BOD) candidates.
- Elements of the nomination process:
  - Individual candidates judged on four criteria: board experience, ability to work by structured consensus, thought leadership, strategic experience.
  - Candidate pool evaluated as a whole and selected to ensure diversity in stakeholder groups, expertise, geography, gender, race, and ethnicity.
- Incorporators selected final slate of 15 board members.

1st Board Meeting Scheduled for October 27th

- Board members will discuss the near and intermediate term direction of the organization.
- The agenda will include the following items:
  - Bylaws
  - AHIC Successor committee structure
  - Staff and budget
  - Value cases and prioritization approach
  - Strategic and business plans

Value Cases and the Prioritization Process

- Value case describes an aspect of health care 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.
- Value case proposals must have:
  - Stakeholder proponents;
  - Stakeholders willing to provide resources to facilitate value case development;
  - Assessments of interoperability value, costs to adopt, and measures of impact.
- Value cases must fit and advance a national interoperability contextual framework.

AHIC Successor/ONC Collaboration on Transition Planning

- Transition Work Group identified high level priorities across seven work groups.
- AHIC Work Group leads provided more granular recommendations for activities to address a “short list” of top priorities for transition to AHIC Successor.
- Recommendations will be presented to AHIC.

Collaboration with HITSP/CCHIT/NHIN

- In coming months, AHIC Successor will collaborate with HITSP, CCHIT, and NHIN to craft strategies for:
  - Implementation of value case prioritization process
  - Increased standards adoption
  - NHIN governance

AHIC Successor Membership

- AHIC Successor will complete an integrated membership and communications plan and begin soliciting members in late Fall.

- AHIC Successor 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; and
  - Provide and share technical resources.

- The Board will develop a tiered membership dues structure that differentiates between non-profit and for-profit organizations.

CONTACT INFORMATION

www.ahicsuccessor.org

lmiller@ahicsuccesor.org

877 835-6506 or 202 629-0366

NHIN Core Services – September Presentation Description

Introduction

This document provides a description of the Nationwide Health Information Network (NHIN) Trial Implementations Core Services presentation for the September 2008 American Health Information Community (AHIC) meeting. These demonstrations showcase the technology that enables NHIN Cooperative participants to look up, retrieve and securely exchange health information, apply consumer preferences for sharing information, and using the NHIN for other business capabilities as authorized by the health care consumer.

Part 1 – Supporting Patient Care

Presentations focus on the ability to deliver a summarized patient record to support an episode of care. The NHIN summary patient record includes a broad set of data needed for a variety of patient care and other health-related processes. Summary record data are exchanged in a form that is both human readable and able to be electronically processed by the receiving organization.

Emergency Care

Lead Demonstrator – Indiana University (Indiana Health Information Exchange)
Responding Exchanges

- HealthBridge (Cincinnati, OH) and
- 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)
- Wright State University (Dayton, Ohio)

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 plays a critical role in the patient's care.

Transfer of Care

Lead Demonstrator – Lovelace Clinic Foundation (New Mexico Health Information Collaborative)
Responding Exchange - Long Beach Network for Health

A patient, Oscar Pena, who lives in Albuquerque and receives ongoing primary care locally, decides to temporarily stay with family in Long Beach, CA. While in Long Beach Mr. Pena is hospitalized, and that care involved tests, a procedure and medication changes. The discharging physician advised Mr. Pena to arrange follow-up care within two 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.

Wounded Warrior

Lead Presenter – Department of Veterans Affairs
Additional Participants

Department of Defense
Kaiser Permanente
CareSpark (Kingsport, TN)
MedVirginia (Richmond, VA)
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.

NHIN Core Services – September Presentation Description

Part 2 – Supporting the Consumer

The presentations in this setting focus 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 will show how the consumer's preference for participation is managed and applied for data exchanged.

Consumer's Decision to Not Participate in the NHIN (Opt out)
Co-Lead Presenter – MedVirginia (Richmond, VA)
Co-Lead Presenter - CareSpark (Kingsport, TN)

In this presentation, 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 will show how Ms. Rooney's decision to not participate in the NHIN is applied when another organization requests it.

Setting 2B – Consumer's Decision to Participate in the NHIN (Opt in)
Co-Lead Presenter – West Virginia Health Information Network
Co-Lead Presenter – Delaware Health Information Network

In this presentation, although the consumer received treatment at several West Virginia Health Information Network facilities over the past few years, he 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 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.

Setting 3 – Business Application of the NHIN

In setting 3, the presentation will show how the NHIN could be applied for a different purpose than patient care with an individual's authorization. In this instance, the NHIN is used to help a patient request records data is processed by another information system for the purpose of determining disability benefits.

Determination of Benefits for SSA Applicant
Lead Presenter – Social Security Administration
Additional Participants-
MedVirginia (Richmond, VA)
NCHICA (Research Triangle Park, NC)

For SSA, the disability decision is based on how a particular condition affects the claimant's ability to perform work. 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 a year or that their condition is expected to result in death. . The demonstration will show how SSA obtains the healthcare consumer's authorization to gather their information, and the value to SSA of enhancing their business process and added value to the consumer in speeding up the claims process.

112 W Main Street
P. O. Box 657
Kingsport TN 37662
www.carespark.com

Who is CareSpark?

CareSpark is a Regional Health Information Organization serving 750,000 residents and approximately 1200 physicians in the 17-county area of southwest Virginia and northeast Tennessee, where significant health disparities and high health care costs cause a burden to patients and communities. Initiated by leaders of a health improvement coalition in existence since 1991, CareSpark was established as a non-profit organization in 2005. CareSpark has engaged physicians, hospitals, public health, insurance plans, employers and community leaders to define a shared vision and a strategic business plan that proposes to improve regional health status through the collaborative use of health information. With an estimated cost of $7M in capital costs over a three-year period and annual operating costs of approximately $1.25M, CareSpark has secured over $5.5M from federal, state and local sources to build the infrastructure necessary for the secure, timely and cost-effective use of health information technology at the point of care (including various electronic medical records systems, inter-connectivity, decision support tools, alignment of financial incentives and clinical process improvement). CareSpark has achieved national visibility as one of nine communities funded in 2004 by the Foundation for eHealth Initiatives and participant in the Nationwide Health Information Network (NHIN) Prototype Demonstration in 2007 and Trial Implementation in 2008.

What is unique about this effort?

- Broad-based grassroots effort arising from community concern about region's poor health
- Focus on long-term population health improvement to reduce significant disparities in multi-state central Appalachian region
- Commitment to inclusion of all providers to enable communication across multiple systems and platforms, with an emphasis on outreach and support of small rural physician practices
- Commitment to standards (technical systems, data formats, terminology, legal / regulatory requirements, and reporting requirements)
- Commitment to data-driven, clinical process improvement through the adoption of clinical best practices and decision support tools for clinicians and patients
- Comprehensive planning process to develop sustainable business model
- National leadership and growth opportunities for local health and technology businesses
- Collaboration among competitors (healthcare providers, insurers, and technology companies) leading to recognition as a ComputerWorld laureate in 2008.

What progress has been made?

- $562,875 in funding and significant in-kind goods and services contributed to complete a comprehensive feasibility and strategic planning process
- Over $5M in funding and over $1.5M in in-kind goods and services secured for development of standards-based infrastructure, operational as of August 2008
- Marketing and contracting for decision support and communications to clinicians and patients underway, enrollment of 32,500 members since April 2007 generating fees from purchasers to support financial sustainability.
- Framework and policies assuring security and privacy of health information exchange
- Tools and processes for continuous improvement in place, earning recognition as a Level 2 Quality Commitment Award recipient from the Tennessee Center for Performance Excellence in 2006 and 2007

CareSpark's Role in the Nationwide Health Information Network Trial Implementation

In September 2007, CareSpark was awarded a contract by the U.S. Department of Health and Human Services to participate as of one nine health information exchanges in the Trial Implementation of the Nationwide Health Information Network, developing and demonstrating core services for secure exchange of a summary medical record, as well as information required for medication management and consumer empowerment use cases. CareSpark's infrastructure is fully compliant with standards defined by HITSP (Health Information Technology Standards Panel) and compatible with profiles established by IHE (Integrating the Healthcare Enterprise).

CareSpark proudly acknowledges the contributions and roles of our technology partners:

- CGI: Lead System Integrator, responsible for overall technical design and project management, application development and hosting www.cgi.com
- ActiveHealth Management ActivePHR, enabling patients to share and update information for registration purposes, as well as information about allergies and medications www.activehealth.net
- AllScripts eRxNOW applications for electronic prescribing and medication decision support www.allscripts.com
- Anakam AnakamTFA solution for secure authentication of end users www.anakam.com
- Deliberaré small business consulting services for security and auditing requirements www.deliberare.com
- ERPWeb.NET small business consulting services for application security and HIPAA compliance www.erpweb.net
- HealthVision Cloverleaf Integration Suite for integration among applications, implementation of enterprise master patient index www.healthvision.com
- Initiate Systems Identity HUB solution for master patient index www.initiatesystems.com
- LucentGlow small business for implementation of interface solutions www.lucentglow.com
- Provider Resources small business consulting services for HIPAA compliance and clinical information management www.provider-resources.com
- Randall E. Sermons, Attorney at Law, small business for legal services www.randalle.us
- TecAccess small business consulting services for accessibility and usability testing www.tecaccess.net
- Wellogic Consult clinician portal for presentation of health information www.wellogic.com

For More Information

CareSpark
Liesa Jo Jenkins, Executive Director
Brenda Getaz, NHIN Project Manager
423-765-9341

CGI Group, Inc.
Richard L. Martin, Vice President
Benson Chang, Executive Consultant
703-227-6000

eCleveland Clinic Overview

eCleveland Clinic is a suite of integrated Health Information Technology (HIT)-based tools that help all Cleveland Clinic personnel involved in patient care and administrative support do their jobs more efficiently and effectively. The foundation of Cleveland Clinic's HIT capabilities is the eCleveland Clinic My**Practice** Electronic Medical Record system, which connects all clinical operations, administrative functions and patient management protocols for the Cleveland Clinic Health System, one of the largest of its kind in the nation.

Cleveland Clinic's main campus includes medical and surgical facilities in 37 building covering more than 130 acres. Staff physicians represent approximately 120 specialties and subspecialties. There are nine Cleveland Clinic Community Hospitals in northeast Ohio, a Cleveland Clinic Florida Hospital in Weston, Florida, and 12 Cleveland Clinic Family Health Centers located across northeast Ohio that provide Primary Care, Pediatric, and a wide variety of specialty care in our patients' neighborhoods.

The eCleveland Clinic My**Practice** Electronic Medical Record system integrates all these facilities and locations and contains the detailed medical histories of over 5.5 million unique patients. This same technology allows Cleveland Clinic to provide outreach services to our patients, and advanced collaborative online tools to the physicians in private practice with whom we work.

Each eCleveland Clinic service (My**Practice**; My**Practice** Community; My**Chart**; My**Consult**; My**Monitoring**, Virtual**Visit**, Dr**Connect**, and e**Research**) is spearheaded by a Managing Director responsible for development and implementation. C. Martin Harris, M.D., Cleveland Clinic Chief Information Officer is eCleveland Clinic's Executive Director. Under his leadership, the program has been recognized as among the most advanced Health Information Technology initiatives in the world.

eCleveland Clinic Services

My**Practice**:
The eCleveland Clinic My**Practice** electronic medical record (EMR) system is the foundation of the Cleveland Clinic's information management capabilities. Containing the electronic medical record information of over five and a half million unique Cleveland Clinic patients, the My**Practice** system is composed of approximately 400 million data elements and is used every day by nearly 30,000 staff, nursing, administrative, pharmacy and other support personnel.

My**Practice** Community:
The My**Practice** Community electronic medical record system is a specially designed version of the same EMR used in Cleveland Clinic facilities that is available to physicians in private practice at an affordable price. Physicians in private practice may customize the system by selecting the features and functionalities that best suit their busy daily workflow. The My**Practice** Community system is supported by a dedicated team of experienced health information technology professionals expert in practice assessment, system installation and staff training and user support.

My**Chart**:
eCleveland Clinic My**Chart** is a secure, Internet-based service that connects Cleveland Clinic patients to portions of their own electronic medical record. Through My**Chart**, patients may view information about their individual health conditions and past appointments (as released by their physician), request prescription renewals and new appointments, receive laboratory and other test results, and utilize a series of links to educational materials to

research the health-related issues in which they are interested.

My**Consult**:
The first Internet-based patient service offered by eCleveland Clinic, the My**Consult** program provides remote second medical opinions for over 600 life-threatening / life-altering diagnoses through a custom-designed, secure Web page. Since My**Consult** first became available in early 2001, patients from nearly every state in America and over 60 international locations have requested and received expert second opinions from Cleveland Clinic specialists. The My**Consult** service is provided as part of the employee health benefits plans of a number of major corporations.

Dr**Connect**:
eCleveland Clinic Dr**Connect** is an Internet-based service specially developed to provide physicians who refer patients to Cleveland Clinic secure, real-time information about their patients' treatment progress. Dr**Connect** connects registered physician users, and identified office staff with proxy security rights, to the information related to the encounters and results contained in the My**Practice** electronic medical record as patients receive Cleveland Clinic care.

My**Monitoring**:
The eCleveland Clinic My**Monitoring** system allows objective data to be transmitted directly into a patient's electronic medical record from implanted devices, allowing physicians to view the status of patients with heart pacemakers, defibrillators, and other medical monitoring systems from home, between office visits.

e**Research**:
eCleveland Clinic's e**Research** program offers professional health informatics consultation to organization's interested in conducting clinical trials related to the development of medical devices and pharmaceuticals. e**Research** services include protocol analysis and standardization, inclusion / exclusion customization, and clinical decision support consultation to maximize the efficiency and effectiveness of large-scale clinical trials across a broad spectrum of study sites.

Virtual**Visit**:
eCleveland Clinic's Virtual**Visit** service utilizes sophisticated, real-time technology to connect Cleveland Clinic physicians with patients requiring specialized consultations, anytime, anywhere, facilitating physician collaboration and minimizing the need for patient travel. With a Cleveland Clinic physician located in a Virtual**Visit** control center, and the patient connected to the physician through a secure video / digital information transfer system, physician and patient see and hear one another and interact through voice and images. With the assistance of a nurse or other caregiver and a set of sensitive medical tools, physicians perform physical examination, ask and answer questions, and document all encounters directly into the eCleveland Clinic My**Practice** Electronic Medical Record system.

Google Health Pilot (special project):
Cleveland Clinic collaborated with Google to pilot features and services of Google Health, a new personal health record service that became available to consumers in May of 2008. Approximately 1,500 eCleveland Clinic My**Chart** users volunteered to test the secure exchange of patient medical record data such as prescriptions, conditions and allergies between their My**Chart** and secure Google Health profile. The goal of Cleveland Clinic's collaboration with Google was to contribute to a patient-centered and controlled health information management model that will ultimately offer patients everywhere the ability to interact with multiple physicians, healthcare service providers and pharmacies.

Now in its 11th year of operation, CHIC is the lead for Northeastern Minnesota's RHIO project, providing secure access to electronic health records within and between healthcare organizations throughout the region. CHIC's network includes nearly 200 provider organizations, higher education institutions, and public health departments covering 18 counties in northeast and north central Minnesota. The area is home to 650,000 residents and 2500 practicing physicians.

