Meeting Report

American Health Information Committee
October 7, 2005

The American Health Information Community, a federally-chartered commission formed to help advance President Bush's call for most Americans to have electronic health records within ten years, held its first meeting on October 7, 2005, at the Department of Health and Human Services**,** 200 Independence Avenue, SW, Washington, D.C. 20201.

The purpose of the meeting was to bring together the Community's 17 members to begin discussion of and initial steps toward ways to achieve its mission of providing input and recommendations to Health and Human Services on how to make health records digital and interoperable, and assure that the privacy and security of those records are protected, in a smooth, market-led way.

Secretary of Health and Human Services 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 will serve two-year terms.

The meeting was chaired by Secretary Leavitt and David Brailer, MD, PhD, National Coordinator for Health Information Technology.

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

Call to Order and Introductions

Secretary Leavitt opened the meeting, telling the committee members how personally appreciative he was of them and that he suspected that over the next couple of years they would become well acquainted with one another. He then asked those at the table to introduce themselves so that they could learn a little more about each other personally.

Counterclockwise, around the table were:

David Brailer, MD, PhD -- National Coordinator for Health Information Technology. An internist involved in clinical practice most of his career, Dr. Brailer has a long time interest in the economics of health care. Prior to his appointment, he was a Senior Fellow at the Health Technology Center in San Francisco, California, a non-profit research and education organization that provides strategic information and resources to health care organizations about the future impact of technology in health care delivery. He also served 10 years as Chairman and CEO of CareScience, Inc., a leading provider of care management services and Internet-based solutions that help reduce medical errors and improve physician and hospital-based performance. Dr. Brailer also designed and oversaw the development of one of the first community-based health information exchanges in Santa Barbara County, California. He told the Community that in the private sector as an entrepreneur he learned methods of getting things done and is "happy to say we are putting these practices together through the federal government."

Kelly Cronin – Senior Advisor to Mark McClellan, MD, PhD, who heads the Center for Medicare and Medicaid Services, which is the largest operative division in the Department of Health and Human Services and one of the largest payors of health care in the world. Cronin represented Dr. McClellan who was unable to attend.

Lillee Gelinas, RN, MSN -- Vice President of the VHA, Inc., a cooperative of 2200 healthcare organizations across the country. Her most important goal right now, she said, is helping her immediate family, who are from New Orleans. "They got out, thank goodness, but there is lot of work to be done," she said. "I told Dr. Brailer if he had had healthcare IT in place prior to that disaster, things would be very different for a whole lot of people, so I am committed both personally and professionally to the work of the group."

Douglas E. Henley, MD – Executive Vice President of the American Academy of Family Physicians, a position he has held for five years. Prior to moving to Leewood, Kansas, for that position, Dr. Henley spent 49 years of his life in North Carolina, doing his medical training at the University of North Carolina at Chapel Hill, and, later, returning to practice medicine his hometown in Southeastern North Carolina. Representing the physician community, he said, "We are here to make sure that health care in this country is one of improved quality, of greater safety and of greater efficiency on behalf of our patients."

William Winkenwerder, Jr., MD -- Assistant Secretary of Defense for Health Affairs. A physician himself, Dr. Winkenwerder has been in management for a decade and a half. In his position he has the responsibility to execute the Department of Defense's healthcare mission to provide and maintain readiness to provide healthcare services and support to members of the Armed Forces during military operations. The program has as beneficiaries about 9.2 million people – active duty, family members, retirees all over the United States and overseas – and operates through a direct-care system of about 70 hopsitals and 800 medical and dental clinics. "We are really committed to the new age of digitizing health care and the delivery of health services," Dr. Winkerwerder said. "A lot of money is going into healthcare delivery for the military and the veterans so there is an opportunity here to do it better, with more efficiency and with higher quality."

David Ayre – Senior VP of Compensation and Benefits for PepsiCo, where he has overall responsibility for policy setting, plan design, and administration of the company's compensation and benefits programs for 80,000 U.S- based employees and 155,000 employees worldwide. Ayer, who has held the VP position for more than 15 years, said PepsiCo is collecting electronic health records. Ayre represented Steve Reinemund, CEO and Chairman of Pepsico, who was unable to attend.

Kevin Hutchinson – CEO of SureScripts, an organization founded by the National Association of Chain Drug Stores and the National Community Pharmacists Association representing both the chain drug stores and individual pharmacies. The organization has launched what is now the largest network for electronic prescribing in the United States, with almost 90 percent of all pharmacies in the U.S. certified on the network. SureScripts, he told the Community, is focused on "building out the infrastructure within the industry to allow electronic health records and electronic prescribing applications to connect to pharmacies – be they independent pharmacies, mail order pharmacies or chain pharmacies, allowing patients to send their electronic prescriptions to the pharmacy of their choice." Prior to joining SureScripts in August of 2002, Hutchinson was the COO of a publicly traded health information technology company named MedicaLogic/Medscape.

Dan Green – Deputy Associate Director, Center for Employee and Family Support Policy, Office of Personnel Management (OPM). The OPM provides health insurance to some 8 million federal employees, retirees and their families through some 250 health plan choices from high-deductible health plans to HMOs and fee-for-service plans. OPM spends 31.5 billion a year on this program, which combined with VA and Department of Defense represents over 100 billion dollars in healthcare spending. Green represented Linda Springer, Director of the Office of Personnel Management, who was unable to attend.

Michelle O'Neill – Acting Under secretary for Technology, U.S Department of Commerce, which includes the National Institute for Standards and Technology. The Department of Commerce has a long history of cooperation with the HHS and a number of healthcare industry organizations in the room, she said. **"**Our goal is to improve the standards of measurement, to help to advance that area." On a personal note, O'Neill said she was born in a military hospital, is a participant in the Federal Employee Health Benefits Plan and has three immediate family members who are doctors. And, having had a child in the past years, she is very much a consumer of health care services.

