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Testimony of
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Chairman Gordon, Mr. Hall, and members of the committee, good morning and thank you for this opportunity to testify on the issues relating to *Meeting the Need for Interoperability and Information Security in Healthcare IT*. This topic is of great importance to my colleagues in healthcare information management and has been for many years.

I am Linda Kloss and I represent the American Health Information Management Association (AHIMA) as its chief executive officer. AHIMA is an association of over 51,000 health information management (HIM) professionals deeply committed to and actively participating in the adoption of standards-based and interoperable health IT. Since 1928, HIM professionals have worked to improve the accuracy, completeness, confidentiality and security of medical record information to support clinical care and improve healthcare of all Americans.

Today, HIM professionals are on the front lines in implementing electronic health records and other technologies to improve health care. This includes information exchange among providers and new ways for consumers to access their own health information. Confidentiality, privacy, security, data integrity, and consumer access are core values we bring to this important work.

As I speak this morning, I must inform you that AHIMA, through its Foundation for Research and Education (FORE) has been a contractor for several health information improvement projects initiated by the Department of Health and Human Services' (HHS) Office of the National Coordinator for Health Information Technology (ONC), the Agency for Healthcare Research and Quality (AHRQ), and the National Institute of Health's (NIH) National Library of Medicine (NLM). These projects have included evaluating the mapping of classification systems, studies of the potential for improved fraud deterrence through the use of electronic health record technology (EHR), analyses of privacy and security roadblocks to implementation of EHRs and health information exchange, and development of best practices for state level health information exchange. The FORE foundation, in conjunction with the Medical Group Management Association (MGMA) also addressed aspects of the collection and reporting of performance measurement data. AHIMA is also one of three organizations that founded the Certification Commission for Health Information Technology (CCHIT) which later received a 3-year contract from ONC and is now an independent not-for-profit organization recognized by the Secretary of HHS as a certifying organization for HIT.

AHIMA is active in a number of standards activities. Currently AHIMA is a voting member of the Health Information Technology Standards Panel (HITSP) and representatives are active on its Security Technical Committee. AHIMA and several of its members have been active for a number of years in the Health Level 7 (HL7) standards development organization (SDO). Currently our involvement is in developing EHR system and personal health record (PHR) system functional models, legal EHR functionality, and the clinical document architecture CDA.

AHIMA is also an active participant in a number of national and international terminology and classification standards organizations. We serve as a member of the ICD-9-CM Coordination and Maintenance Committee with the American Hospital Association (AHA), the Centers for Medicare and Medicaid Services (CMS), and the Centers for Disease Control and Prevention's (CDC), National Center for Health Statistics (NCHS). We also serve as a member of the Cooperating Parties, the group that sets the guidance for use of ICD-9-CM in the US, the editorial advisory panels for the American Medical Association's Common Procedure Terminology (CPT®), and the Healthcare Common

Procedure Coding System (HCPCS) which is operated by CMS. Internationally we have been appointed by the NCHS to serve with the World Health Organization's (WHO) education, and ICD-10 and ICD-11 reference terminology work groups. We also have worked with the International Healthcare Terminology Standards Development Organization (IHTSDO), which is the standards group that has taken up the SNOMED® terminology system.

Costs and Benefits

Standards-based electronic health record technology is the essential building block for much of what we seek to achieve in interoperability. After years of slow and inconsistent progress, I believe that considerable progress is now being made to define core functionality and data exchange standards and to drive their adoption. The greater focus on standards over the past 5 years has led to progress by SDOs, formation of the Health Information Technology Standards Panel and the Certification Commission for Health IT and other collaborative projects which have in effect broken the log jam. However, the recent momentum must be supported so progress can continue and even accelerate. With the continual evolution of technology and growing experience of those who are using it, this work will require effective leadership, incentives for adoption, and financial support for the effort for some years to come.

With a solid road map and full support, the benefits of interoperability include the ability to:

- Exchange crucial health information between healthcare providers so that medical treatment for any individual can be rendered accurately and completely.
- Access, transfer and use the extraordinary body of knowledge about medical care and personal health and to grow that body of knowledge through accelerated research and dissemination of learning. .
- Report and transfer crucial public health data in seconds to improve effective local and national response to individual and population events and be effective participants in improving global health.
- Achieve a high performing health system in terms of outcomes, safety and cost through performance improvement and public reporting.
- Engage people as full participants in improving their health and wellness.
- Understand effective ways to transform care delivery, including how we pay for it.

There are numerous forecasts and models about the costs of implementing EHRs and health information exchange by researchers at Rand, The Center for Information Technology Leadership, the Robert Wood Johnson Foundation, and the Commonwealth Fund to name a few, as well as studies by AHRQ and ONC. While the specific estimates may vary some depending on the sets of assumptions used in the forecasts, the conclusion is clear: The benefits will outweigh the cost of investing in secure and interoperable health IT. But it will not be inexpensive and the return on investment will not be quick. Any consideration of cost must take into account the costs of the current state of healthcare. For example,

- What is the cost of treating patients with limited and inaccessible information about their medical condition and history?