One major accomplishment of CHIC is its work with the Minnesota Immunization Information Connection (MIIC), a confidential, computerized network of shared immunization records. It provides clinics, schools and parents with accurate, complete and up-to-date immunization records. MIIC has had a discernible impact on improving immunization rates for the community, and won widespread praise from the area's pediatricians—both for the better care they can provide to their patients, and the diminished administrative burden on their staffs, freed from tracking down past immunization histories.

Another achievement is CHIC's impact on the quality of care for patients being discharged from hospitals to nursing homes. In the past, the information carried over with patients has been spotty and unreliable; in its place, CHIC has established a secure, encrypted e-mail discharge notification, which transmits critical patient information, such as medication history and special needs, to the nursing home immediately upon discharge.

CHIC is now piloting use of HealthBio™, an online personal health record designed for adults with developmental disabilities and others interested in sharing key health histories with their personal physicians and other healthcare providers. While the pilot project was designed for vulnerable or special needs populations that might have difficulty communicating their health histories, HealthBio™, may offer significant benefits to a wider population, including those with chronic conditions, seniors and children in foster care.
As the administrative coordinator for the Emergency Preparedness planning in the Northeast region of Minnesota CHIC is exploring how HealthBio™ could be used to deliver coordinated and effective care to victims of terrorism and other public health emergencies. One of CHIC's first focuses for this initiative is the evacuation of patients from nursing homes, a direct response to lessons learned from Hurricane Katrina. With instant access to HealthBio™, patients could be directed to facilities best suited and ready to address their needs, able to quickly initiate appropriate treatment upon their arrival.

Speedy location of medical records for emergency room patients is another vital service offered by CHIC, particularly for rural hospitals. While Minnesota law precludes electronic transmission of patient records without patient consent, the CHIC Record Locator Service instantly identifies all locations where a patient's records reside, allowing ER personnel to quickly track down needed patient clinical data.
We are very proud to have MEDNETWorld as a partner in helping us bring our hospitals and clinics to interoperability to meet state mandates, please see their information on the reverse.
If I can be of further assistance, feel free to contact me.

Contact information:
Cheryl M. Stephens, MT(ASCP), MBA, PhD
Executive Director
Community Health Information Collaborative
404 W Superior St, Suite 250
Duluth, MN 55802

Gina Perez, Executive Director
www.dhin.org
302-678-0220

What is DHIN?

The Delaware Health Information Network (DHIN) was established by the Delaware General Assembly in 1997 as a public instrumentality of the State to advance the creation of statewide health information and electronic data interchange network for public and private use. The DHIN is a public-private partnership, which provides the organizational infrastructure to support a clinical information sharing utility. The Delaware Health Information Network (DHIN) Clinical Information Exchange Utility is a service designed to provide for the secure, fast, and reliable exchange of health information between the many providers (hospitals, physicians, laboratories) treating patients in the State of Delaware.

Operational Health Information Exchange Model:

On May 1, 2007 DHIN went live, becoming the first operational statewide health information exchange. Utilizing the Medicity interoperability platform, hosted in the Perot Systems state-of-the art managed data center services, DHIN provides secure results delivery of laboratory and pathology results, radiology reports and admission face sheets from three hospital systems and LabCorp statewide. These participants provide over 80% of laboratory tests and hospital admissions performed in the State. There are currently 650 users of the system in physician practices across Delaware. Physician practices receive clinical results via an electronic inbox, which can be set to auto print or directly interfaced to their electronic health record system.

Quest Diagnostics as well as another hospital in Delaware are in the process of interfacing to the DHIN. DHIN also provides electronic reporting of chief complaint data from the hospital emergency rooms to the Delaware Division of Public Health; and in the fall, will implement lab reporting for public health reportable diseases. This will enhance the states bio-surveillance system and lead to better outbreak investigation and disease control efforts.

What physicians are saying about DHIN:

It's a great product; it saves a lot of time."

"I received a critical result as soon as the test result was ready—it would normally have been days before I got the information. Because of DHIN, I was able to take immediate action."

"We get information faster than we would normally."

"DHIN listens to us and responds to our needs very quickly"

"We are as pleased as can be. With DHIN, we have taken days off preparation time for office visits, especially for post-hospital office visits."

"Technical support has been excellent."

"Set-up is so easy that they couldn't have made it any easier."

"Since communication is from provider to provider, DHIN gives us another way to show we are HIPAA compliant."

Beginning in 2009, DHIN will implement a patient centric record search function, including clinical results and reports as well as medication history. Further functions to be rolled out in 2009 include electronic order entry from an EHR and a patient portal.

DHIN's Vision:

To develop a network to exchange real-time clinical information among all health care providers (office practices, hospitals, labs and diagnostic facilities, etc.) across the state to improve patient outcomes and patient-provider relationships, while reducing service duplication and the rate of increase in health care spending.

Goals of DHIN:

1. To improve the care received by patients served by Delaware's health care system and to reduce medical errors associated with the inaccurate and incomplete information available to providers of medical care.
2. To reduce the time and financial costs of exchanging health information among health care providers and payers (necessary for patient care), by reducing the complexity of the current distribution methods and drastically increasing use of electronic means.
3. To improve communication among healthcare providers and their patients to provide the right care at the right time based on the best available information.
4. To reduce the number of duplicative tests and to afford specialists a better understanding of the patient upon referral from his/her primary physician.
5. To improve the efficiency and value of electronic health records (EHR) in the physician office and to assist those physicians without an EHR to better organize and retrieve test results.

DHIN Governance:

The Public-Private Board of Directors is comprised of diverse organizations all representing the primary stakeholders of health information exchange. They include representatives from the following constituency groups, organizations and agencies:

- Consumers
- Delaware Healthcare Association (representing hospitals) and the Medical Society of Delaware (representing physicians)
- Payors, including Blue Cross Blue Shield of Delaware and Delaware Physicians Care, Inc., a wholly owned subsidiary of Aetna and Medicaid.
- Delaware State government agencies: Delaware Health Care Commission, Department of Insurance, Department of Technology and Information, Division of Public Health, Office of Management and Budget
- Delaware State Chamber of Commerce, large employers and the University of Delaware

Fact Sheet

Department of Defense Military Health System

Military Health System (MHS) Mission: Our team provides optimal Health Services in support of our nation's military mission — anytime, anywhere.

The Military Health System (MHS) is a unique partnership of medical educators, medical researchers, and healthcare providers and their support personnel worldwide. This DoD enterprise consists of the Office of the Assistant Secretary of Defense for Health Affairs; the medical departments of the Army, Navy, Marine Corps, Air Force, Coast Guard, and Joint Chiefs of Staff; the Combatant Command surgeons; and TRICARE providers (including private sector healthcare providers, hospitals and pharmacies).

The MHS is prepared to respond anytime, anywhere with comprehensive medical capability to military operations, natural disasters and humanitarian crises around the globe, and to ensure delivery of world-class healthcare to all DoD service members, retirees, and their families. The MHS promotes a fit, healthy and protected force by reducing non-combat losses, optimizing healthy behavior and physical performance, and providing casualty care.

MHS Vision:

- The provider of premier care for our warriors and their families
- An integrated team ready to go in harm's way to meet our nation's challenges at home or abroad
- A leader in health education, training, research, and technology
- A bridge to peace through humanitarian support
- A nationally recognized leader in prevention and health promotion
- Our nation's workplace of choice

A Week in the Life of the MHS:

Inpatient Admissions	18,500
Outpatient Encounters – Direct Care Only	664,000
Prescriptions	2.28 M
Births	2,240
Dental Visits	102,000
Claims Processed	3.7 M
Weekly Bill	$809

DoD and MHS Leadership:

Robert M. Gates, PhD	Secretary of Defense
Gordon England	Deputy Secretary of Defense
S. Ward Casscells, MD	Assistant Secretary of Defense for Health Affairs
Stephen L. Jones, DHA	Principal Deputy Assistant Secretary of Defense for Health Affairs
MG Elder Granger	Deputy Director, TRICARE Management Activity
LCDR Steve Steffensen, MD	DoD NHIN POC

For Additional information, visit http://www.health.mil/

Department of Veterans Affairs (VA)
www.va.gov

VA Mission Statement

To fulfill President Lincoln's promise – **"To care for him who shall have borne the battle, and for his widow, and his orphan"** – by serving and honoring the men and women who are America's veterans.

VA Vision

To provide veterans the world-class benefits and services they have earned – and to do so by adhering to the highest standards of compassion, commitment, excellence, professionalism, integrity, accountability, and stewardship.

VA Core Values

Compassion – We will treat all veterans and their families with the utmost dignity and compassion. We will provide services in a caring manner, with a sympathetic consciousness of others' distress together with a desire to alleviate it.

Commitment– Veterans have earned our gratitude and respect. Their health care, benefits, and memorial service needs to drive our actions

Excellence – We strive to exceed the expectations of veterans and their families. We strive to perform at the highest level of competence and take pride in our accomplishments.

Professionalism– Our success depends on maintaining a highly-skilled, diverse, and compassionate workforce. We foster a culture that values equal opportunity, innovation, and accountability.

Integrity– We recognize the importance of accurate information. We practice open, truthful, and timely communication with veterans, employees, and external stakeholders. By carefully listening and responding to their concerns, we seek continuous improvement in our programs and services.

Accountability– We will perform in a manner at all times that makes us accountable, responsible, and answerable to veterans and their families, our leaders and other employees as well as external stakeholders.

Stewardship– We will ensure responsible stewardship of the human, financial, and natural resources as well as data and information entrusted to us. We will improve performance through the use of innovative technologies, evidence-based medical practices, and sound business principles.

Strategic and Enabling Goals

Goal 1 – Restore the capability of veterans with disabilities to the greatest extent possible, and improve the quality of their lives and that of their families.

Goal 2 – Ensure a smooth transition for veterans from active military service to civilian life.

Goal 3 – Honor and serve veterans in life, and memorialize them in death for their sacrifices on behalf of the Nation.

Goal 4 – Contribute to the public health, emergency management, socioeconomic well-being, and history of the Nation.

Enabling Goal – Deliver world-class service to veterans and their families through effective communication and management of people, technology, business processes, and financial resources.

About VHA

Veterans Health Administration

VHA Mission

The mission of the Veterans Healthcare System is to serve the needs of America's veterans by providing primary care, specialized care, and related medical and social support services. To accomplish this mission, VHA needs to be a comprehensive, integrated healthcare system that provides excellence in health care value, excellence in service as defined by its customers, and excellence in education and research, and needs to be an organization characterized by exceptional accountability and by being an employer of choice.

VHA Vision

Healthcare Value begins with VA. The new Veterans Healthcare System supports innovation, empowerment, productivity, accountability and continuous improvement. Working together, we provide a continuum of high quality health care in a convenient, responsive, caring manner — and at a reasonable cost.

VHA Leadership

Under Secretary for Health, Dr. Michael J. Kussman, heads the Veterans Health Administration (VHA) and is responsible for the operation of the nation's largest integrated health care system. The Office of the Under Secretary for Health provides oversight of VHA programs, initiatives, organizations, field facilities, and 21 Veterans Integrated Service Networks (VISNs) that manage field facilities.

VA NHIN POC: Tim Cromwell RN, PhD; Director, Standards and Interoperability; CHIO, VHA OI; Tim.Cromwell@va.gov; 801-588-5222

May 2008

An Overview of Who We Are

Patient information available when you need it most

Quick Facts

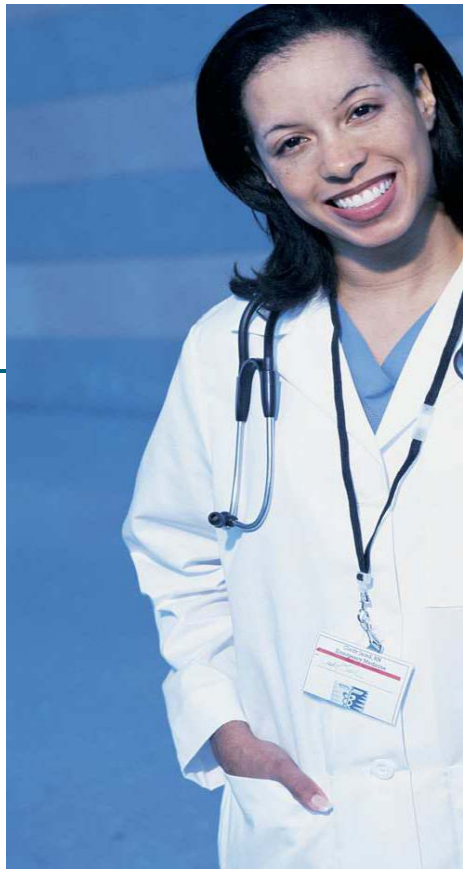
- **Founded in 1997, HealthBridge is one of the nation's largest and most successful health information exchanges (HIE).**
- **HealthBridge is a nonprofit organization that provides secure, electronic exchange capability for the Greater Cincinnati region.**
- **HealthBridge is one of only a handful of HIEs nationwide that has a self-sustaining, cash-positive business model that does not rely on grant funding for ongoing costs.**
- **Because of its success, HealthBridge also assists a number of other communities and states with their HIE efforts.**

Health care leaders in the United States have long sought approaches to dealing with cost, quality and access issues in the US health care system. Business leaders, state and federal officials and health care innovators are looking increasingly to health information technology (HIT) and health information exchange (HIE) as ways to address concerns with health system performance and cost containment.

HealthBridge is a not-for-profit corporation founded in 1997 as a community effort to develop a common technology infrastructure for sharing of health information. HealthBridge is located in Cincinnati and serves the Greater Cincinnati tri-state area. As a result of HealthBridge's infrastructure and the support of the community, the Cincinnati region is the most advanced region in the country for using electronic health information to improve the quality and efficiency of health care.

HealthBridge shares electronic health information in a secure manner between dozens of different hospitals and health systems, laboratories, diagnostic and imaging facilities, and physician offices and clinics. HealthBridge's partners include Mercy Health Partners, St. Elizabeth Medical Center, The Health Alliance of Greater Cincinnati, The Christ Hospital, Children's Hospital Medical Center of Cincinnati, St Luke's Hospitals, TriHealth, Deaconess, McCullough Hyde Memorial Hospital, Adams County Hospital, Margaret Mary Community Hospital, LabCorp, Quest, ProScan Imaging, and the Kentucky Diagnostic Center. Local health departments and community health centers are also connected to health information through HealthBridge.

Recognized across the US as a national leader in e-Health, HealthBridge also provides advice and consultation to numerous state and local HIEs. HealthBridge is involved in ongoing partnerships with several other community HIE's including healthLINC in Bloomington, Indiana, and the Clark and Champagne County Health Information Exchange (CCHIE) in Springfield, Ohio.



HealthBridge Statistics

- Through its shared technology, HealthBridge is able to deliver more than **2.3 million clinical results each month** to thousands of health care professionals, making it one of the largest HIEs in the nation.
- HealthBridge data suppliers and users include **24 hospitals**, nearly **4400 physicians**, **17 local health departments**, dozens of physician offices and clinics, nearly all of the commercial labs and many of the large diagnostic facilities in the region.
- The HealthBridge system had more than **800,000 logins** in 2007.