Nancy Davenport-Ennis – founder of two organizations – the National Patient Advocate Foundation and Patient Advocate Foundation. Last year, the Patient Advocate Foundation served 3.2 million Americans who were having some sort of access-to-care issue when they contacted the Foundation. The people the Foundation helps have some sort of chronic, life-threatening and debilitating illness; 83 percent are cancer patients, she said. The Foundation maintains electronic records of every patient served in its seven locations and uses that data to be able to talk with regulators and policymakers to help them understand what the Foundation sees day in and day out through the consumer experience.

Davenport-Ennis, once a writer and high school English teacher, changed career paths following a battle with breast cancer. Her husband, who is also her business partner, was undergoing cancer treatment at Duke University at the time of the meeting.

Scott Serota – President and CEO of the Blue Cross Blue Shield Association, serving 93 million Americans in every state of the U.S. and a provider of Part A and Part B Medicare benefits. "We connect with 90-plus percent of the physicians in America and 90-plus percent of the hospitals in America," Serota told the Community. "We want to be sure that we can provide leadership and expertise." Serota began his career as an administrative fellow at a hospital in Tulsa, Oklahoma. Later, he began his own HMO, which he sold to Prudential prior to joining Blue Cross Blue Shield in 1996.

Mark Warshawsky, PhD – Assistant Secretary for Economic Policy, U.S. Department of the Treasury. The Treasury Department's interest in health care is not specific to the various programs, he tells the community, "but is more of an economic perspective in terms of concern and interest in getting high-value health care, efficient health care, given that health care represents one out of every seven dollars of the gross national product of the United States." His background is as an economist with the specialty in research on employee benefits. In addition to his professional interest in health information technology, Warshawsky says that as a father of four he is personally interested in a way to eliminate the innumerable forms he must fill out every summer when his kids go to camp and in the fall when they return to school.

Charles N. (Chip) Kahn III – President of the Federation of American Hospitals, which represents 15 percent of the nation's hospitals, but works closely with the entire hospital

community. Kahn, who has lived in Washington for 25 years and has spent a lot of time working on Capitol Hill, was heavily involved with the development of HIPPA, which he says, "in some was foreshadows this group and in other ways may shadow it, depending on your attitude."

Kahn shared a poignant story of a situation in his own life that illustrated the need for electronic health records. In the 1980s, after his son's discharge from a lengthy hospitalization for leukemia, Kahn received a call from his insurance company refusing to pay for his son's hospitalization because his medical records were gone. Although the medical records were never recovered, Kahn ultimately won the fight to have his bill paid and his son's doctors were able to reconstruct the details of his tests and treatments. "But hopefully the work here will lead to that thing not evening happening," he said.

Jonathan Perlin, MD -- Under Secretary for Health, Department of Veterans Affairs and Veterans Health Administration. Dr. Pelin said he hopes he represents a point of optimism that the Community's vision is not only possible but possible rapidly. Ten years ago, he told the Community, four out of 10 VA patients did not have their medical records available at the time of their appointment. Today, such records are available virtually 100 percent of the time to all patients, including 62,000 who evacuated out of New Orleans in the wake of Katrina. The VA encompasses 1300 sites of care used by 75,000 physicians, and every one of those 1300 sites has electronic health records available, he said.

An internist and neurophysiologist, Dr. Perlin occasionally sees patients at the Washington VA Medical Center. As proud as he is to be able to help individual patients, he says that electronic records are able to show what can be done with a population base. For example, by increasing the vaccination percentage of VA patients with emphysema from 29 to 94, they were able to save 6000 lives and halve unnecessary hospitalizations.

Dr. Perlin also introduced Robert Kolodner, MD, Veterans Health Administration's (VHA) Chief Health Informatics Officer, who would be representing him at the table later in the meeting.

Julie Gerberding, MD -- Director of the Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. Representing not just the CDC but the public health perspective on the electronic health record, Dr. Gerberding says she "learned through her training at CDC how difficult it is to get integrated information and get that information into the hands of people who can use it to make effective decisions." As a physician, she says she has experienced the frustration of not having access to information when and where you need it. Dr. Gerberding said she met and fell in love with her husband while he was developing an electronic health record in the city and country of San Francisco. "So we have a kind of family interest in this issue as well," she said.

The day after the Community meeting, Dr. Gerberding was to travel to Asia with Secretary Leavitt to work with countries at risk for avian influenza.

E. Mitchell (Mitch) Roob – Secretary of the Indiana Family and Social Services Administration, the largest state agency with 9,000 employees and an annual budget of $7 billion. Last year, the administration's health programs – including Medicaid, Tenet Mental Health and long-term care – served 1.1 million people. Earlier in his career, Roob ran the Marion County Health and Hospital Corporation, with responsibility the Health Department and Wishard Public Hospital. He brought a copy of his own electronic health record to the meeting.

Craig Barrett, PhD – Chairman of the board for Intel, who prior to that was an engineering professor at Stanford University for 10 years. Representing the high-tech community and computer software organizations throughout the world, Barrett says his interest is two fold: First, he said, "the healthcare industry is the largest industry in the United States. Unless it is a competitive industry, it is hard to see how the U.S. economy is competitive long term. And secondly, just having my annual checkup at a large, unnamed clinic and having to fill out the same seven pages three times in two days, it seems to me that IT can be more usefully spread throughout the healthcare industry."

"Ultimately," Barrett said, "I would like my doctor or any doctor to be able to know as much about me as amazon.com knows about me."

Following the introduction of the Community members, Dr. Brailer introduced five people who will be leading the Office of the National Coordinator and working closely with Federal agencies and other organizations represented at the meeting. They were:

- Captain Robert Wah, MD, Acting Deputy of the National Coordinator's Office
- Dana Haza, Acting Director for Programs and Collaboration, who will aid in the Office's outreach activities
- John Loonsk, MD, Acting Director of Interoperability and Standards on detail from CDC
- Karen Bell, MD, Acting Director of Information Technology Adoption, who is not present at the meeting
- Jodi Daniel, Acting Director of Policy and Research on Detail from the Office of General Counsel

Dr. Brailer then asked to have the staff stand that work for the Office of the National Coordinator either directly in the office or as affiliates in other agencies. These included the Assistant Secretary for Budget Technology and Finance, the Centers for Medicare and Medicaid Services, the Assistant Secretary for Planning and Evaluation, Actuarial Research Corporation; the CDC, the Department of Defense, the VA, the Department of Commerce, and the Department of the Treasury.