- What is the cost of our inability to manage an individual's care across a multiple number of providers just in trying to get the information needed?
- What is the cost increased administrative duties and operations due to our inability to exchange uniform data electronically for secondary purposes such as research, claims processing and a variety of other administrative activities that are now restricted by our paper-based information system, restrained by our ability to review and analyze paper data, and our ability to locate and exchange information when and where it is needed?
- What is the cost of having our limited data due to the inappropriate use or limits placed on our terminology and classification standards and systems?
- What is the cost in loss of life and poor health, because the right data is not available at the right time?

Real improvements are being documented by medical practices and hospital that are using health information technology. Except for delivery systems such as the Veteran's Health Administration, other integrated systems and networks such as e-prescribing, improvement are for the most part isolated. Without consistent standards it is difficult to accrue the values that require interoperability.

Standards, Guidelines, and Coordination.

I will address three interoperability and security issues in my comments today that we believe are important for the Committee to take into account in its work. These are: terminologies and classifications, data stewardship, and the harmonization of standards.

Terminologies and Classifications

The US needs greater uniformity and coordination of healthcare terminologies and classifications, a type of health information standard that is perhaps not as well understood as are other types of standards. Clinical terms and concepts are the language of medicine and form the information content in electronic health records. Terminologies and classifications catalogue these terms and concepts so they can be stored, exchanged, retrieved and analyzed. Interoperability requires that the sender and receiver understand the exchange and interpret it correctly. Terminology and classification systems are critical for information exchange, for public health reporting, performance measurement, quality reporting, research, and billing and payment for healthcare services.

AHIMA and the American Medical Informatics Association recently published a white paper entitled *Healthcare Terminologies and Classifications: An Action Agenda for the United States.* I have attached a short summary of that paper and its recommendations, Healthcare Terminologies and *Classifications: Essential Keys to Interoperability* to my testimony. This report was prepared by a joint task force of experts who call for the establishment of a public- private authority responsible for ensuring the US has:

- Robust and up-to-date terminologies and classifications for interoperability between systems;
- Standards for developing terminologies and classifications in the EHR and PHR, including implementation guides;
- Principles and guideline for development, distribution, and maintenance of systems and coordination across systems;

- Timely and reliable industry guidance;
- A coherent set of policies and procedures to ensure openness and performance for terminologies, classifications, and the systems that convert data encoded in one terminology or classification to another; and,
- Business process automation to ensure cost-effective development of systems and cost-effective use by providers, payers, and other organizations.

While federal and private entities have made genuine progress, the task force recommends public funding for a research and development project to design a permanent governance mechanism and formulate strategies and plans for:

- Contemporary and standardized processes for development, adoption, and maintenance of terminologies and classifications;
- The structure, function, and operating practices for a US public/private authority to oversee terminologies and classifications;
- Gaining commitment of terminology and classification stakeholders – developers, end users, and other service and technology suppliers- to principles and guidelines for open and transparent approaches that permit cost-effective interoperability of complete and accurate information; and
- US participation in the IHTSDO – the international organization now addressing SNOMED terminology which we believe is the base terminology for a standard EHR.

AHIMA and AMIA are prepared to coordinate such an effort, and I ask your consideration to support this effort. Without standard and consistent data content– which comes from terminologies and classifications – the US will not achieve interoperability of useable information. As described in the task force report, the US has fallen behind other countries in developing; deploying and using these critical and new approaches to coordination are urgently needed.

Data Stewardship

A second and similar effort is needed in the area of quality measurement and secondary data. Recently, AHRQ issued a request for information related to the data measures, data sets, or standards used for the collection of quality measurement information – the potential to have a data steward to coordinate the groups and the group processes for developing data collection. This concept was expanded to include data also collected for a variety of secondary purposes, research, public health, reimbursement, and other public policy requirements.

As I noted earlier, the ability to use secondary data from a large population offers vast opportunities to improve the health of this nation and reduce error and costs. At the same time secondary data also supports reimbursement for healthcare services not only in the traditional sense of the billing claim, but also in the form of information to support effective payment policy.

As with terminologies and classifications, the US lacks a coordinating body with requisite authority to set a vision and operating policies for secondary use of data, a data stewardship entity. An acknowledged data steward entity would coordinate the various public/private groups working on quality measurement and the employer/purchaser, research and public health communities which use these data. AHIMA's members oversee the collection of these data in many health care organizations. They report that lack of uniformity in the data sets requested and uniformity of definitions results in

costly manual work and concerns about the quality and validity of data used to measure quality. Standardizing measures and policies regarding secondary uses of health information will enable the IT industry to design solutions capture data once and use it for multiple legitimate and authorized purposes.