HealthBridge

11300 Cornell Park Drive
Suite 360
Cincinnati, OH 45242
Phone: 513.469.7222
Fax: 513.469.7230

Find out more at

www.healthbridge.org

What We Do

Some of the services HealthBridge offers:

- **Clinical Messaging** – A secure Interface delivers the following clinical information to physicians of record via an electronic in-box, fax machine or into an electronic medical record (EMR):
  - → Lab results
  - → Radiology images
  - → Transcribed reports
  - → Cardiology
  - → Pathology
  - → Microbiology
  - → Admissions, Discharges and Transfers (ADT)

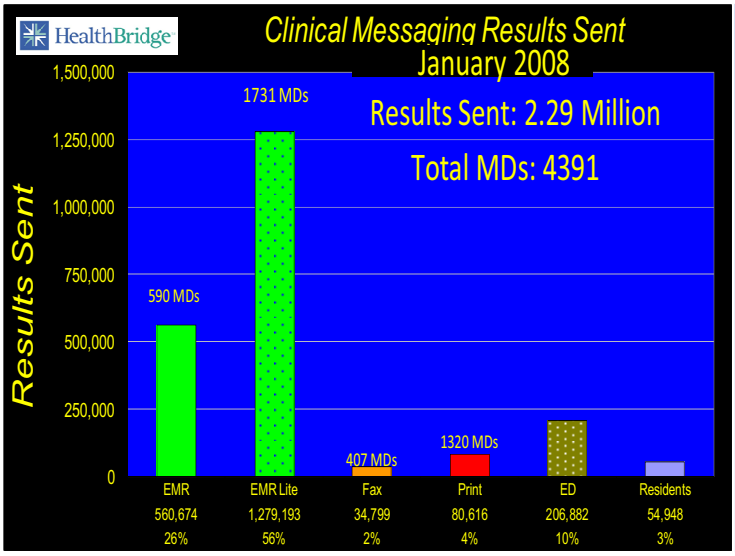
- **Secure connections between systems** – Through HealthBridge, physicians can access hospital information systems as well as their own office EMR systems; billing companies can access the clinical information needed for billing purposes; and hospitals and physicians no longer have to worry about developing separate interfaces between a hospital and a physician office EMR.

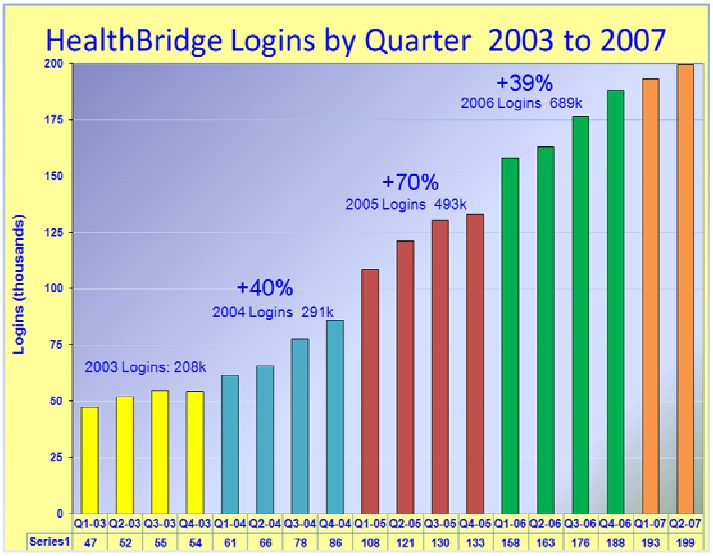
- **Coding assistance and clinical reference tools** – Billing software for physician offices dramatically reduces billing errors and improves reimbursements. Online reference tools assist with clinical decision support.

- **Administrative Functions** – Hospital and physician office staff can verify insurance eligibility of patients, check the status of claims, submit referral requests online, and search for National Provider Identifier numbers, saving time and making office workflow more efficient.

- **Electronic Disease Reporting and Public Health Alerts** – Hospitals and labs can meet their mandated public health reporting requirements within minutes rather than days due to the automatic disease reporting capability within the HealthBridge system. The web portal also provides public health alerts to health care practitioners.

- **Ambulatory Order Entry (AOE)** – HealthBridge operates a community-based ambulatory order entry system allowing hospitals to receive lab orders from physician offices electronically with medical necessity and order management tools and order manifests.





healthLINC
CONNECT. CARE. COLLABORATE.

September 2008

HealthLINC
https://www.healthlinc.org
714 S Rogers Street
Bloomington, IN 47402
(812) 353-4025

HealthLINC Overview

The mission of HealthLINC is to provide the infrastructure, support services, and a collaborative environment that enables providers and public health to share clinical information across organizational lines to improve the quality, safety, and efficiency of care in South Central Indiana. Over time, services will be expanded to involve consumers, employers, and health plans. HealthLINC is one of the only operational HIEs that successfully extends its reach to rural areas.
HealthLINC's key responsibilities are to:
1. Establish a shared vision, direction, and goals
2. Represent community-wide stakeholder interests to ensure that the requisite infrastructure is developed and maintained to support a fully integrated electronic health care delivery system and HIE
3. Interface with other communities, granting agencies, and regional and national electronic organizations.

Impact

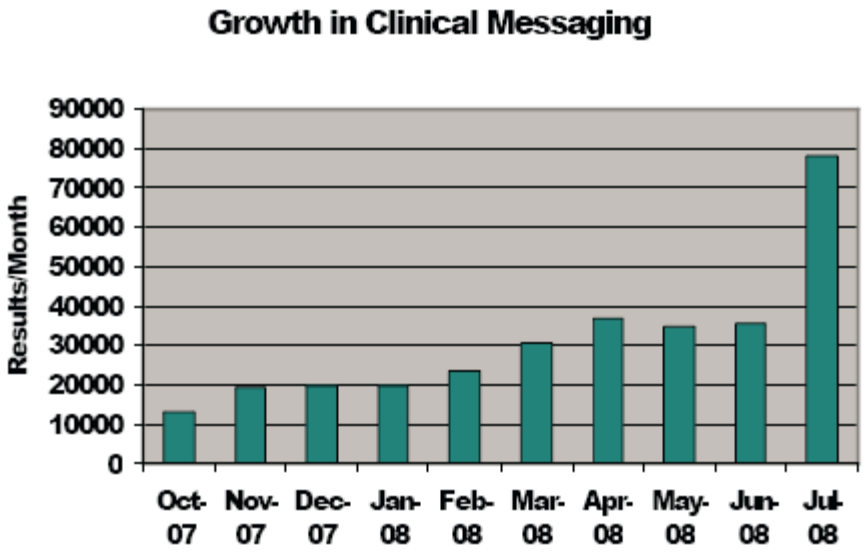
In 2003 only 0-3 percent of the medical practices used an EMR in Monroe and Orange Counties for their patients. By 2008, 50% of the physician practices in Monroe and an amazing 76% of the practices in Orange have functional electronic medical records for their patients. This progress was directly facilitated by HealthLINC activities.

HealthLINC governs a regional HIE that provides secure, clinical messaging system that delivers greater than 70,000 medical results per month between the hospital, private practices and the two indigent care clinics. This system reduces redundant testing and "turns the paper off" resulting in cost savings that will translate into reduced health care costs. These systems also benefit the community by reducing the incidence of lost or misplaced test results and, therefore, ensure timely medical action is taken if needed.

HealthLINC is a true community collaboration that includes greater than 85% of the community physicians and has benefited from funding directly from the physician community. Community partners are numerous and include Bloomington Hospital, Centerstone Research Institute, Internal Medicine Associates, Southern Indiana Radiological Associates, and Volunteers in Medicine of Monroe County.

Partnerships

HealthLINC members include greater than 85% of the physician practices in a multi-county area of South Central Indiana. Key Partners include:
Bloomington Hospital
Bloomington Hospital of Orange County
Centerstone Research Institute
Internal Medical Associates
Southern Indiana Radiological Associates
Volunteers in Medicine of Monroe County



HealthLINC Leadership

Todd Rowland, MD
Executive Director t: (812) 353-4025 e: trowland@bloomingtonhospital.org
Kathy Church, BSN, PMP
Clinical Operations – t: (812) 353-4026 e: kchurch@bloomingtonhosptial.org

Last updated September 12, 2008

HIEx™, **H**ealthLink **I**nformation **Ex**change is robust web based integrated health information data system that captures demographic, social services and clinical data at point of care, and organizes the data by household and by individual in a central data repository. This shared community health record is designed as a "public information utility" using current industry standards and best practices. HIEx™ was developed by Wright State University's www.wright.edu Center for Healthy Communities www.wright.med/chc/ with initial support from the Community Health Access Initiative, Health Resources Services Administration, US Department of Health and human Services, to provide an electronic shared community health record facilitating increased access to care, and improved coordination and quality of care for underserved members of the community. HIEx™ is offered on an annual low cost subscription basis, and accessed across a VPN to authorized users from public sector safety net organizations providing health and social services. The collaborative governance structure for the HIEx™ system is HealthLink Regional Health Information Organization (HealthLink RHIO).

The **HealthLink RHIO** is administered by the Center for Healthy Communities as West Central Ohio's focus for health information exchange. HealthLink has worked as a community collaborative since March 2000 and has representation from all major safety net providers in the Dayton area. Information about the work of this collaborative is documented at www.med.wright.edu/healthlink .

Contact Kate Cauley, PhD, Project Director at Katherine.cauley@wright.edu or 937 775 1120

Last updated September 12, 2008

Key Stakeholders

Dayton Public Schools

CareSource Managed Care Group

Clark and Champaign County Health Information Exchange

Compunet

Health Policy Institute of Ohio

Kettering Health Network

Montgomery County Job and Family Services

Ohio Department of Job and Family Services

Ohio Department of Health

Ohio Health Information Partnership Advisory Board

Premier Community Health

Wright State University Boonshoft School of Medicine Departments of Community Health, Family Medicine, Geriatrics, and Pediatrics

WRIGHT STATE UNIVERSITY

BOONSHOFT SCHOOL of MEDICINE
WRIGHT STATE UNIVERSITY

INDIANA UNIVERSITY
SCHOOL OF MEDICINE

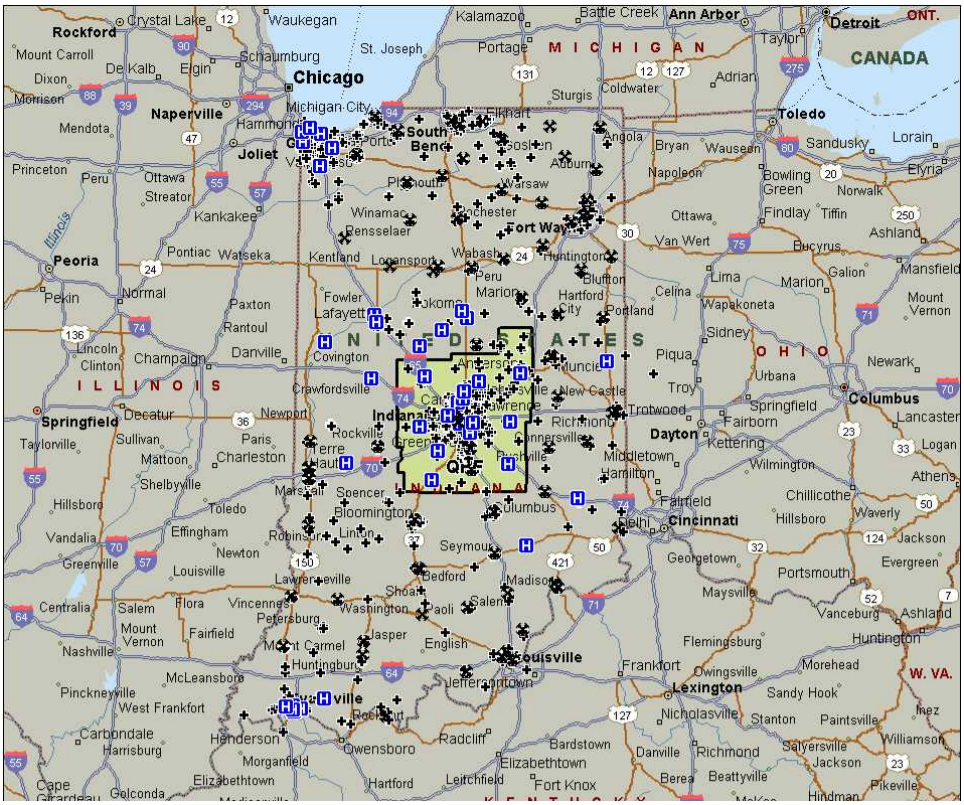
Regenstrief Institute
Advancing health care through research, development and education.

INDIANA UNIVERSITY / REGENSTRIEF INSTITUTE

Indiana provides health information exchange services such as public health surveillance and a clinical messaging service to citizens (approximately 6.5 million) across much of the State of Indiana, and more extensive services, such as a shared clinical data repository and a quality improvement program to residents of Central Indiana (approximately 1.7 million).

The health information exchange includes a broad array of participants and members including competing health systems, physician practices, public health agencies, payors, Indiana State Medicaid and researchers. The Regenstrief Institute, acting on behalf of the participants created and operates the exchange including serving as the custodian of the data. The Institute is a not-for profit supporting organization of Indiana University.

Figure 1. The "H" designates hospitals, and crosses are provider practices (almost 10,000)



Clinical Data Repository: Indiana Network for Patient Care (INPC) – The INPC is a 13-year old operational community-wide secure data exchange. It is a centrally managed federated clinical data repository that supports a variety of services, and is a long-term partnership among the major Indianapolis hospital systems which provide care for the 553 square mile Indianapolis urban metropolitan area.

Today, it collects nearly 13 million HL7 messages per month from over 25 geographically separate hospitals, public health departments, and more than 100 clinics and imaging facilities, distributed across Indianapolis and its collar counties and continues to expand. The INPC repository carries over 1 billion discrete observations; 25 million text reports; over 80 million radiology images; and 750,000 EKG tracings and 16 million different patient registrations.

INPC participants deliver registration records (demographics), laboratory data, ED, inpatient and outpatient encounter data including free-text chief complaint, and coded diagnoses and procedures (including length of stay) for hospital admissions and emergency room visits. The system standardizes all clinical data as it arrives. INPC allows physicians working in an emergency department and within other hospital settings in any of the participating hospitals to view a patient's previous care information from all participating institutions as a single virtual record.

Public Health Electronic Syndromic Surveillance (PHESS) – Indiana passed a law to require hospitals with emergency departments to electronically provide a certain core set of data elements to the Indiana State Department of Health (ISDH) on a real-time or near real-time basis, such as chief complaint. Currently, there are 76 hospitals (represented by the numbered squares on the map) out of 114 live, and over 6,000 ED encounters are delivered to ISDH daily as well as to BioSense through the ISDH.

Clinical Messaging: DOCS4DOCS® service (D4D) – This system receives lab result and other clinical messages from the participating data sources (e.g., a hospital's lab), converts the clinical results into a consistent, easy to use report format, and delivers it to a secure, web-based inbox for the intended responsible provider. The results can also be transmitted via HL7 directly to a practice's EMR system or via fax for physicians who prefer fax. D4D service delivers electronic copies of discharge summaries, operative notes, EKGs, and radiology reports from the five major Indianapolis hospitals, and more are being added. D4D service currently connects to more than 3,200 Indianapolis practices and 9,600 individual physicians, and delivers approximately 50,000 results per day.