Dr. Brailer also introduced Fran Schrotter, Senior Vice President and Chief Operating Officer, American National Standards Institute (ANSI), the Office's new contractor to coordinate the health information technology standards; and Mark Leavitt, Chairman of the Certification for Health Information Technology.

Opening Remarks

Following introductions, Secretary Leavitt addressed the group, saying that he wished today not to spend any time on the *promise* of heath IT. "The work of the community needs to be about actual progress – serious, measurable, urgent progress toward a goal that we all share, and that is a goal that the President has laid out for health information technology," While hundreds of different organization are working to make progress in the area, Secretary Leavitt said the difference between the Community and these other organizations can be expressed in two words – market power.

The federal government – representing more than 40 percent of the $1.8 trillion in healthcare expenditures in this country – has the power to create a forward-leading momentum, he said. But without the full involvement of innovators in the market, it might move the wrong way. "This has really been a marriage of the market power of the national, local and state government and the

innovation power of the marketplace," he told the community. "This is one of the things that make this very different from the other opportunities."

Secretary Leavitt referred to the Community as a collaboration and told the group that good collaboration was more than just compromise. "There are problem-solving expeditions. They create a tireless momentum toward a defined end goal. . . . Sometimes they are messy, sometimes they are difficult, sometimes they are complicated, but in markets this complicated, they are absolutely indispensable," he said.

As a federal advisory committee, the Community's charter empowers it to serve as an advisor to the Secretary of HHS. Secretary Leavitt said it was his intention to weight very heavily the advice he receives from the Community and added, "It will, of course, need to be converted to action."

Other key points in Secretary Leavitt's address included:

- **The concept of community.** "There are 17 people sitting at this table. Seventeen people do not a community make," he said. "The American Health Information Community needs to be the hub around which the activities of other organizations working in this area operate and the place where advice can best be consolidated and then implemented."

- **The harmonization of standards.** In order to move forward, a good share of the Community's work will require a conclusion on what the standard should be, he said. There are dozens of standards organizations, but multiple standard don't work. Ultimately there has to be a harmonization of those standards. Therefore, it will be important to incorporate in this the work of the Health Information Technology Standards Panel.

  For any system to work, he told the Community, there has to be some means of creating an independent group that is outside of government that can look at products and certify them as compliant with the harmonization standards. He said the Community would bring in public dialog as part of this, holding meetings, workshops forums, mini-summits and maybe some major summits.

- **The model of consensus.** Secretary Leavitt told the group he wants to move with a model of consensus. To him, he said, consensus is not unanimous. It's unlikely the Committee will reach a unanimous agreement on everything. He said he intends to manage the group as a chairman that will determine when they are for the most part in agreement. In some cases, he said, he might have votes, "but for the most part I intend to keep us moving forward in a very constructive way so that we are not bogged down in details that might not be as weighty as the conclusions otherwise would be."

- **Interoperability vs. adoption.** There is a disconnect between those who have to ultimately pay for technology (for example, small practitioners) and those who get the benefits of it, Secretary Leavitt said. This manifests itself in interoperability (the existence of the technology itself) and adoption (the actual use of the technology). "I want be clear that I believe we have to deal with both problems," he said. "Unless we are able to create adequate adoption, interoperability is a hollow victory. On the other hand, it is my belief that adoption will never adequately occur until there is a level of certainty about the market.

"We will take on adoption as a department and a government," he continued, "but our efforts here need to be more about how to create connectivity and interoperability."

- **Balancing "pure vision" and immediately available progress.** Just as there is a cross pressure between interoperability and adoption, Secretary Leavitt said there is also a cross pressure between what he refers to as the "pure vision of interoperability" and immediately available progress.

  While it may change over time and be different for different people, Secretary Leavitt said he believes there is in everyone's mind a pure vision – "where everything goes into the right block and everything is uniform and everyone uses the same term for everything and the information is electronically exchangeable." The pure vision will take a decade or more to achieve and it will only get better over time. It will never be finished," he said. On the other hand, the Community cannot just look for the immediate progress that's available unless it somehow connects to a pathway that will lead toward the pure vision. "So part of our job here is to balance the immediately available progress with the long-term pure vision."

- **The importance (and possibility) of quick accomplishments.** The world of IT will be watching the group carefully, the Secretary said. "If they see us bogged down into an intransigence that has occurred with many other groups over time or what they otherwise expect of something sponsored by the government, we will not have succeeded. However, if we can choose a series of early breakthroughs and accomplish them, the combination of that action and our ability to move the market with our expenditures will signal great progress."

  To make the point that major accomplishments can happen quickly, he used the example of the recent Katrina Project, in which Dr. Brailer and a number of organizations, including the AMA, Markel Foundation and the Louisiana and Mississippi Departments of Health, got together and in the course of a week created a system where a physician could go onto a secure Web site and reassemble prescription drug records of virtually all of the people in the areas affected by Hurricane Katrina. "Don't tell me it should take a year or two or three to make substantial steps forward in health IT," he said.

Secretary Leavitt likened the group's working process to that which his grandmother once used to solve jigsaw puzzles, laying all of the pieces on a table and then, over the course of time, locating and assembling the border pieces and corner pieces and sorting the remaining pieces into piles according to color. At that point, he said, she would call the family members together, assigning each a sector of the puzzle to work on. As the puzzle-working progressed, the process would get easier because they could see the pieces they were hooking to.

"I believe that we here in this Community are essentially solving a puzzle," said Secretary Leavitt, who continued the puzzle analogy throughout the meeting. "I would also suggest that to a large extent we have aligned the border pieces and we have begun to put in the corners to form a standards organization in the form of a certification organization. Soon we will put into place an architecture, we will announce the results of an RFP that will begin to allow us some alternative architecture."

The next step will be for the Community to begin to divide up the pieces of the puzzles that they want to solve. He suggested dividing tasks or undertakings into three general categories, one of which would be consumer-related endeavors to capture the imagination of the American people.