Quality Improvement: Quality Health First® program (QHF) – The QHF program was designed by the Indiana Health Information Exchange, Inc. (IHIE) and the Employers' Forum of Indiana. It builds upon the Indiana Network for Patient Care (INPC) system that securely aggregates and accurately delivers patient information such as lab results, reports, medication histories, treatment histories and more in a standardized, electronic format, across all providers. As a disease management, preventive care and reporting service, the QHF program provides physicians and staff with disease management reports and clinical alerts and reminders, along with population-based reports to participating health plans.

Contact Information:
J. Marc Overhage, M.D., Ph.D.
Professor of Medicine, Indiana University School of Medicine
Director of Medical Informatics, Regenstrief Institute, Inc.
410 West Tenth Street, Suite 2000, Indianapolis, IN 46202-3012
Web sites: http://www.regenstrief.org/medinformatics/inpc and http://www.ihie.com

KAISER PERMANENTE®

About Kaiser Permanente
Kaiser Permanente is America's leading integrated health plan. Founded in 1945, the program is headquartered in Oakland, Calif. Kaiser Permanente serves 8.7 million members in nine states and the District of Columbia. Today it encompasses Kaiser Foundation Health Plan, Inc., Kaiser Foundation Hospitals and their subsidiaries, and the Permanente Medical Groups. Nationwide, Kaiser Permanente includes approximately 159,000 technical, administrative and clerical employees and caregivers, and 14,000 physicians representing all specialties. The organization's Labor Management Partnership is the largest health care partnership in the United States. It governs how more than 130,000 workers, managers, physicians and dentists work together to make Kaiser Permanente the best place to receive care, and the best place to work.

Building the World's Largest Civilian Electronic Health Record
Kaiser Permanente HealthConnect™ is a comprehensive health information system that includes one of the most advanced electronic medical records available. It securely connects 8.6 million people to their health care teams, their personal information, and the latest medical knowledge, leveraging the evidence-based approaches to health care available at Kaiser Permanente. KP HealthConnect facilitates communication between members and Kaiser Permanente professionals to help make staying healthy and getting well even more convenient.

- More than 100,000 physicians, nurses and other employees in more than 430 medical offices and 36 hospitals consult KP HealthConnect to care for their patients on a daily basis.
- As of April 2008, all Kaiser Permanente members are cared for with an electronic medical record during outpatient encounters.
- A fully integrated inpatient-outpatient electronic medical record is currently available in 16 hospitals, covering more than 5 million members. That will increase to nearly seven million over the next two years.
- Integrated electronic disease registries draw on KP HealthConnect data to provide a patient-centered view of various chronic conditions facilitating the delivery of recommended care.

The development, implementation, and maintenance of KP HealthConnect is a multi-billion dollar strategic investment for Kaiser Permanente – one that is already improving the quality of care and service to our members. It ensures patient safety and quality care by providing access to comprehensive patient information and the latest best practice research in one place. KP HealthConnect also supports the coordination of patient care between primary care and specialty physicians' offices, the hospital, radiology, the laboratory, and the pharmacy – eliminating the pitfalls of incomplete, missing, or unreadable paper charts. Various efforts throughout the organization have begun to demonstrate opportunities to redesign care to improve clinical outcomes, patient satisfaction, and system effectiveness. In addition, KP HealthConnect will ultimately enable us to streamline and retire many outdated information systems.

Taking Personal Health Records to a New Level
While other personal health records (PHR) allow patients to view their information online, at Kaiser Permanente, we provide them with the tools to manage their health. My Health Manager on kp.org takes the PHR to new levels by linking directly to KP HealthConnect. By providing our members with access to their clinical record and unique time-saving tools to interact with both their providers and health plan, My Health Manager goes well beyond standard PHRs.

- More than 2.3 million Kaiser Permanente members have activated their PHR on kp.org, making it one of the most actively used PHRs in the world.
- More than 500,000 secure e-mail messages are sent each month to Kaiser Permanente doctors and clinicians, demonstrating growing consumer interest in e-visits.
- More than 12 million lab test results have been viewed online by Kaiser Permanente members.

For more information, contact us by e-mail at KPHealthConnectCommunications@kp.org.

LBNH AS A HEALTH INFORMATION EXCHANGE:

Long Beach Network for Health (LBNH) is a non-profit organization created in 2003 as a Health Information Exchange (HIE) in the Los Angeles metropolitan area. As a public private collaboration of physicians, hospitals, health care organizations, and patient advocates, LBNH is committed to improving the quality and continuity of healthcare for area residents through the improved access and use of relevant clinical data.

LBNH MISSION AND GOALS:

LBNH's mission is to promote enhanced health for the greater Long Beach community through:

- Improving the timely availability of clinical data across care delivery networks and locations
- Providing an infrastructure to enable real-time access to current clinical data from disparate data sources at the time and point of care

OUR APPROACH:

To begin to realize these goals, LBNH has been awarded funds to initially facilitate Emergency Department (ED) providers in supporting health consumers and enhance quality of care. LBNH seeks to provide an integrated view of patient information to EDs by building a virtual medical record from the participants' information systems.

Participants include:

- Long Beach Memorial Medical Center
- LA County Harbor – UCLA Medical Center
- Talbert Medical Group
- Memorial HealthCare IPA
- Miller Children's Hospital

COMMUNITY FOCUS:

LBNH supports the community by closely aligning with public health goals and keeping those at the center of their mission. LBNH recognizes that providing care to the safety net population represents a significant expense to and responsibility for the Long Beach health care community. Therefore, LBNH supports the community through improved access to quality healthcare for all and improved care coordination across multiple providers.

PARTNERSHIPS:

LBNH seeks to enhance coordination of health care agencies through real time access to health data. Partnerships include: State and Local Health Departments, Community and Privately-run hospitals, Medical groups, Clinics, and Health Plans.

LOOKING TO THE FUTURE:

LBNH looks forward to improving patient health outcomes by supporting the implantation and utilization of cutting edge technology. In the coming years, LBNH will endeavor to provide additional services and support to the public health community through:

- Health Information Exchange Portals in Safety Net Settings
- Expansion of Data Contributors
- Disease Management Applications
- Community Health Assessments
- Health Literacy Materials
- Referral Management

FOR MORE INFORMATION:

Visit our website at www.lbnh.net

Email: lbnhinfo@lbnh.net

ENABLING QUALITY HEALTH CARE – FOSTERING HEALTHY COMMUNITIES

New Mexico Health Information Collaborative (NMHIC)

Operated by Lovelace Clinic Foundation (LCF)

The New Mexico Health Information Collaborative (NMHIC) is the name of New Mexico's rapidly growing health information exchange (HIE) network and the community collaborative that has supported its development with time and funding. The collaborative includes important New Mexico stakeholders representing health care providers, payers, employers, state agencies and consumers. NMHIC was created in 2004, and continues to be fully staffed and operated by the Lovelace Clinic Foundation (LCF). LCF is a 501(c)(3) non-profit applied health research organization.

Mission

To create a statewide health information exchange network that is sufficiently trusted and valued by all stakeholders (employees/patients, employers, physicians, health systems and health plans) so that it will improve coordination and continuity of care.

Goals

- Improve statewide benefits, such as continuity of care and lower costs, by providing rapid access to patient health care information from multiple health care facilities across the community.
- Provide additional cost savings for the community by reducing redundant clinical tests and results reporting for the same patient.
- Secure the trust of consumers, patients and providers by providing strong privacy and security safeguards for health care information.
- Implement appropriate interoperability, privacy and security capabilities so that NMHIC can be certified by the Certification Commission for Health Information Technology (CCHIT).
- Interoperate with other NHIEs within the Nationwide Health Information Network.
- Facilitate improved public health services, including mandatory reporting, monitoring of health status, and the ability to respond more quickly to health emergencies.
- Empower consumers to understand and access personalized health information to facilitate active management of their health.
- Utilize health information technology to provide health care services to rural and underserved populations.
- Encourage the adoption of electronic health records systems in New Mexico by making it easier and less costly to securely share information over electronic networks.
- Facilitate public reporting of patient outcomes and quality measures.

NMHIC Network Services

The NMHIC Clinician Portal includes:

- Summary Patient Record: Access to a patient's Summary Patient Record, also referred to as a Continuity of Care Record, portable amongst different health care systems and providers, for key patient data. This data would usually include: problem list/diagnoses, medication list, allergy list, immunizations, procedures, and dates of service and names of providers, viewed through the NMHIC Clinician Portal.
- Lab Results: Access to a patient's laboratory results from multiple laboratories, viewed through the NMHIC Clinician Portal.
- Radiology and Imaging Reports: Access to a patient's radiology and imaging reports from multiple radiology providers, viewed through the NMHIC Clinician Portal.
- Discharge Summaries: Access to a patient's discharge summaries from multiple hospitals, viewed through the NMHIC Clinician Portal.
- Access to patient record information via the Nationwide Health Information Network (NHIN). NMHIC users will also be able to access patient record information from other organizations that are connected to the NHIN, including the Veterans' Health Administration, the Department of Defense Military Health System, the Indian Health Service, etc., viewed through the NMHIC Clinician Portal.

NMHIC Service Area

The State of New Mexico has a population of 2 million persons.

LCF/NMHIC Executives

Margaret J. Gunter, PhD, President and Executive Director of LCF
Jeffrey S. Blair, MBA, Director of Health Informatics
Robert E. (Bob) White, MD, MPH, Director of Medical Informatics
David Perry, Chief Information Officer

NMHIC Technology Partner

MedPlus, Inc. (513) 229-5500, 4690 Parkway Drive, Mason, Ohio 45040

NMHIC Stakeholders Participating in NHIN Trial Implementations

Presbyterian Healthcare Services: Dennis Angellis, MD, Chief Medical Officer of Presbyterian Health Plan
TriCore Reference Laboratory: Erv Klink, PhD, Chief Information Officer
Department of Health, State of New Mexico: Robert Mayer, Chief Information Officer
Holy Cross Hospital, Taos, New Mexico: Kean Spellman, Chief Executive Officer
Albuquerque Ambulance: Robert Garcia, Regional New Mexico VP of Operations

NMHIC Contact:

Jeff Blair
(505) 938-9904
jeff.blair@lcfresearch.org
Lovelace Clinic Foundation
2309 Renard Place SE
Albuquerque, NM 87106
www.LCFresearch.org

MEDVIRGINIA

Central Virginia's Regional Health Information Organization

About MedVirginia

MedVirginia LLC, established in 2000, is owned by a consortium of not-for-profit hospitals and physicians in Central Virginia. Its organizational purpose is to improve quality, safety and efficiency through the use of health information technology. Its vision is for Central Virginia to be the most electronically connected medical community in the U.S. At its core is an operational community-based health information exchange (HIE) linking clinical data from physicians, hospitals, labs and pharmacies.

MedVirginia Solution[sm]

MedVirginia Solution is a single source for patients' clinical information. It links healthcare providers enabling them to share clinical information through a secure, HIPAA compliant, on-line portal. MedVirginia Solution collects clinical data from multiple data sources, e.g. hospitals, outpatient centers, labs, pharmacies, and organizes it into a patient-centric electronic chart. Secure messaging is provided amongst users.

Solution provides a "stepping stone" approach to technology adoption. Providers may begin with basic functionality free of charge and later add a cost effective suite of services that includes: Practice Management System Interface, Surescripts-certified e-Prescribing, and integration of Practice Notes.

MedVirginia Statistics and Facts

- MedVirginia's HIE has been operationally live since January, 2006.
- Its Master Patient Index houses over 500,000 patients.
- More than 1 million messages are processed each month.
- Its User Base has 100+ practices, 330+ physicians and over 1,100 total users.
- Technology partners include Wellogic and IBM.
- MedVirginia automated Richmond-area free clinics using funds from Gov. Kaine's Health IT Council.
- Participates in the Nationwide Health Information Network Trial Implementation under contract with the U.S. Dept of Health and Human Services.
- Its CEO serves as state-wide Convener for the CMS EHR Demonstration and authored the Commonwealth's winning application that will provide CMS funding for EHR adoption.

Board Members and CEO

James E. Ratliff, M.D., Board Chair
John D. Bowman, M.D., Board Member
Jeffrey D. Burke, Board Member
Eric P. Cote', M.D., Board Member
William F. Moore, M.D., Board Member
Michael Matthews, CEO

MedVirginia, 2201 W. Broad Street, Suite 202, Richmond, VA 23220 ph 804.359.0671 www.medvirginia.net

New York eHealth Collaborative (NYeC)

Executive Director: Rachel Block

The New York eHealth Collaborative (NYeC) was founded by health care leaders across the state, with leadership and support from the New York State Department of Health, based on a shared vision of the urgent need to improve health care quality, safety and efficiency in New York. NYeC is a public-private partnership that serves as a focal point for health care stakeholders to build consensus on state health IT policy priorities, and to collaborate on state and regional health IT implementation efforts, in order to improve the organization, delivery and outcomes of health care for all New Yorkers. NYeC is a trusted, independent voice that can reflect a diverse array of interests and perspectives on key policies and standards to ensure that health IT implementation efforts are successful, and to realize the state's return on investment under HEAL-NY and other funding mechanisms.

NHIN Project

NYeC's NHIN core services project involves two regional health information organizations (RHIOs), the Manhattan-based New York Clinical Information Exchange (NYCLIX) and the Long Island Patient Information Exchange (LIPIX). Computer Sciences Corporation is overseeing technical implementation of the NYeC NHIN project. NYCLIX's technical solution is implemented by MedPlus, and LIPIX's technical solution is implemented by InterSystems.

In June 2008, as part of the NHIN project NYCLIX and LIPIX demonstrated the secure exchange of patient information between providers operating in two separate New York metropolitan area communities. A Visiting Nurse Service of New York (VNSNY) nurse used the NYCLIX network to securely access medical history for a patient from North Shore LIJ Health System's records through the LIPIX network; in addition a North Shore LIJ physician was able to access the history for a patient from VNSNY's records through NYCLIX. This type of live clinical data exchange between RHIOs, utilizing different technical vendors and national standards, is one of the first of its kind in the United States, and provides valuable lessons for broad nationwide application.

The results and lessons of the NHIN project will inform the statewide collaborative process managed by NYeC which is setting policies and technical requirements for the Statewide Health Information Network of New York (SHIN-NY). Development of the SHIN-NY is a key part of New York's strategy to improve health care quality and efficiency through interoperable health information exchange and electronic health record adoption.

NYeC is working with several other organizations to demonstrate its two NHIN use cases. Two other RHIOs, the Albany-based Healthcare Information Xchange of New York (HIXNY) and the Buffalo-based HealtheLink, will demonstrate the medication management use case; the New York City Department of Health and Mental Hygiene and Taconic Health Information Network Community (THINC) RHIO will demonstrate the Quality Use Case.

NYeC Contact Info:
Phone: 646-619-6726
Email: alow@nyehealth.org
Web Site: http://www.nyehealth.org

What is LIPIX?