To begin the process, Secretary Leavitt had provided the Community with a list of 14 potential puzzle parts for discussion and consideration. The list, he said, is not exhaustive list. Over time he hopes there will be many pieces – suggested by the Community, other groups and the public -- that will become an inventory of "breakthrough" projects. The group would look at those begin to organize workgroups, chaired by one or two Community members. Over time, he told the group, "the picture will become perpetually clearer, the parts will become easier to connect as the momentum of our progress accelerates."

Secretary Leavitt concluded his comments, telling the Community about one potential part he thought was of compelling national interest -- a way of rapidly identifying and reporting a potential pandemic virus or bioterrorism attack. Traditionally, recognizing a disease outbreak has often taken two to three weeks as it has taken time for doctors to in emergency rooms and clinics to identify the symptoms and report them through public health channels, he said. "That is unacceptable – it needs to be between two and three hours, because our capacity to respond to either a pandemic situation or in a bioterrorism event absolutely depends on our capacity to define the area in which it has occurred. " He asked that the group put forward as one of its breakthrough projects a system of biosurveillance that would allow the capacity to accelerate dramatically the reporting of public health threats. "It's the only puzzle part I have absolute certainty about," he said. "It is the one in which I believe we have a responsibility to act."

Before calling a break, he reiterated that the Community was going to be an active group. "I think our success is dependent on our ability to deliver serious momentum and action," he said. "It is my fundamental belief if we don't lead the market we will be a drag on the market, we will have failed, and I have no intention of failing and I know that is not the reason you are either."

Breakthrough Discussions

This portion of the meeting began with Dr. Brailer describing the 14 potential breakthroughs, which he defined as "health information technology applications that could produce a specific and tangible value for health care consumers that could be realized within a two-to-three year period." The breakthroughs, which fell into three categories, were as follows:

Category 1 – Consumer Empowerment -- things that will help individuals manage their health care and advocate for themselves as they use health care services. Potential breakthroughs in this category include:

- **Personal health record** – the primary example in this category. This would be something an individual can use to access their (or their child's or an ill parent's) information – prescriptions, lab test results, claim data, allergies, etc. The record could take a lot of different forms – even something as simple as a PDF document that could be assembled on the patient's behalf and that the patient and provider could access through any computer with an Internet connection.
- **My medication history** – which would have data concerning specific medications and the exact dosages prescribed available in one location, available to the individual and each authorized healthcare provider.
- **My health record locator** – a secure health information search tool that would help patients and clinicians locate test results, medical history and prescription data from a variety of sources.
- **My registration information** – an electronic health registration that would make it easier for individuals to give and update information such as name, address, insurance,

medications, allergies, etc., without having to fill out the same paperwork for every clinician and at every office visit.

Discussion:
Discussion in this breakthrough area focused largely on personal accountability and capability as well as the technical and privacy issues of an Internet-based medical record.

Following are some highlights of discussions on these and other areas:

Privacy issues.
"I think from a consumer perspective it is a fair statement to say that moving forward in this particular item [personal health record], we would have to spend a fair amount of time addressing concerns around privacy and security because that is absolutely expressed to us in conversations we have with groups across the country as one of the major concerns .. it is going to take assuredness that their privacy and security as it relates to job discrimination, future health insurance discrimination, life insurance discrimination, ability to borrow money and that type of financial discrimination they're protected against." – Davenport -Ennis

"What we have seen in the VA is that for [for older patients] – 49 percent of our patients are over 65; obviously the Medicare population falls into that – the issue of privacy is less important than getting information to the providers, so there are people who will choose this because they trust the technology or because they don't have a job that's at risk or health insurance that's at risk." – Dr. Kolodner

"I feel very protective of the capacity to protect [individuals'] privacy. As an individual, a lot of this is convenience for me and I would just like to have it . . . It wouldn't be the end of the world if [someone unauthorized went into my medical records], but I ought not give them up for anybody else and what I see ultimately happening here is we continue to work toward the pure vision and the pure vision in my mind is somehow the capacity for the data that is resident in everyone's system is electronically interconnectable and if that person is not capable or whatever circumstances not able to use that data on a voluntary basis, it would be available to some caregiver who would want it." – Secretary Leavitt

"I don't think there is anything unique in the healthcare industry. I think privacy is just as important in financial transactions as in health care." – Dr. Barrett

Personal accountability
"I think that the consumer and patient community has demonstrated to us over and over again that if they are instructed in what their responsibility is in the new process they will engage." – Davenport-Ennis

"This part of the breakthroughs really represents personal accountability. I think that the more of that pushed to the consumer the better. . . . It's an imperative that has really been heightened by this national disaster [the permanent loss of paper medical records during Hurricane Katrina]. It does put accountability back where accountability should be and that is with the consumer, and I honestly think most consumers would be very excited to be a part of the process to make it happen." – Gelinas

"I think it is important if we move along this path of personal accountability and personal health records, it's got to be coupled with some mechanism to improve health literacy in folks, because

we can't ask people to be accountable for things they don't understand. And we have a large portion of the population that either don't have access to a computer or who aren't computer literate. I worry that we may exacerbate the uninsured issue and create even greater spreads between the haves and have-nots. . . . When we give people accountability, make sure we also give them the tools to accept that." – Serota

"A person doesn't have to be technologically savvy. They can have someone do it on their behalf and there will be entities that arise -- just like the bank takes care of my money." – Dr. Kolodner

"If we look at the sort of dynamic of who's more likely to need this system and be sick versus who's not, probably [those who can't use technology] use a lot more health care proportionately because of the nature of the population. Whatever we do, I think accountability is critical, but I think we have to be realistic about accountability." – Kahn

"Don't underestimate our consumers who adapt to accommodate to get where they need to go . . . like my mother who at one time I had to show how to use a microwave and now calls me on her Blackberry." – Ayre