LIPIX is an independent not-for-profit corporation established to develop a Regional Health Information Organization (RHIO), aka a Health Information Exchange (HIE), on Long Island.

Participant Organizations

North Shore University Hospital	Nassau Universtiy Medical Center
Long Island Jewish Hospital	South Nassau Communities Hospital
NSLIJ Home Care	North Shore IPA
Core Lab	Cold Springs Nursing Home
NSLIJ's Center for Emergency Medical Services	Nassau County Department of Health
Southside Hospital	

Our Mission

To create an achievable, sustainable and replicable solution for integrating clinical information across multiple health care organizations, which supports New York State and Federal strategic HIT plans to improve access to patient data at the point of care, improve health care quality, and reduce inappropriate health care resource utilization.

Secondary Goals

* Foster collaboration amongst disparate health care entities.
* Promote interoperability through the use of nationally defined standards.
* Create project monitoring and evaluation tools to measure clinical benefits and reductions in inappropriate utilization and cost associated with HIEs.
* Demonstrate improvements in public health through the implementation of innovative functionality to support regional public health initiatives.
* Create a revenue model that provides financial sustainability to HIE projects.

Contact Information

Benjamin Stein, MD
Executive Director
LIPIX, Inc.
1554 Northern Blvd., Suite 202
Manhasset, NY 11030
Phone: (516) 719-3728
Email: BStein1@NSHS.edu

www.nyclix.org

New York Clinical Information Exchange

A not-for-profit regional health information organization (RHIO) collaborative that includes New York City's premier academic medical centers and other key health care stakeholders in a partner ship designed to create a robust clinical data exchange across the care continuum.

NYCLIX Member Organizations

Manhattan

Bellevue Hospital Center
Continuum Health Partners
- *Beth Israel*
- *Roosevelt Hospital*
- *St. Luke's Hospital*

Memorial Sloan-Kettering Hospital
Mount Sinai Medical Center
New York- Presbyterian Hospital
NYU Langone Medical Center
St. Vincent Catholic Medical Center

Home care
The Visiting Nurse Service of New York

Long Island
Long Island Jewish Medical Center

Brooklyn
Kings County Hospital
SUNY Downstate Medical Center

Staten Island
Staten Island University Hospital

Physician Organizations
Institute for Family Health
Columbia University Medical Center Faculty Practice Organization

Services

The NYCLIX interoperable clinical data exchange will provide members with patient data from multiple disparate sources via a secure Web-based portal. The initial use case for the NYCLIX exchange is designed to enable emergency care practitioners to access aggregated, multi-site, historical patient data that includes clinical documentation, prescription drugs, and laboratory and radiology results. The breadth and depth of the patient information will improve emergent care by giving the care team the information they need to provide safe, high quality care, especially to the vulnerable population with chronic disease and multiple co-morbidities. Going forward, the NYCLIX platform will also support our members' commitment to achieving safe and successful acute and chronic disease management transitions at all levels of care.

www.nyclix.org

Population Served

NYCLIX members provide care to New York City and surrounding area residents, accounting for 1.15 million physician visits, 8400 hospital beds, 2.5 million patient days, 700,000 emergency room visits, and 2 million home care visits annually.

KEY EXECUTIVES

Gilad Kuperman, MD, PhD (Board Chair)
NewYork-Presbyterian Hospital

Thomas Check (Vice Chair)
Visiting Nurse Service of New York

Bert Robles (Secretary)
SUNY Downstate Medical Center

Paul Conocenti (Technical Committee Chair)
NYU Medical Center

Catherine Egan (Deputy Executive Director)
NYCLIX, Inc.

CONTACT INFORMATION

Gilad Kuperman, MD, PhD
Board Chair
NYCLIX, Inc.
c/o 525 East 68th Street, Box 437
New York, NY 10065
Phone: 212-585-6847
Fax: 212-585-6750
gkuperman@nyp.org

NCHICA

North Carolina Healthcare Information and Communications Alliance, Inc.

Improving health and care in NC by accelerating the adoption of information technology and enabling policies

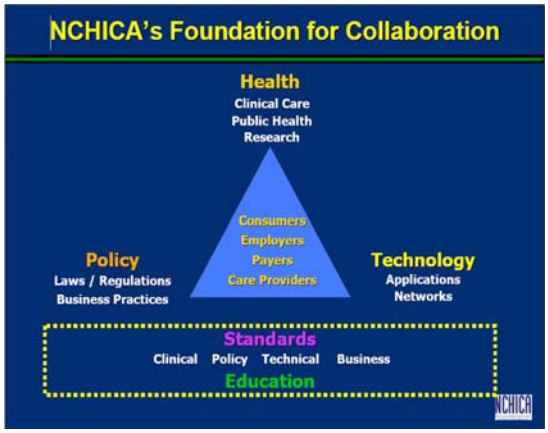
NCHICA has participated in both Phase 1 (Architectural Prototypes) and Phase 2 (Trial Implementations) of the Nationwide Health Information Network (NHIN) contracts awarded by Health and Human Services.

The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA) is a unique and nationally recognized nonprofit consortium that serves as an open, effective and neutral forum for health information technology (health IT) and policy initiatives that improve health and care in North Carolina, the nation's tenth most populous state. Approximately 200 members include leaders in business, government, healthcare, research and information technology.

Since being founded by an Executive Order of the Governor of North Carolina in 1994, and working in collaboration with its members, NCHICA has demonstrated the unique ability to convene and form partnerships to advance health IT and consensus-based policy adoption. NCHICA's leadership in conducting demonstration projects, hosting educational sessions and fostering collective efforts within North Carolina has positioned the state at the vanguard of national health IT and health information exchange (HIE) acceleration.

NCHICA members include:

- Hospitals, clinics, medical practices, and public health organizations
- Professional societies and associations
- State, local and national health agencies
- NC employers and health plans
- Legal and accounting firms
- Healthcare consulting firms and vendors
- Health education and training providers
- Research Organizations



NCHICA: Initiatives and Impact

NCHICA conducts projects that demonstrate the value of IT in healthcare

- Nationwide Health Information Network Phases One and Two (HHS/ONC)
- Health Information Security and Privacy Collaboration (HISPC) contract phases one to three (RTI/ONC)
    - Currently participating in HISPC Consent – Policy Options and Interorganizational Agreements collaborative efforts

NCHICA hosts educational sessions including

- NCHICA Annual Conference and Exhibition
- Academic medical center conferences
- HIPAA education and training sessions
- Workshops on advanced clinical topics

NCHICA fosters collaborative efforts through committees and workgroups

- NC Health Information Exchange (HIE) Council
- NC Consumer Advisory Council on Health Information
- Privacy and Security Officials Workgroup
- CIO Roundtable
- Transactions, Code Sets and Identifiers Workgroup
- National Provider Identifier (NPI)Task Force

NCHICA's major state initiatives

- Statewide Patient Information Locator (MPI): 1994-1995
- NC Model Privacy Legislation: 1995-1999
- NC Immunization Database/PAiRS: 1998-2005
- NC Emergency Department Database (NCEDD-NC DETECT): 1999-Present

NCHICA's contributions to major national initiatives

- HIPAA Regulations (model policies and compliance tools): 1996-Present
- National Governors Association State Alliance for e-Health, Security and Privacy Task Force: 2006-Present
- Timeline (CPM) Scheduling and Planning tool for Implementation of Federal Regulations: 2007-Present
- Policy Template for Protection of Laptops and Removable Media Security, and related Vendor RFP Template: 2007

NCHICA is engaged in three 'Use Cases' (scenarios of health information exchange) for NHIN 2

- Consumer Empowerment: Access to Clinical Information - Personal Health Records
- EHR: Lab Results Reporting
- SSA Authorized Release of Information to a Trusted Entity

NCHICA: NHIN 2 Trial Implementation Collaborators

NHIN 2 participating providers provide input and interaction at the clinical level

NCHICA members with NHIN 2 key solutions/ applications

NHIN 2 additional solution providers

- Allscripts
- Apelon
- eClinicalWorks
- Interfaceware
- Meditech
- NoMoreClipboard.com

NCHICA: NHIN 2 Trial Implementation Progress in North Carolina

Ongoing NHIN 2 activities include development of sustainability plans, consent policies, data use and reciprocal support agreements as well as the deployment of technology and enabling policies to enable statewide and region-wide HIE. The coordination and focusing of these efforts have provided significant foundational value to North Carolina.

NCHICA is proud to be a participant in this important second phase of the NHIN project which uses nationally accepted standards to prove the value of local, community based exchange of information within a nationwide network of networks. As the sole organization exercising the Consumer Access to Clinical Information, NCHICA expects to better understand consumers' interest in the secure, private, and reliable HIE capabilities within individual control.

NCHICA established a Steering Committee for the NHIN contract and the NC HIE Council to provide comprehensive guidance on policies and procedures and to develop a consensus-based strategy for deployment of HIE statewide across all settings of care. NCHICA's activities complement the technical, architecture and project management methodology provided by its leading subcontractor, IBM.

The comprehensive NHIN project lays the groundwork for significant impact to the nine million residents of the state by creating a trial environment for provider's connectivity in NC, a means to develop policies to govern HIE in the state, and a business plan for the use of HIE across the state. Future plans include involving NC healthcare stakeholders in using NHIN-developed HIE to respond to the demands for information at the community level between hospital to physician. The NHIN initiative may also be leveraged to support statewide programs such as the Medical Home Movement led by the North Carolina Community Care Network / NC Medicaid for which NC is considered a national leader.

NCHICA envisions an ever increasing network of networks within the state, and among interstate HIE, as needed to securely provide information for the best possible health outcomes. The SSA Use Case is providing NC an exposure to practical implementation of the extended value possible from standards based HIE. NCHICA will continue to work to enable successful exchange of health information for the residents of North Carolina.

NCHICA
PO 13048, 3200 Chapel Hill/Nelson Blvd.
Cape Fear Building, Suite 200
Research Triangle Park, NC 27709-3048
919-558-9258 (ph); 919-558-2198 (fax); www.nchica.org

Social Security Administration

6401 Security Blvd.
Baltimore, MD 21235
www.ssa.gov

General Overview

The Social Security Administration (SSA) touches the lives of virtually every person in America. Whether it is at the onset of disability, after the loss of a loved one, or during the transition from work to retirement, the Agency's programs and employees provide support to the people of this country, often during times of personal hardship, transition, and uncertainty.

Strategic Goals

All of the work done by SSA is intended to advance the administration toward four strategic goals:

- To deliver high-quality, citizen-centered service – Service to the public requires not only a high degree of compassion, but also accuracy, productivity, cost-effectiveness, timeliness, and service satisfaction. SSA is firmly committed to continuously assessing Social Security programs and services to meet the needs of current and future generations.
- To protect the integrity of Social Security programs through superior stewardship – Superior stewardship goes beyond sound money management. It includes strengthening the integrity of the Social Security number, securing SSA's information systems, and protecting the integrity and privacy of the personal information that SSA maintains.
- To achieve sustainable solvency and ensure Social Security programs meet the needs of current and future generations – The aging of the Nation's population has profound, long-term implications on the sustainable solvency of Social Security programs. New patterns of work and earnings, marriage, divorce, and childbearing affect the characteristics of families. Individuals are living longer and healthier lives. The first wave of the baby boomer generation will be eligible to retire in 2008. SSA is working with elected officials and other executive agencies to secure Social Security for meeting the needs of current and future generations.
- To strategically manage and align staff to support the mission of the Agency – To address the coming retirement wave, SSA has developed a strategic *Human Capital Plan* detailing how SSA will use staffing to meet the Agency's mission and goals.

Workloads

Annual major workloads include:

- Social Security Cards - SSA issues about 18 million new and replacement Social Security cards.
- Social Security Benefit Claims - SSA processes more than 6.5 million new claims for retirement, disability, and survivors benefits each year.

- Supplemental Security Income (SSI) Claims - SSA processes over 2.5 million new claims for SSI benefits each year.
- SSI Redeterminations - SSA conducts over 1 million SSI reviews each year.
- Changes to existing records - SSA processes over 39 million changes to existing Social Security and SSI records each year, such as a change of address.
- Payments and checks - SSA processes over 52 million actions relating to payment of monthly SSI and RSDI checks and all activities related to conversion from one type of RSDI benefit to and other.
- Annual earnings - SSA processes approximately 270 million annual earnings reports.
- Office visits - Nearly 43 million people visit a Social Security office each year.
- Telephone calls (800 number) - Over 58 million calls are handled by SSA's nationwide toll-free telephone service each year.
- Social Security Online - Last year SSA had over 54 million visitors to its Internet site.

Scope of Coverage

Social Security provides financial protection to more than 160 million workers and their families, and pays approximately $580 billion annually in benefits to more than 49 million Americans who receive monthly Social Security retirement, disability or survivors benefits. The Supplemental Security Income (SSI) program pays monthly benefits to more than 7 million Americans who have little or no resources and who are aged, blind or disabled.

From a disability standpoint, over 2.5 million of the more severely affected individuals or their representatives apply for disability benefits with SSA annually. Some apply based on having paid for this disability insurance while working; others apply based on financial need for additional support. All of these people deserve to have SSA minimize the effort and difficulty associated with pursuing a disability claim, and allow them to concentrate their energy and resources on addressing their disability.

Leadership

The Commissioner of Social Security is Michael J. Astrue. Astrue was nominated by President George W. Bush on September 14, 2006, and confirmed by the United States Senate on February 2, 2007. Commissioner Astrue has a distinguished history of public service. He is a former employee of the Social Security Administration, having served as Counselor to the Commissioner. He served as General Counsel of the U.S. Department of Health and Human Services and as the Acting Deputy Assistant Secretary of Legislation. Astrue also served briefly as Associate Counsel to the President of the United States during parts of both the Reagan and Bush administrations. Before becoming Commissioner, he also served as a senior executive of several biotechnology companies.

The Social Security Administration is an independent federal agency headquartered in suburban Baltimore with a national workforce of about 62,000 employees and 1,500 facilities nationwide.

100 Dee Drive
Charleston, West Virginia 25311
304.558.4503
304.558.7001 fax
www.wvhin.org

Contact Information Sallie Milam, JD, CIPP/G
Executive Director
smilam@hcawv.org

The West Virginia Health Information Network (WVHIN) will support the state's physicians, health care providers and consumers through providing optimal patient care via the electronic delivery of medical data.

As a public/private partnership created in 2006 at the request of Governor Joe Manchin III, WVHIN will furnish data services to the broad range of health entities serving patients. "It's important to realize information technology's impact on productivity and profitability in other businesses. If we can make similar investments in information technology for health care, we can bend the curve of overall spending from more than 20 percent of gross state product, which is the highest in the nation, to something more manageable, while increasing the health and economic status of our citizens," stated Governor Manchin.

A 17-member board of directors representing both public and private stakeholder organizations manages the WVHIN. Twelve of these have permanent appointments as designated in the enabling legislation. The governor appoints five public members.

The WVHIN board chairman, Julian Bailes, MD. West Virginia University, stated, "Our paper-based methods are becoming obsolete as health care becomes more computerized and we respond to the national mandate for West Virginia to convert to an electronic medical records system."

The WVHIN is projecting a third quarter 2009 rollout of clinical messaging services aimed at increasing efficiency and saving costs by replacing paper results with electronic ones.

The second phase will allow physicians and providers to request patient data at the time and place needed for care delivery. Referred to as the "query" phase, it will reduce duplicate testing and improve care coordination.

The third phase will facilitate longitudinal analysis of date from multiple sources enabling huge strides in ultimate patient care.

West Virginia's patient population has been, and will continue to be, of primary importance in the network. The WVHIN board established a consumer/employer committee that recently forwarded its recommendations regarding privacy and security policies. The committee's agenda focused on;

- individual rights and participation,
- consumer notice,
- HIPAA requirements,
- security safeguards, and
- consent and authorization.

The WVHIN staff and board have become experts in the histories and current operations of health information exchanges across the country. This knowledge is facilitating the state's network construction to emulate the successes.

WVHIN
WEST VIRGINIA HEALTH
INFORMATION NETWORK

September 2008

HealthLINC
https://www.healthlinc.org
714 S Rogers Street
Bloomington, IN 47402
(812) 353-4025

HealthLINC Overview

Highlights

1. **HealthLINC began operations in October 2007 and includes greater than 100,000 in its community patient index**
2. **HealthLINC is sending greater than 70,000 secure clinical results per month**
3. **Physicians contributed significantly to the start up costs for HealthLINC**
4. **HealthLINC is a collaborative community partner with HealthBridge**

The mission of HealthLINC is to provide the infrastructure, support services, and a collaborative environment that enables providers and public health to share clinical information across organizational lines to improve the quality, safety, and efficiency of care in South Central Indiana. Over time, services will be expanded to involve consumers, employers, and health plans. HealthLINC is one of the only operational HIEs that successfully extends its reach to rural areas.

HealthLINC's key responsibilities are to:

1. Establish a shared vision, direction, and goals
2. Represent community-wide stakeholder interests to ensure that the requisite infrastructure is developed and maintained to support a fully integrated electronic health care delivery system and HIE
3. Interface with other communities, granting agencies, and regional and national electronic organizations

Impact

In 2003 only 0-3 percent of the medical practices used an EMR in Monroe and Orange Counties for their patients. By 2008, 50% of the physician practices in Monroe and an amazing 76% of the practices in Orange have functional electronic medical records for their patients. This progress was directly facilitated by HealthLINC activities.

HealthLINC governs a regional HIE that provides secure, clinical messaging system that delivers greater than 70,000 medical results per month between the hospital, private practices and the two indigent care clinics. This system reduces redundant testing and "turns the paper off" resulting in cost savings that will translate into reduced health care costs. These systems also benefit the community by reducing the incidence of lost or misplaced test results and, therefore, ensure timely medical action is taken if needed.

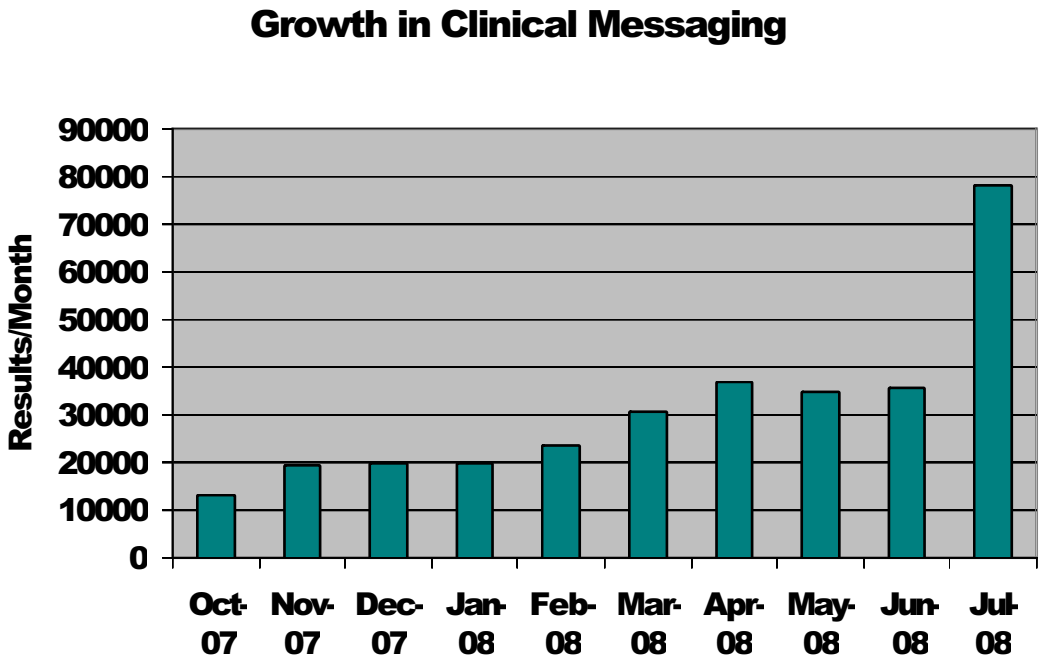
HealthLINC is a true community collaboration that includes greater than 85% of the community physicians and has benefited from funding directly from the physician community. Community partners are numerous and include Bloomington Hospital, Centerstone Research Institute, Internal Medicine Associates, Southern Indiana Radiological Associates, and Volunteers in Medicine of Monroe County.

Partnerships

HealthLINC members include greater than 85% of the physician practices in a multi-county area of South Central Indiana.

Key Partners include:
Bloomington Hospital
Bloomington Hospital of Orange County
Centerstone Research Institute
Internal Medical Associates
Southern Indiana Radiological Associates
Volunteers in Medicine of Monroe County

HealthLINC is breaking new ground…



HealthLINC Leadership

Todd Rowland, MD

Executive Director t: (812) 353-4025 e: trowland@bloomingtonhospital.org

Kathy Church, BSN, PMP

Clinical Operations – t: (812) 353-4026 e: kchurch@bloomingtonhosptial.org

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

American Health Information Community

Confidentiality, Privacy, and Security Workgroup Recommendations

Deven McGraw, Co-chair
Center for Democracy and Technology

Jill Callahan Dennis
American Health Information Management Association

Jodi Daniel
Office of the National Coordinator for Health IT

September 23, 2008

Confidentiality, Privacy, and Security (CPS) Workgroup Member List

- **Co-chairs:**
  - Kirk Nahra — Wiley Rein LLP
  - Deven McGraw — Center for Democracy and Technology

- **Members:**
  - Jill Callahan Dennis — American Health Information Management Association
  - Steven Davis — Oklahoma Department of Mental Health and Substance Abuse Services
  - Don Detmer — American Medical Informatics Association
  - Flora Terrell Hamilton — Family and Medical Counseling Service, Inc.
  - John Houston — University of Pittsburgh Medical Center, and National Committee on Vital and Health Statistics
  - Leslie Shaffer — Department of Defense, TRICARE Management Activity
  - Susan McAndrew — DHHS/Office for Civil Rights
  - David McDaniel — Department of Veterans Affairs, Veterans Health Administration
  - Alison Rein — AcademyHealth
  - Tony Trenkle — DHHS/Centers for Medicare and Medicaid Services
  - Paul Uhrig — SureScripts-RxHub, LLC
  - Thomas Wilder — America's Health Insurance Plans
  - Sylvia Au — Hawaii Department of Health
  - Jodi Daniel — DHHS/Office of the National Coordinator

CPS Workgroup Overview

Broad Charge:

Make recommendations to the AHIC regarding the protection of personal health information in order to secure trust, and support appropriate interoperable electronic health information exchange.

Specific Charge:

Make actionable confidentiality, privacy, and security recommendations to the 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.

Summary of CPS Workgroup Actions

- AHIC accepted recommendations
- AHIC transition
- Final recommendation letter

Final Recommendation Letter Context and Scope

- To identify those issues that introduced new challenges to, or revealed gaps in, the policies that currently protect health information
- To identify those issues we believe warrant additional consideration by HHS and other policy makers
- To establish a body of work to guide future policy evaluation and direction

Final Recommendation Letter Structure

- To address policy factors, challenges, and considerations for protecting electronic health information in the following areas:
  - Policies Regarding Network Access
  - Policies Regarding a Network's Own Activities and Operations
  - De-identification
  - Consistent Rules for Personal Health Information
  - Roles, Rights, and Responsibilities of Consumers
  - Safeguarding Information in a Personal Health Record

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.

Policies Regarding Network Access (cont.)

- **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.

Policies Regarding Network Access (cont.)

- **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

- **<u>Recommendation 3.0</u>:** 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.

Roles, Rights, and Responsibilities of Consumers (cont.)

- **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.

Action Requested

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

September 23, 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 (AHIC) has identified and prioritized several health information technology applications, or "breakthroughs" that could produce specific and tangible value to health care consumers. To address these breakthrough areas, the Confidentiality, Privacy, and Security Workgroup (the CPS Workgroup) was formed and given the following broad and specific charges:

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

Specific Charge: 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.

Over the past two years, the CPS Workgroup has discussed and made recommendations (summarized in Appendix A) to advance the charges stated above. As the Department of Health and Human Services (HHS) prepares to transition AHIC to a new entity, the CPS Workgroup has set forth below some additional considerations for future work by the HHS or any successor to AHIC. These considerations reflect much of the ongoing deliberations of the CPS Workgroup in recent months. In this letter, we identify issues where we have developed a consensus as to desirable approaches, as well as issues that pose challenges ahead, even if the CPS Workgroup has not reached a consensus on the recommended approach. Our goal is to inform HHS and the AHIC of the results of our recent deliberations.

Introduction

The development of confidentiality, privacy, and security policies for an electronic health information exchange environment will take time, coordination, and a better understanding of the potential opportunities and challenges that may arise as electronic health information exchange becomes more widespread. Throughout our deliberations, the CPS Workgroup recognized that existing Federal and State privacy and security laws constituted a foundation for safeguarding the electronic exchange of health information. This foundation covers many of the situations that exist in these new electronic health information exchange environments. Therefore, we sought to identify those issues that introduced new challenges to, or revealed gaps in, the policies that currently protect health information. To date, through both testimony and public comment, we have heard from over 50 experts and members of the public regarding electronic health

information exchange activities and the types of challenges they face with respect to confidentiality, privacy, and security.

The development of health information technology (health IT) and electronic health information exchange continues to progress at a rapid pace. Initiatives have launched to electronically connect health providers, health plans, laboratories, pharmacies, public health entities, and others. There are also initiatives to provide consumers with the ability to collect and personally control their health information through tools such as personal health records (PHRs) and health record banks. We have found, however, that the maturity of these efforts varies greatly, as does their ability to electronically exchange health information. Few of these networks are at a mature stage; in fact, one of the key pieces of information provided to the CPS Workgroup is how limited many of these ongoing efforts are at this point, in terms of their ability to electronically exchange health information. Consequently, we recognize that many of these initiatives will change over the next several years with respect to how they electronically exchange health information and, as a result, we have been cautious about making overly restrictive policy recommendations based on speculation. We also have avoided suggesting significant new privacy and security restrictions based on possibilities that are not present either today or in the near term. As noted above, existing Federal and State laws provide some protections for personal health information,[1] and any recommendations for new policies or revisions to current law should build on this existing foundation.

A policy framework promoting confidentiality, privacy, and security is important to build trust in electronic health information exchange. Such a framework should support the development of electronic health information exchange initiatives that have the potential to benefit health care delivery, transparency, quality improvement, research, and population health. The CPS Workgroup has issued some recommendations with respect to this policy framework – but the Workgroup is quickly nearing the end of its tenure. Below we have identified issues, as well as some recommendations, that we believe warrant additional consideration by the HHS and other policymakers as they look at the appropriate protections to apply to the access, use, and disclosure of personal health information within an electronic health information exchange environment.

[1] Throughout the letter we use the term "personal health information" for two reasons: 1) to refer generally to an individual's identifiable health information, and 2) because health information in an electronic health information exchange environment may be maintained by entities outside the scope of the Privacy and Security Rules under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The CPS Workgroup uses the HIPAA term "Protected Health Information" when we intend to refer to information expressly protected by HIPAA.

Policy Factors, Challenges, and Considerations for Protecting Electronic Health Information – Electronic Health Information Exchange Networks

1 - Policies Regarding Network Access

Electronic Health Information Exchange Networks Raise New Challenges

Throughout our deliberations, we have focused on whether there are differences between an electronic exchange environment and the health care environment today that raise new confidentiality, privacy, and security issues not fully resolved by current rules. For example, when a provider converts paper records to an electronic format, we see few, if any, new privacy and security challenges from those that exist today. But the availability of personal health information through electronic health information exchange networks (also referred to as "networks" throughout the letter) is a new development in health care. Thus, the Workgroup looked at the potential benefits of these networks and the greater availability of health information; the new confidentiality, privacy, and security questions raised as a result; and whether this new paradigm warrants the imposition of new requirements to ensure adequate protections for electronic personal health information.

Many of our conversations about these new networks focused on who has access to them and for what purposes. For example, with an electronic health information exchange network, depending on its overall structure, it may be possible for a health care provider or caregiver (and potentially others) to access or request personal health information: 1) without a patient's knowledge, and 2) without the knowledge of the provider whose record is the original source of that information. Further, it may be possible for those with access to a network to obtain 1) an individual's information for purposes other than Treatment of the individual (as that term is defined in the HIPAA Privacy Rule) and 2) information about an individual with whom a provider has no current or prior relationship. In addition, as these networks continue to grow, health information will become more readily available, and the purposes for which these networks are used will likely expand as well. These possibilities – which exist in some network situations – can create new challenges to ensuring the confidentiality, privacy, and security of personal health information.

Going forward, careful consideration must be given to the type, function, and roles of entities gaining access to personal health information through electronic health information exchange networks. While specific rules for these networks have not been defined at the Federal level, existing Federal and State laws, the voluntary policies adopted by these networks, the CPS Workgroup's prior recommendations, and recommendations by others such as the National Committee on Vital and Health Statistics (NCVHS), the Markle Foundation's Connecting for Health Initiative, the eHealth Initiative, and consumer groups form an appropriate starting point. In considering how to appropriately address the new confidentiality, privacy, and security concerns raised by these networks, we recognize that placing overly stringent and unjustified limits on the purposes for which information may be accessed through a network may limit its

utility as a public good. At the same time, we also acknowledge the need to build public trust in these networks.

The recommendations we set forth below should help facilitate the future development of a confidentiality, privacy, and security framework to govern these networks.

Application of HIPAA

Concerns have been raised that entities not covered by the HIPAA Privacy and Security Rules may be able to access personal health information in electronic health information exchange networks. Under our June 12, 2007 recommendation (the June 12th recommendation), these concerns could be alleviated if the HIPAA (or equivalent) privacy and security rules were made to apply to all those who directly participate in these networks. We recognize, however, that simply instituting such a "blanket HIPAA coverage" approach may not allay all concerns. In some situations, for example, the rules that were developed for a HIPAA covered entity may not be appropriate for another participant in an electronic health information exchange network (e.g., a public health entity or PHR vendor). In other situations, the CPS Workgroup recognized that it may not make sense to impose all HIPAA obligations on a network itself. For example, as detailed in our April 22, 2008 recommendations, we do not see an affirmative reason to require networks to send individual privacy notices to (and perhaps receive individual acknowledgments from) all individuals whose information flows through those networks, unless the networks have an independent relationship with these individuals.[2]

What Rules Should Govern Network Access and Use?