Personal and technological capability

"The fact [the Internet] contains so much information with standard technology, it is inconceivable to me that you can't engineer a system with existing technology to also provide a personal health record to allow you to encrypt, password protect, biosensor protect or something that you could have your record inputted. .. I have to encourage the community to recognize that this vehicle already exists to search and sort information with existing technology. We are just not using it in this particular case." **–** Dr. Barrett

"I find it really interesting that we are here in the United States talking about this subject and you go to a country like Brazil, which has far less than 10 percent PC Internet penetration, over 95 percent of income tax forms are input electronically. It's entirely possible for countries with essentially no infrastructure to go 100 percent electronic for something like filing tax forms. We may be discounting the capability of the average citizen in the United States to use this capability." – Dr. Barrett

"I am a bit more optimistic in terms of where medical records are today. . . .For the least insured and most at-risk patients we probably have somewhere in our data bases of a lot of that information already in the public health clinics that provide a great deal of indigent care. Those records likely exist electronically in more cases than the folks that are privately insured." – Roob

"I am thinking there is an analogy to banking and recognizing there is kind of third step and that is when the bank begins to send you information or alert you that this is a problem with your account or something you should do. . . . These elements of the personal health record would also lend themselves to that kind of alerting. You know, 'you are 50 years old and you need those 50-year-old tests or you need to seek medical attention for this or that or the other thing.' So there is a way that ties this into the second category of health improvement without relying on the consumer to have the knowledge to make use of the information directly." – Dr. Gerberding.

"What we don't want to happen is for that patient to show up with a memory stick with that data or a Web site and somebody to have to go into it and re-key it and re-enter that information. It has to be able to flow into other systems freely, interoperably, so that hands don't have to touch it any more in terms of mistakes that could be made. . . . Wherever the data is it has to flow freely from point A to point B to point C." – Dr. Henley

"We've got to get over this idea that the technology has to be different for health care. Now there are different requirements in health care and different resources and so forth, but the technology needs to be seamless throughout the world." – Dr. Henley

"It would seem to me that if we could from this process create enough of a standard that the way information was recorded at a Web site or on a chip or whatever the medium of carriage is that [the some 200 vendors that make practice software] could begin to adapt over time their software so that when I give it to them on a chip or link to the Internet or whatever it was that immediately it populates that field that require my insurance information for the seventh time." – Secretary Leavitt

Beginning with small steps toward the pure vision
"I hear time and over again from physicians – and I know this is about consumers on this particular piece – but 'if I could just get to labs and meds and some other key elements and I could learn a lot about a patient just having that information in front of me.' It's not a complete record, but it's a start and there is value in that and the same thing with allergy information. As we look at these pieces under the personal health record, I think that's something we have to break down. It's not the complete record day one, but what the elements and pieces we can deliver…" – Hutchinson

"I think we are already at a point in health care where we can take advantage of some sources of information that is already in an electronic form. . . . There will some manual entry you may want to add to the record itself, but we already have sources of data that can be electronic – whether it is pharmacy or payors or labs that we would be able to input and send this information electronically." – Hutchinson

"If only 10 or 15 or 20 percent of the population takes those early adopter steps, it does provide value, but it provides value to everybody because as you get to the pure vision, those who benefit in the last crunch of the doctors have benefited in what has been learned in the capacity to move in steps toward the pure vision." – Secretary Leavitt

Paper-technology interface
"I don't know if I contacted my internist today he would be willing to give me my record [to enter electronically]," said Kahn. Further, if a physician were willing to do it for one patient, could he or she do it for all? Most medical records are on paper – who in a physician's office would be responsible for making massive number of copies?

Concluding remarks and consensus

Secretary Leavitt began to conclude the discussion on Consumer Empowerment by suggesting that "my registration information" might be a good place to start. He proposed forming a workgroup who could begin to examine what's possible with existing technologies to take an incremental step toward the pure vision of interoperable health care. The workgroup would explore the public policy ramifications, the economic circumstances and the privacy implications and bring back to the community a discussion of what would need to be done to begin implementing in the context of the entire personal health record, not simply the component parts.

The Secretary asked for the assembly of such a group and the creation of a formalized charge, time table, work plan and whatever budget requirements they would have for discussion at the Community's next meeting. "And if we can agree at the point or we can reach a consensus on it," he said, "I will then implement it as Secretary."

Category 2 -- Health improvement -- which is how doctors, nurses and other clinicians do their work. Health improvement breakthroughs will help physicians and hospitals deliver safe and timely therapy and keep up with medical advances and innovation. Potential breakthroughs in this area include:

- **Electronic health record** – which will give a clinician direct access to a person's medical history, allowing the provider to electronically manage all aspects of care, enabling the provider to retrieve/capture data for treatments in an effort to support provider-patient activities such as review, encounter and follow-up. Possible benefits include improved health maintenance, disease management and error reduction in clinical decision support.
- **E-prescribing** – which allows a physician to send a prescription instantly to a pharmacy electronically, checking for dangerous drug interactions, allergies and formulary requirements.
- **Quality monitoring and reporting** – a standardized, timely and low-cost automated means of collecting quality information and sending it to its relevant entity. This will enable consumers to have access to comparative data that helps them make informed healthcare choices when choosing a health plan or hospital.
- **Chronic disease monitoring –** automated tools that support the collection and transmission of health status information and thereby help reduce the morbidity and consequences of chronic diseases.
- **Employee empowerment tool –** which would allow employees to have access to their health information and claims data to help manage their own illness or their health savings account.

Secretary Leavitt suggested the Community might pick one, or a maximum of two, of these breakthroughs to begin to develop a workgroup on. "This is revealing an early bias," he said, "but I am seeing a huge movement in chronic disease wellness programs, diabetics and heart patients being tested in the home with the capacity to send information back to their physician."

The ability to monitor at home and then link to an electronic record is likely to be a very big part of the future, he said, but one thing that inhibits it appears to be a lack of standards in terms of how that data is communicated technically and what the various metadata formats are.

"So that would be a place where if we were to embark on that particular one, we would need to bring a group together and I think bring them back and we would drive the cause forward quite a bit if we had that," he said.