While there is a substantial debate about the appropriate purposes of these networks, there is widespread agreement that effective and improved treatment (i.e., better outcomes and care coordination) should be at the heart of these networks. Moreover, improving treatment is one area – and perhaps the only area – where there is no significant debate or disagreement regarding appropriate access to these networks.

We understand that many of these networks would allow health care providers to query the network for all available information on a patient for Treatment purposes. Such a query would be similar to a health care provider calling each hospital, primary care provider, and specialist in a given area to ask for personal health information about a patient. The administrative efficiency gained by this new capability is readily apparent. But improvements in efficiency alone would not necessarily justify the creation of new privacy and security rules. The Workgroup believes that further conversation about the new challenges raised by networks should focus primarily on whether networks yield new opportunities to obtain and use data that warrant additional protections. Additionally, the ease with which information will be accessible outside of the Treatment context raises some concerns. For example, the National Committee on Vital and Health Statistics (NCVHS), released a report entitled "Enhanced Protections for Uses of Health Data: A Stewardship Framework for "Secondary Uses" of Electronically Collected and Transmitted Health Data" that discusses this issue in greater detail.[3]

---

[2] We did recommend that these networks be required to make their privacy policies and practices publicly available on their websites (or through other means) (see Appendix A for further details).
[3] http://ncvhs.hhs.gov/071221lt.pdf

The CPS Workgroup considered whether it could come to consensus on a recommendation that would allow network participants to access information in the network for Treatment, Payment and Health Care Operations (as those terms are currently defined in the HIPAA Privacy Rule) – or at least certain Health Care Operations (primarily those operations identified in the HIPAA Privacy Rule where one covered entity can provide information for another covered entity's health care operations – 45 CFR 164.506(c)(4)). Although CPS Workgroup members were comfortable with allowing participants to access the network for Treatment purposes to the extent permitted under Federal and State laws, some members raised concerns about allowing participants to access the network for Payment and some or all Health Care Operations. Others believed that a regulatory framework that "matched" the HIPAA environment – meaning one where uses and disclosures for Treatment, Payment, and those Health Care Operations identified above - was more appropriate. Thus, the Workgroup believes that appropriate network uses should be the subject of further consideration by HHS, and that any HHS approach should be sufficiently flexible to not only regulate today's practices but also anticipate future technological and public policy changes.

Of note, much of the Workgroup discussion focused on appropriate uses of the network by participants – those entities with some contractual obligation to, or rights in, the network. The CPS Workgroup acknowledges that entities that are not technically network participants could seek to gain access to information in the network – and HHS should also consider the terms of such access, if any.

> ***Recommendation 1:*** 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.

Application of Minimum Necessary to Network Uses

The CPS Workgroup discussed the "minimum necessary" provisions of the HIPAA Privacy Rule. Some CPS Workgroup members raised questions about whether the minimum necessary standard needs to be reevaluated for a networked environment, particularly since the requirement does not apply in the context of disclosures to or requests by a health care provider for Treatment. CPS Workgroup members have also raised concerns that the minimum necessary provision is inconsistently defined and frequently misunderstood;[4] and others point out that the standard is consistent with fair information practices and meant to be flexible and vary in its application depending on the context. If our June 12th recommendation is implemented, electronic health information exchange networks would be subject to the minimum necessary

[4] Privacy and Security Solutions for Interoperable Health Information Exchange: Nationwide Summary (07/2007) - http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_661884_0_0_18/Nationwide.pdf

standard and thus would need policies on minimum necessary that would apply to all uses and disclosures outside of Treatment.

Nonetheless, the application of minimum necessary to an electronic health information exchange network raises several questions:

- Does the current minimum necessary requirement appropriately address the activities of electronic health information exchange networks?
- If an electronic health information exchange network uses a record locator service model and does not store personal health information, does the network need to establish "minimum necessary" policies? As an alternative, should the network rely on the sender and/or receiver of personal health information to comply with any minimum necessary requirements?
- Is it important for electronic health information exchange networks that maintain personal health information to have similar minimum necessary policies? Would variation amongst networks' policies create potential exchange or interoperability challenges?
- How will network policies on consumer choice (for example, policies that require consumers to opt-in to having their information exchanged through the network or allow them to opt-out, or that allow consumers to restrict information in sensitive categories) interact with policies regarding "minimum necessary" – and what impact will that have on electronic health information exchange?
- Should data recipients be notified if the information has been limited in some way because of rules established by a participant or a consumer's choice (e.g., through a minimum necessary policy, State law restrictions, or consumer preferences)?

> ***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.

Use of Networks for Research and Public Health

The CPS Workgroup also considered the extent to which current research rules apply to persons or entities that access data from an electronic health information exchange network for research purposes. In a paper environment, a researcher would have to go to each source to obtain health information, but in a networked environment they could potentially gather information from multiple sources through one organization or network. Also, in today's environment, presuming that the information at issue is controlled by HIPAA covered entities, whether the information is paper or electronic, the HIPAA research rules would apply. Thus, many research entities would not have direct access to most health care information. If our June 12th recommendation were implemented, researchers who were network participants would need to follow the HIPAA Privacy and Security Rules directly. Our June 12th recommendation, however, does not address the question of whether researchers should in fact have direct access to these networks and, if so, whether the HIPAA Privacy and Security Rules are practical or effective in this context. Accordingly, HHS (and others) should give further consideration to how researchers can access

information from these networks, and the terms and conditions of such access. Because the Institute of Medicine is currently conducting a study of the impact of HIPAA on research, the CPS Workgroup decided it was premature to give further consideration to 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.

With respect to uses of a network for public health purposes, the CPS Workgroup received testimony on the current and anticipated public health uses of electronic health information exchange networks. Based on this testimony, such current and future uses include improving the current public health reporting structure by providing more efficient and effective mechanisms for health care providers to electronically report public health information to public health authorities as authorized or required, and using network connectivity as a tool to send public health information from public health authorities to health care providers. The Workgroup does not believe these activities raise any new confidentiality, privacy, or security issues. If in the future public health authorities anticipate or propose any new or broader uses of these networks, particularly as vehicles for direct access to information by public health entities, HHS should examine the impact on confidentiality, privacy, and security.

> ***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.

2 - Policies Regarding a Network's Own Activities and Operations

One key difference that exists in an electronic health information exchange environment is that a network operator could become a repository of, or potentially access, substantial amounts of personal health information. Therefore, it is critical to evaluate what uses the network itself or its operator can make of this information. Today, similar issues arise in the context of certain business associates (for example, a pharmacy benefit manager who may have prescription information for numerous health insurers). We encourage consideration of whether the business associate model offers the appropriate level of control in this area, or whether more stringent controls should be placed on how a network itself uses and discloses information. This discussion needs to incorporate both the potential purposes and public benefits of these networks, as well as appropriate consideration of the business models utilized by these networks. Therefore, the CPS Workgroup believes that limits on the extent to which the network or its operator can access and use personal health information that it maintains or exchanges may need to be established.

> ***Recommendation 2:*** 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.

3 - De-Identification

Additionally, the ability of the network to connect previously segregated information may also create new opportunities for health data analysis and "data mining" for a variety of purposes. With respect to information that is individually identifiable, our prior recommendations with respect to the application of the HIPAA Privacy and Security rules to network participants, as well as to the networks themselves, should help resolve the confidentiality, privacy, and security issues raised by the use of networks for these purposes. However, the HIPAA Privacy Rule does not cover the use of de-identified health information, as long as such information meets the HIPAA standard for de-identification. The growth of these networks – as well as the increased availability of information via public databases – may make it easier for recipients of de-identified health information to re-identify it. The CPS Workgroup briefly considered – but did not have the opportunity to fully evaluate – whether the current de-identification standard developed over seven years ago would need to be revised in order to ensure that information accessed from networks cannot be easily re-identified.

> ***Recommendation 3:*** 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.

4 - Consistent Rules for Personal Health Information

In an environment where health care providers may receive numerous pieces of personal health information from a number of sources in order to treat an individual, it is important that the rules they have to follow with respect to protecting personal health information do not become so overly complex that they provide disincentives to using electronic health information exchange networks or create obstacles to providing patient care. During its discussions, the CPS Workgroup has been careful to identify and think through the potential impact new rules might have on the current environment. We believe that as policies develop for electronic health information exchange both for participants and the networks, such policies may vary by type of entity but should not require a particular entity to treat information differently depending on its source (i.e., from a network, generated by the provider, or obtained directly from another provider). For example, when a health care provider accesses personal health information on a patient using a network, such information will, in most cases, be included in the provider's record of care for that patient, and the same rules regarding how that information in a record can be accessed, used, and disclosed should apply. Two sets of rules – one governing information obtained from a network and one governing information generated by the provider or obtained from other sources – would be impractical and could have significant cost, care, and efficiency implications.

> ***Recommendation 4:*** 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.

5 - Roles, Rights, and Responsibilities of Consumers

Participants in electronic health information exchange networks across the country have engaged in discussions about ways to empower consumers and enable them to take a greater role in their own health care. Providing consumers with certain choices regarding how their personal health information is exchanged is important. However, rules governing networks must also consider the needs of health care providers and other entities to access, use, and disclose such information in order to function and properly treat patients.

The CPS Workgroup also recognizes that relying solely on consumer consent or choice without additional rules governing an electronic health information exchange network would not be an appropriate or sufficient way to protect the privacy and security of information in these networks, as such an approach places the burden solely on consumers to protect their personal health information. While the question of what consumer choice should be provided is an open one (and one where the CPS Workgroup has not reached a consensus), we are of the view that consumer choice alone is not the solution to privacy and security concerns in this exchange environment.

> ***Recommendation 5:*** 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.[5]

Policy Factors, Challenges, and Considerations for Protecting Electronic Health Information – Personal Health Records

6 – Safeguarding Information in a Personal Health Record

With personal health records (PHRs) and other tools designed to help consumers become more engaged in their health care, we are witnessing an increasing migration of personal health information out of the traditional health care system, which raises new confidentiality, privacy, and security concerns. PHRs are "an electronic record of health-related information on an

[5] In making this recommendation the CPS Workgroup did not discuss who should be responsible for educating the consumer. We recognize that consumer education can be done through multiple venues and using different resources, and we leave to further deliberation the most appropriate ways to accomplish this goal.

individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual." [6] Some PHRs are currently offered by covered entities, others are not. Some PHR service providers will participate in electronic health information exchange through a network, and some may not. If our June 12th recommendation were implemented, those PHR service providers that directly participate in these networks will be responsible for complying, at a minimum, with the HIPAA Rules to the extent they participate in the network. And of course, those PHRs offered by HIPAA covered entities should be covered under HIPAA. But PHR service providers that do not participate in networks, and that are not offered by covered entities, will not be covered by HIPAA. Many of these "uncovered" PHR service providers are entering into business alliances with covered entities to make their PHR products available to these entities' patients or enrollees. But it is not clear as a legal matter whether such PHR service providers would be required to enter into HIPAA business associate agreements in order to download a patient's protected health information into his or her PHR, because the patient likely will have authorized the disclosure of that information. Indeed, the premise of the most visible PHR service providers involves consumer authorization to access health care records.

The Federal Trade Commission (FTC) has some authority to regulate PHR service providers under the Federal Trade Commission Act. For example, if a PHR service provider does not abide by its privacy policies, the FTC may bring an action on behalf of the individuals with PHR accounts for deceptive trade practices. But such protection is fairly limited, as the PHR service provider is bound only by what it has promised in the privacy policy; the policy itself does not necessarily have to meet any particular requirements.

Some policymakers have considered, and some stakeholders have recommended, that all PHR service providers be required to comply with the HIPAA Privacy and Security Rules. But others have questioned whether HIPAA is the right regulatory framework for protecting personal health information in PHRs. HIPAA may, in fact, provide PHR service providers with "too much" ability to use and disclose health care information. For example, Microsoft, Google, and Dossia significantly restrict in their privacy policies their own uses and disclosure of personal health information. While these approaches are driven (presumably) by business concerns, we do not want to encourage an environment where PHR service providers believe they should increase their use and disclosure of personal health information beyond the best practices developing today.

Because PHRs contain copies of information from the electronic records of health care providers or health plans, in addition to any information that may be entered into the record by individuals (the subject of the record in question), information in PHRs should be controlled solely by the individual or persons acting on their behalf – and the CPS Workgroup agrees that, as a policy matter, consumers should have the sole right to choose whether information held in a PHR is accessed or disclosed, to whom, and for what purposes. In contrast, the HIPAA rules were designed to govern the access, use, and disclosure of protected health information by entities in the traditional health care system, which is why the rules permit the use and disclosure of protected health information for a number of purposes (such as Treatment, Payment, and Health

[6] The National Alliance for Health Information Technology Report to the Office of the National Coordinator for Health Information Technology on Defining Key Health Information Technology Terms, April 28, 2008.

Care Operations, and public health) without the consent or authorization of the individual. Such a regulatory framework may not be an appropriate fit for PHRs, where information in the record can only be accessed, used, and disclosed with the express authorization of the individual.

> ***Recommendation 6:*** 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 PHR.[7] 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.

Finally, to reiterate a point we have made above, if different policies are developed for uses and disclosures of personal health information by a PHR service provider, once the information is transferred (per authorization of the consumer/patient) to a health care provider or health plan, and stored in that provider or plan's record, the rules that govern the provider or plan's subsequent use of that information should be the same as the rules that provider or plan follows with respect to information currently stored in their records.

Conclusion

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

[7] For example, NCVHS released recommendations on PHRs in February 2006, and the Markle Foundation's Connecting for Health Initiative Released a Common Framework for Consumer Access Services in June of 2008.

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

Sincerely yours,

/Kirk J. Nahra/
Kirk J. Nahra, Co-Chair
Confidentiality, Privacy, and Security Workgroup

/Deven McGraw/
Deven McGraw, Co-Chair
Confidentiality, Privacy, and Security Workgroup

Appendix A – Recommendation History

On May 16, 2006, the AHIC received, and accepted, a joint recommendation from its Consumer Empowerment, Electronic Health Records (EHRs), and Chronic Care Workgroups to create another AHIC Workgroup comprised of privacy, security, clinical, and technology experts to frame the privacy and security policy issues relevant to all AHIC Workgroup charges and solicit broad public input and testimony. The joint recommendation charged the CPS workgroup to 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; and a scope of work for a long-term independent advisory body on privacy and security policies.

- Our first set of recommendations, which were accepted at the 1/23/2007 AHIC meeting, focused on patient identity proofing. We recommended that:
  - Entities that offer electronic access to data and services through secure messaging, personal health records (PHRs), or EHRs follow our framework for patient identity proofing;
  - For the purposes of secure messaging and accessing data through a PHR or EHR, information used solely for purposes of identity proofing a health care consumer or their authorized proxy(ies), if kept, should be securely maintained separate from the health care consumer's clinical data;
  - Converting from a paper-based health care practice to one that uses EHRs does not require a health care entity to identity proof their patients unless such conversion provides patients with access to data within the EHR;
  - Entities providing patient access to personal health information via secure messaging or a PHR should follow our identity proofing framework; and
  - Where applicable, the Certification Commission for Healthcare Information Technology (CCHIT) should develop certification criteria for the systems and networks they certify to support the identity proofing practices in our recommendations.