Discussion:

In discussion that followed, the majority of Community members expressed a preference of pursuing quality monitoring and reporting. Discussion on the subject of health improvement focused on that and the other four potential breakthroughs as well as the importance of making long-term investments. Following are some highlights of those discussions.

Electronic Health Record

"I think the greater vision here is where we need to be going and that is the electronic health record – functional, interoperable, connected. . . . At least speaking for the physician community, there is a significant movement in the last two years moving that way and I think the wave is building and moving rapidly and that's where we need to put our efforts."

"I serve as a commissioner on the Certification Commission for Health Information Technology (CCHIT) and in this issue we haven taken the tack at the CCHIT to focus on certifying full electronic health record technologies. To the extent that there are others in the market who wish to have an e-prescribing component that may or may not yet be part of the EHR but probably will be, then they will have to plug and play with the certification standards of the CCHIT. I think we need to focus on the big picture here, which is the fully integrated health records and this part needs to be embedded in those systems." – Dr. Henley

"One thing about the childhood immunization record is it is probably the only category that has 100 percent inclusion, because almost all children have immunizations. So you would actually develop a cohort of the entire population over a period of time as a base for the content of those health records. It's probably relatively easy to do because pieces of it exist and it would have tremendous value for being able to have access to a population of people over time." – Dr. Gerberding

"I think one thing that's not clear is the relationship between the community and some of the major efforts that were introduced and already going. So where we talk about the [electronic health record] is that something that becomes a breakthrough or it something where that is one of the major efforts and what we are looking at is something to boost all that's moving forward?" – Dr. Kolodner

"We are triangulating a huge amount of federal, state and public sector resources on making the electronic health record come about – not as a standalone but as part of a continuum in an interoperable infrastructure. As some of you know, in the original draft of this document, breakthroughs did not have an electronic health record on it because, like the oxygen, we felt like we need not say it, but there was some discussion that I think just to make this discussion very practical this group must deal with issues that we bring before it around the electronic health record. Our contractors will feed things to you and our actions will determine that [Secretary Leavitt] will determine where we go as a department and others will as well. The question is you're going to form a workgroup that will take it on and carry it further if you believe we have enough apparatus." – Dr. Brailer.

E-prescribing and Chronic Disease Monitoring

"So many people think of e-prescribing as being new prescriptions and renewals going back and forth between a patient's choice of pharmacy and a physician. But the reality is there is a lot of initial clinical exchange of information – allergy information that is exchanged between physicians and pharmacists as well as medication history information to be exchanged along with that to provide a safer infrastructure.

"I think as we look at chronic disease monitoring, we should consider the fact that 15 percent of the physicians in the United States write 50 percent of the prescriptions and 30 percent of the physicians write 80 percent of the prescriptions. So you have a unique population in that outpatient environment to really focus on improving chronic disease through monitoring . . . and an infrastructure that allows that to happen though the ability to exchange prescription information between providers" – Hutchinson

"I would totally second the prescription issue for two reasons. For one, I think there is a quality issue there and an interaction issue with allergies and drug interactions, but it also drives everyone to become electronic and it's a simple way to do that. The other area I would focus on . . . would be the 85/15 rule [where 15 percent of participants in a health plan account for 85 percent of services]. The people who are chronically ill form a subset of people who are most

interested in their medical history and are most likely to take advantage of the data that are provided. I would vote for e-prescription and chronic disease monitoring." – Dr. Barrett

"All the people that serve on the board of my company are still grappling for a business model regarding outpatient e-prescribing because doctors are just not buying retail the instrumentation, which is not that expensive, to get into e-prescribing. So I think the reality of it is that the infrastructure is a no-brainer. The problem is here the physician community – for whatever reason – has not moved and I don't know what we can do." – Kahn

Quality Monitoring and Reporting

"This is a huge area of the future of Medicaid and Medicare. It is going to be a conversation that pressurizes very quickly on Capitol Hill because of the physician reimbursement rates and the connection it has here. A step forward in this would be a remarkable contribution. I do see this as a highly complicated, difficult area that we need to take on. I think the question is going to be is this the first one to take on or do we need to take it on in a longer-term perspective because it is going to take a while, it looks to me." – Secretary Leavitt.

"I just want to mention a relatively small lane in this category that may be a test bed for these ideas, and that has to do with the reporting of hospital infection rates for which more than 20 years has been done using some standard for what in the data elements and more recently a standardized reporting has been created . . . Many states are adopting this system as their method for reporting hospital infection rates, so it might be a useful test bed for exploring this idea on a broader scale." – Dr. Gerberding.

"It frankly scares a lot of people because what we will do in this whole quality monitoring and reporting piece that is being heightened by the pay-for-performance movement – or as we like to say at VHA, it is really no pay for poor performance – is this notion of making transparent bad care." – Gelinas

"I can't think of anything we could invest in in this category more important than developing a quality monitoring process. As I speak to our insurers and our customers and others around the country, the question I always get is 'why can I find out more about a television set or a computer that I can about my doc? I am going to get health care and I can't find out anything about that quality, but I can find out every component and where it's made who's faster . . . about virtually any other equipment that I buy that has much less of an impact. . . . We have 30 percent of the market and most places we have 40 percent of the market and we don't have enough data – even with our database – to do this kind of monitoring program, because when you break it down into the components of who's performing well in each individual small category, nobody has enough information data individually so it has to be a collective effort in order for the physicians to believe it has any credibility in the hospitals." – Serota

"I think from a macro perspective we have to as a society totally embrace this quality monitoring for pay for performance and any of those things to have any meaning to really get commitment from physicians and hospitals and other ancillary providers to commit to it." – Serota

"I had my first discussion on monitoring and health care and why doctors and hospitals didn't publish success ratios 25 years ago. I think we have made a bit of progress since then, but it's still a topic that covers the waterfront." – Dr. Barrett

"From the perspective of the consumer, the issue of quality monitoring and reporting becomes, for many, a life and death issue when they are making a decision about where to seek health care

and the best quality of care available to them. And that applies across the board – whether it's a person with a chronic, life-threatening debilitating illness or whether it's a parent making a determination of where to go for the best service for a tonsillectomy for an eight-year-old child." – Davenport-Ennis

Concluding remarks and consensus:

The Secretary said the group needs at some point to have an important discussion on how it orders projects in the long term. He proposed a box of ideas – much like a box of puzzle pieces – that he would put out on the table, and where at each meeting the Community would decide whether to put out another area of the puzzle, which is active discussion area. Then at some point, the group would decide whether to put it back in the box or move it forward to a work group. He gave immunization as an example. "Clearly we've got to do that, but do we start today or do we do it in October of next year or do we do it in July?"

He said the group has to do some long-term investing – tackling complex issues with few immediate results – but he wants to keep the agenda fairly clean in the beginning, because he wants "to deliver some stuff – fast."

"I want to do some short-term investments for short-term victories to make it clear we've got a pattern that can be implemented," he said. "At the same time, I want all of that to be headed toward a longer term vision." The natural conclusion, he said, is that quality monitoring and reporting is an issue the group has to deal with.

He proposed that at the next meeting the group would discuss that potential breakthrough and how to best break it up and look at it. He also proposed a briefing on e-prescribing and an active discussion on a path forward with respect to quality monitoring and reporting and then forming a workgroup on chronic disease monitoring that could help develop a plan the community could rapidly deploy.

Following additional comments, Secretary Leavitt declared a consensus around the proposition.

Category 3 – Public health protection – which would allow for monitoring and management of public health threats that result from episodic or unexpected events that affect whole population. Breakthroughs in this area might include:

- **Emergency information network** – a system that would ensure that relevant information follows Americans they seek care in emergency situations – be it an accident or acute illness requiring treatment in an emergency room or displacement by a disaster that necessitates treatment in an emergency shelter far from home.
- **Biosurveillance and pandemic surveillance –** a system, as Secretary Leavitt discussed in his opening comments, that would enable the detection of broad public health threats early and then manage them and mobilize national and local resources to save lives.
- **Adverse drug event reporting and notification –** an electronic monitoring and notification system that would detect potential problems with drugs and alert federal authorities and physicians, who could then notify patients when a problem is verified.

Due to time constraints, the Community was not able to discuss this third category of breakthroughs, but Secretary Leavitt reiterated his belief that there was a "compelling national need on biosurveillance."

He asked for the group's forbearance of an acknowledgement that he intends to form a workgroup on that breakthrough and bring it back to the Community with an agenda and time frames.

At the next meeting, he told the Community, they would also have

- an extensive discussion on quality monitoring and reporting
- a workgroup formed on chronic disease management and monitoring
- a briefing for discussion on e-prescribing
- the formation of a workgroup to bring back a product and path forward on the whole category of consumer-driven electronic records that will merge into the pure vision.

With that, he dismissed the meeting for short break and, because he was leaving for a meeting with the President, asked Dr. Brailer to take his place as chair for the remainder of the meeting.

Public Comment

After a short break, Dr. Brailer took over as chair for the meeting, thanking the community members for taking the time to participate and for the wonderful discussion. "The Secretary and I were just talking that this is really a remarkable and unprecedented discussion around health IT," he said.

With that, Dr. Brailer opened the floor to members of the public, who had been watching the meeting on a big screen on the first floor of the HHS building**.**

He asked members of the Community to listen and reflect on the comments and that the documents are being recorded and will be available with the entire meeting on the Web at http://www.hhs.gov/healthit/.

He asked the members of the public to limit their comments to two to five minutes and to focus on the work that the Community has set out and to avoid promotional activities. People who want to comment but can't do so in person today, he said, may mail them to 200 Independence Ave, SW, Washington, DC 20201 or e-mail them to Onchit.request@hhs.gov.

Speaker Number 1 -- Katheryn Serkes, representing the Association of American Physicians, "a national nonpartisan association since 1943, dedicated to preserving the sanctity of the patient-physician relationship." She expressed two concerns.

First was the issue of informed consent. "We urge that any of the recommendations that come from this committee -- whether it is about identified or de-identified information -- be included in electronic records only with the conformed consent of the patient," she said.

Second was the issue of quality monitoring and a statement made that many providers are afraid of transparency because it would expose bad care. "The implication," Ms. Serkes said, "is that the only people who resist some of this are bad doctors and bad providers." She said her organization is not concerned about the technology itself, but that it forces doctors to practice following rigid guidelines and rewards successful outcomes – regardless of an individual patient's issues. "If only paid for successful outcomes, physicians who desire to remain financially solvent have a problem – do they take sick patients or do they not take sick patients? We are concerned that this will move the doctors away from taking sicker patients if they are being measured only in outcomes."

Ms. Serkes also disagreed with a statement that quality *control* was the most important thing, saying that she believed quality was the most important thing. "If we put the resources that might be targeted into electronic reporting and some other things into actual delivery of medical care, it would be money better spent."

Finally, she posed three questions to the committee:

1) Who in the committee was designated as the privacy expert?
2) Under what circumstances the Community would foresee calling a secret meeting as allowed by the charter under the Federal Advisory Committee Meeting Act
3) How does the community envision interfacing with the National Committee on Vital and Health Statistics, which has already been in formed and is advising the Secretary on issues of standards of technology and medical technology?

Dr. Brailer's response:
Dr. Brailer thanked Ms. Serkes for her comments and told her he would have answers to her questions posted as part of the minutes of the proceedings after having the chance to review them.

Speaker Number 2 – Agi Lurtz from Oklahoma. She told the Community that she was excited to hear about the Community and shared a story of caring for her elderly father, who lived well into his 80s. For her father's last 10 years of life, she said, she went with him to all of his medical appointments and can relate to all of the stories she has heard today about filling forms – often multiple times for a single office visit or procedure. "If I had failed to write all of the medications each time, it could have killed him," she said.

Ms. Lurz told the community she has a Web-based medical data service that has been up and running now for two years, and offered her services or input to the Community.

Speaker Number 3 – Brian Holland of Deloitte, a provider of audit, tax, consulting and financial advisory services that represents a number of hospital systems across the country. He called on the Community to think of the human pieces of health information technology and asked them to think of the workforce training that will be necessary for members of the hospital community to adopt the new technology.