- In June 2007, we issued another recommendation, which marked a significant step forward in our efforts to determine what, if any, additional protections beyond those currently provided in federal and state law are needed to ensure the confidentiality, privacy, and security of individually identifiable health information in an electronic health information exchange environment. This recommendation was accepted at the 6/12/2007 AHIC meeting and provided that:
  - All persons and entities, excluding consumers, that participate directly in, or comprise, an electronic health information exchange network, through which individually identifiable health information is stored, compiled, transmitted, modified, or accessed should be required to meet enforceable privacy and security criteria at least equivalent to any relevant Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements (45 CFR Parts 160 and 164). Furthermore, any person or entity that functions as a Business Associate (as described in 45 CFR §160.103) and participates directly in, or comprises, an electronic health information exchange network should be required to meet enforceable privacy and security criteria at least equivalent to any

relevant HIPAA requirements, independent of those established by contractual arrangements (such as a Business Associate Agreement as provided for in HIPAA).

- Our third set of recommendations, accepted by AHIC on 4/22/2008, further refined our previous recommendation by pragmatically exempting health information exchange networks that do not currently have direct relationships with patients from having to directly comply with certain requirements of the HIPAA Privacy Rule. With respect to those networks that do not currently have direct relationships with patients;
  - The obligation to provide the following "individual rights" under the HIPAA Privacy Rule would remain with the health care provider or health plan who is the original source of the patient data and who today has a direct relationship with the patient:
    - §164.520 Requirement to provide the patient with a notice of privacy practices for protected health information and to have receipt of that notice acknowledged by the patient;
    - §164.522 Right to request a restriction on protected health information;
    - §164.524 Right of individuals to access (inspect and copy) their protected health information;
    - §164.526 Right to seek amendment of protected health information; and
    - §164.528 Right to an accounting of disclosures of protected health information.
  - Our recommendation also provided that electronic health information exchange networks which have direct relationships with consumers or patients should be required to meet all of the requirements of the HIPAA Privacy Rule. Moreover, we recommended that electronic health information exchange networks be required to make publicly available on their website (or through other means) a document that reasonably and accurately describes in plain language how they use and disclose health information and their privacy policies and practices, as well as how they safeguard patient or consumer information.

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

American Health Information Community

The ONC-Coordinated Federal Health IT Strategic Plan 2008 - 2012

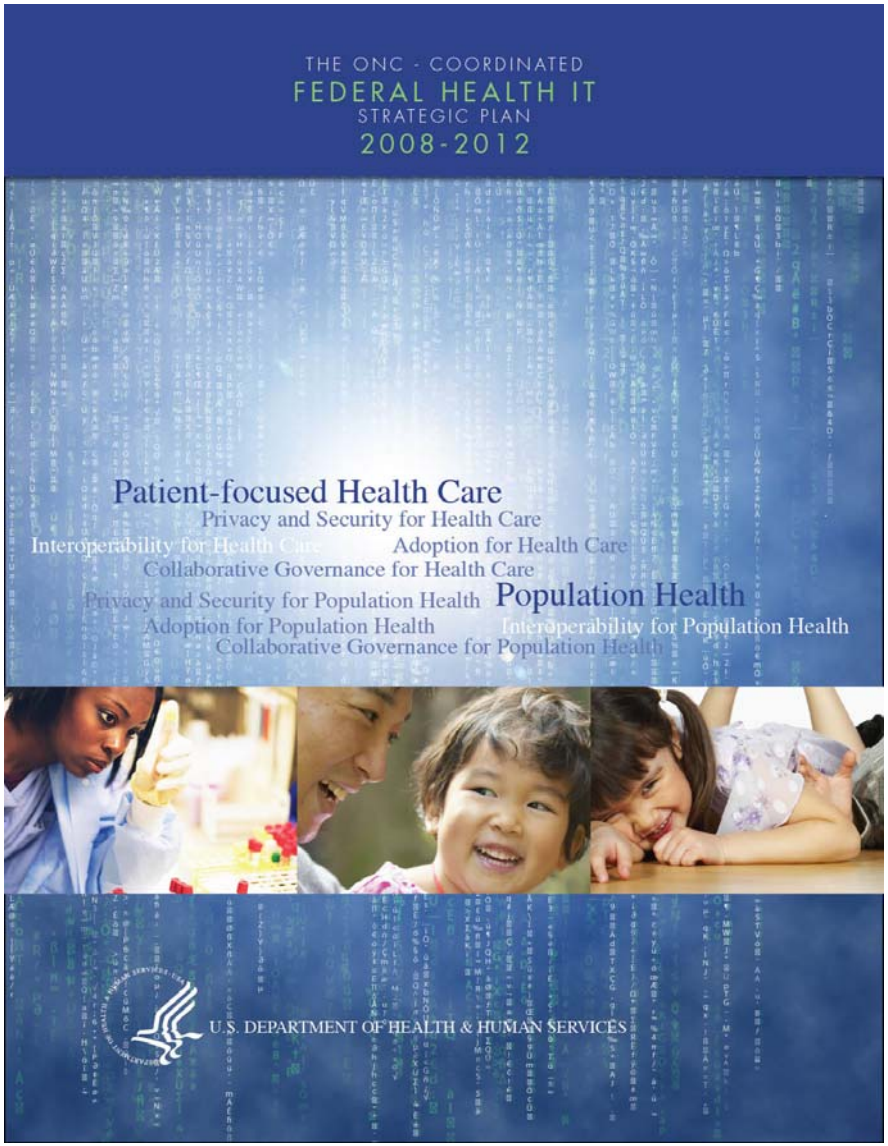
Dr. Robert Kolodner

Dr. Charles Friedman

Office of the National Coordinator for Health Information Technology

September 23, 2008

ONC-Coordinated Federal Health IT Strategic Plan 2008 - 2012



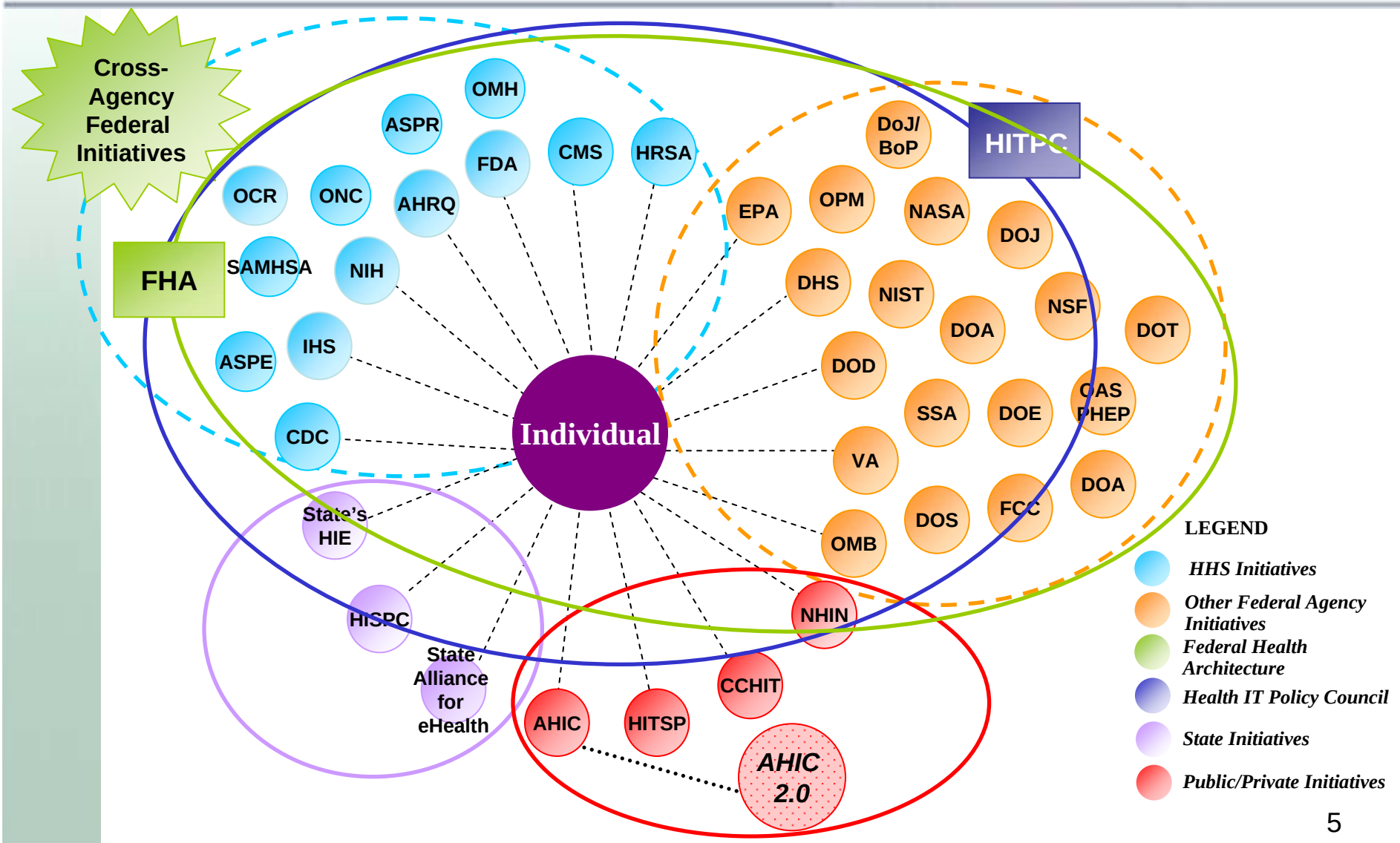
Motivators of the Strategic Plan

- Provides clarity, guidance, and a way to measure progress
- Many have asked for the Plan
  - Presidential Executive Order 13330
  - United States Congress
  - Observations from the Institute of Medicine
  - Natural obsolescence of the Strategic Framework
  - Need for collaboration across the Federal Government
  - Need for clarity and guidance

Characteristics of the Plan

- **Collaborative**
  - Across the government: Seven Departments/Agencies outside HHS
  - Department of Health and Human Services' OpDivs and StaffDivs
- **Integrative**
  - One infrastructure serves the needs of two goals
- **Complete**
  - Eight objectives that improve quality and efficiency of health care and population health
- **Disciplined**
  - Communicate and coordinate
  - How projects of multiple agencies work in pursuit of shared goals

ONC-sponsored Federal Collaborations and National Health IT Initiatives



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.

“The Plan” – 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.

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.

Strategies Are Listed For Each Objective

- **<u>Objective 1.3</u> – *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.

Strategies Are Listed For Each Objective

- **<u>Objective 2.3</u> – *Adoption:* Promote the nationwide adoption of information technologies that enable the reliable and efficient exchange of electronic health information to continuously improve population health activities and individual health care services.**
  - **Strategy 2.3.1**: Establish mechanisms to optimize the exchange of information between care providers using EHRs and authorized users of population health data, as well as among authorized users and recipients of population health data.
  - **Strategy 2.3.2**: Minimize burden on health care providers when reporting clinical data for population health purposes using EHRs and other health IT, while ensuring consistent health information protections.
  - **Strategy 2.3.3**: Establish mechanisms for the electronic exchange of health information among authorized users of population health data, communities, and individual consumers.

Each Strategy Has a Milestone Listed in Appendix A *[first sample below]*

- **<u>Strategies for Objective 1.3</u> - *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.*

Each Strategy Has a Milestone Listed in Appendix A *[second sample below]*

- **<u>Strategies for Objective 2.3</u> - *Adoption:* Promote the nationwide adoption of information technologies that enable the reliable and efficient exchange of electronic health information to continuously improve population health activities and individual health care services..**
  - **Strategy 2.3.2:** Minimize burden on health care providers when reporting clinical data for population health purposes using EHRs and other health IT, while ensuring consistent health information protections.
    - *Milestone 2.3.2: By 2012, certified EHRs will have features that enable them to transmit automated data to population health agencies.*

Index to Current Federal Activities is Provided for Each Objective *[partial table shown below]*

Table 1.2 – Current Health IT Initiatives and Federal Advisory Committees Addressing Objective 1.2
Federal Agency and Department Initiatives
AHRQ: Health IT Portfolio (Page A30), United States Health Information Knowledgebase (USHIK: Page A31)
CMS: ICD-10 (Page A36), Medicaid Information Technology Architecture (MITA: Page A36), Medicaid Transformation Grants (Page A36), Beneficiary Information Services (Page A35)
FDA: Structured Product Labeling for Products (Page A38)
HRSA: Health IT Electronic Health Record and Innovations Grants (Page A39), Telehealth Grants (Page A39), Regional Genetic and Newborn Screening Service Collaboratives (Page A39)
IHS: Resource and Patient Management System (Page A41)
NIH: Cancer Biomedical Informatics Grid (Page A42), Support, Maintenance, & Dissemination of Standard Clinical Vocabularies (Page A43)
ONC: Planning for AHIC 2.0 (Page A48), Certification Commission for Healthcare Information Technology (CCHIT: Page A46), Federal Interdepartmental Health IT Collaborative [Multi-agency] (Page A46), Federal Health Architecture (FHA) [Multi-agency] (Page A47), Healthcare Information Technology Standards Panel (HITSP: Page A47), Nationwide Health Information Network (NHIN: Page A47), Use Case Development (Page A49)
HHS/OS: Personalized Healthcare (Page A52), Value-driven Health Care (Page A53)

Descriptions of Initiatives, Programs, and Projects Are Provided in Appendix C *[sample shown below]*

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 improve care. Under the demonstration, primary care doctors who use certified 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 health care 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.

Relationship of Goals and Objectives to the Federal Activities is Summarized in a Table in Appendix B *[partial table shown below]*

	Goal 1				Goal 2			
	Obj 1.1	Obj 1.2	Obj 1.3	Obj 1.4	Obj 2.1	Obj 2.2	Obj 2.3	Obj 2.4
ONC-Coordinated Federal Health IT Strategic Plan	Privacy and Security	Interoperability	Adoption	Collaborative Governance	Privacy and Security	Interoperability	Adoption	Collaborative Governance
Department of Health and Human Services								
Agency for Healthcare Research & Quality (AHRQ)								
AHRQ: Health IT Portfolio	☑	☑	☑	☑				
AHRQ: United States Health Information Knowledgebase (USHIK)		☑				☑		
Assistant Secretary for Planning and Evaluation (ASPE)								
ASPE: Health Information Activities		☑	☑			☑	☑	
Assistant Secretary for Preparedness and Response (ASPR)								
ASPR: Homeland Security Presidential Directive 21						☑	☑	☑
ASPR: Pandemic All-Hazards Preparedness Act (PAHPA)						☑	☑	☑
Centers for Disease Control and Prevention (CDC)								
CDC: BioSense						☑	☑	
CDC: EPI-X						☑		
CDC: National Healthcare Safety Network						☑		
CDC: Public Health Information Network						☑	☑	
CDC: Public Health Preparedness Systems						☑		
Centers for Medicare & Medicaid Services (CMS)								
CMS: Beneficiary Information Services		☑	☑					
CMS: EHR Adoption Demonstration			☑					
CMS: E- Prescribing Efforts			☑					

For More Information or a Copy of the Strategic Plan

http://www.hhs.gov/healthit/resources/reports.html