Speaker Number 4 -- Steve Lieber, president and CEO of Healthcare Information and Management Systems Society (HIMMS). He told Community that HIMSS offers its endorsement of the group's charter. He applauded their efforts and offered the following suggestions:

- He encouraged the Community to consider his organization's 17,000 individual and 270 corporate members as valuable resources in areas ranging from national public policy discussions on interoperability and health care delivery to local data-sharing initiatives. "HIMSS believes the AHIC success will be greatly enhanced by interaction with HIT subject matter experts, particularly through the breakthrough discussed today," he told the Community.

- He said HIMSS encourages the community to get to know that inoperability exists in health care already. "There are examples for you to see and observe," he told the Community. "Integrating the health care enterprise is a seven-year initiative between HIMSS and several other national associations that made connectivity a reality for many health care stake holders. Also there are other demonstrations and exhibitions that show very practical solutions and first-hand experiences of interoperability.

Following the public comments, Dr. Brailer reminded others they could still send their comments by mail or e-mail.

Final comments

In the final segment of the meeting, Dr. Brailer opened the table to the Community for thoughts or reflections on the meeting and approaches they should begin considering in the agendas for forthcoming meetings. Their final comments, concerns and suggestions included:

Putting together expert lists. Nancy Davenport-Ennis suggested that before the next meeting Community members provide a list electronically of names of organizations that have programs in any of the areas discussed that might be helpful to the community in reviewing and evaluating how those programs are working. Dr. Brailer agreed and asked members who knew of people, projects or groups involved in the areas where the Community has identified some going-forward strategy to forward their names.

The appropriate process for getting others involved. Dr. Brailer addressed this concern by Lillee Gelinas, saying, first, that the workgroups will be considered subcommittees of this Federal Advisory Committee and their work will be subjected same transparency in public access that any members of the Community are, meaning the Community has a burden diligence in assuring that the people appointed are qualified and don't represent undisclosed biases. At some point Community members will be asked for advice on people to name to those committees; people nominated for the Community, many of whom indicated interest in serving on workgroups, will also be considered.

Meeting schedules. Craig Barrett brought up the challenges of traveling across the country to meetings. He asked if the next several meetings would be scheduled so that he and others not in the Washington area could schedule travel to several meetings in advance. Dr. Brailer answered that he is working to have six months of meeting scheduled.

Formation of subcommittees. Barrett also asked what was next in terms of forming subcommittees and how the mechanics of that would work. Dr. Brailer reminded the group that there would be a briefing on e-prescribing, which is going to lead to a decision point in the group about whether there is further work or a specific charge to delegate to a workgroup. The group is also planning a similar briefing with a similar process on quality monitoring.

In the areas where the Community does have a charge, they will first create an ad hoc group that will come together "more as a scaffolding to help us work through issues so we can then have chargeable items," he said, "and that group will start with an environmental scan, potential specificity of projects that have this kind of two-year outlook and a quick summary of what actions that are needed to get there."

In chronic disease monitoring and biosurveillance, the Community will move quickly – though perhaps not before the next meeting – to put together a workgroup that will start again with an environmental scan and begin working on the goals, the time table, specificity and then the barriers and actions.

Dr. Brailer stressed the importance of being very specific with the groups about what they are to achieve, particularly given so much other activity going on in these areas. "Otherwise I think we could set them up to be just part of the continuum," he said.

The importance of acting quickly. Dr. Barrett expressed concerns about not waiting six weeks or two months to get started on forming the workgroups. Dr. Brailer responded that he plans to start the workgroups with Federal staff – who won't require the kinds of clearance and screening needed for others – so they can work quickly to define an issue and then begin bringing in outsiders and people from the private sector and other settings to supplement that. He said it is the Secretary's and his expectation that by the end of this calendar year there will be three or four specifically charged groups with deadlines, specific goals, well-defined barriers and recommendations on the staffing support and other resources needed to begin.

Will ideas outpace ability to act? Dr. Gerberding asked whether the group was working on any "landing ground" for the new ideas and charges that emerge from the workgroups. "I always fear that we can work very fast to find out what to do," she said, "but then the how-to-get-it-done in government might be the right limiting step in the process unless we really think that through now." Dr. Brailer admitted that is a question before him now. He offered two examples where his office has had to work with or through other agencies or institutes to make its work possible. "That's part of the regulatory tools piece that we are going to be asking the federal staff to understand what could be done and how do we make sure we get the get the result as expeditiously as our boss wants it." he said.

Role of NCVHS in the process. Concern was expressed about how NCVHS fit into the process with all they have been doing in this area. Dr. Brailer responded that he had met with Simon Cohn, director of the NCVHS, and the executive committee of the NCVHS a number of times about this and sees them to some degree "providing a little bit of a counterweight to the community in this sense."

"The U.S. needs to have a singular set of standards – not just in cross section, but over time," Dr. Brailer said. "This is a charge NCVHS has taken." The same is true of privacy, he said. He wants to make the committees' work available to the community, so he sees them working together in that sense.

In the areas of both privacy and standards, Dr. Brailer said he "sees the rubber hitting the road, because the issue is going to become not the global privacy issue or the global standards question, but what are we going to do about the standards we need for chronic disease monitoring breakthroughs? How does that fit into a long-term standards context? That polarity of short term versus long term is where we would see the interchange between this and NCVHS, so that's ready, everyone's decided that's what we are going to do, but we now need the specific subject matter to put into that to get the findings."

Financing for the Community's work. Gelinas raised the issue that at some point the group needs to address the budget availability for the capped portions of this subgroup. Dr. Brailer responded that the charter for the group "essentially carves a way to those questions of financial recommendations to the federal government." That occurred, he said, "because there was a sense that we had trade off that is perceived between adoption and interoperability and we are trying to bolt those two together very clearly so that each step we take brings both adoption and interoperability."

Swearing In

At the conclusion of the meeting, the Community members present were sworn in and Dr. Brailer dismissed the meeting. Three members who were not present will be sworn at a later date.