Standards Harmonization

The third area relates to the harmonization of technical standards and consistent guidelines for their use, including standards for clinical terminologies and classifications, as described earlier.

In the 1980s HL7 was formed to address healthcare institutions' inability to share data between or among their own data systems and programs. Today, HL7 and other SDOs have become and are addressing international information exchange.

Throughout the US, industries are sharing data and cutting their administrative costs because they are using uniform standards, such as the Accredited Standards Organization X12 standards. Besides using standards, however, these industries also use and require guideline standards – how the particular industry's members will use a chosen standard, under what conditions it will be used, and what data sets will be used, and so forth.

This has not been the case in the past in healthcare. For instance today we use standards required by HIPAA. We, therefore, adopted an X12 standard for claims, the X12-837. Unfortunately as testimony last year at the National Committee for Vital and Health Statistics (NCVHS) indicated there are now over 1,000 different instructions for the use of the X12-837 in the healthcare industry. If we are to achieve interoperability and use standard like other industries, this should not happen or be allowed to happen.

The healthcare industry has over 1 million providers, thousands of health plans and payers, a potential consumer base of over 300 million individuals, and some 1.44 million employers offering some level of healthcare, along with numerous government agencies, clearinghouses, and vendors. Achieving consensus on complex standards and an understanding of their uniform application is a monumental task even with a shared vision. In the US, our standards data organizations are essentially groups of volunteers that come from industry and the professions. It is difficult to get and keep volunteers who work for provider organizations working on standards, yet their participation is critical.

To address the consistent use of a standard, the harmonization of standards – to make the standards work with each other, and to choose the collection of standards necessary to perform a function or functions requires a significant effort. Over the last three years we have seen, through the efforts of HHS, ONC, and the American Health Information Community (AHIC), the establishment of the Health Information Technology Standards Panel (HITSP). HITSP and its numerous volunteers have addressed the need for standards for a variety of healthcare functions and performed the harmonization task. While the question of adherence to this harmonization still remains to be seen, the task is the first time (outside of some limited and similar work done by the NCVHS with e-prescribing and the HIPAA standards) such an effort has occurred in healthcare.

AHIMA has three concerns with HITSP in its current capacity. First, it is largely a volunteer effort and while this improves acceptance, it is a slow process. HR 2406, introduced in this committee, has the potential to provide some of the resources, through the National Institute of Standards and Technology (NIST), needed to sustain and accelerate the role that HITSP plays. This does not negate the need for an industry (public-private) oversight group with a role to approve, reject, or amend the final choices for harmonization of standards. Public/private involvement is crucial for acceptance, buy-in and use.

Similarly, NIST could also provide some of the tools for groups like CCHIT, whose role is to identify and test that the standards harmonized by HITSP and other groups, and ensuring those standards are contained and functioning within the products sold on the market. This assures buyers that the products they are purchasing technology that will allow them to be interoperable with the industry and the networks under development.

Our second concern related to the need for coordination among HITSP, CCHIT, and the entities charged with coordinating terminologies and classifications , data stewardship, health information exchange and other related functions critical to achieve an secure, interoperable system. Such an entity and role is currently under discussion throughout the industry, and I will not comment further at this time since that is not the nature of today's hearing.

Our third concern with HITSP is funding. How does the nation fund such a body that does not itself develop standards, but rather proves the harmonization process? In other industries there are councils, but no such body exists in healthcare. If the benefits from harmonization and eventual interoperability accrue to the population, should the population, as a whole, pick up this cost? That is a discussion Congress should undertake. Should HR 2406 become law and the NIST involvement occur, the investment in NIST will assume some of the costs incurred in the harmonization process, but not all.

Barriers to Interoperability

I was asked to address barriers to interoperability and I have already mentioned several. Let me recap: Industry consensus guidelines for the prioritization, adoption and use of standards,

- Financial support and staffing for the coordination and harmonization of standards and the development of guidelines,
- A mechanism for uniform adoption and implementation of standards, and
- The current reimbursement system for healthcare.

To date, the US healthcare system has only limited success with the adoption and use of standards. The standards chosen to be included under HIPAA were reviewed by the NCVHS and the guidelines were written by the ASC X12. SDOs normally do not write the guidelines for their standards, but there was no other group to do so. The NCVHS, while holding considerable public comment would not, today, be considered a public/private entity that engages the industry and government. The result, as I have noted, is a limited adoption of several of the HIPAA standards, and an inconsistent use of the more common claims standard and remittance standard.

More recently we have seen the HITSP work diligently to harmonize standards and recommend guidelines, but we have not had an opportunity to see if the industry will actually be able to adopt and

consistently use the standards HITSP has proposed. Without consistent adoption and use we cannot achieve uniformity. This does not have to mean that all products have to look the same, but the data being exchanged, and the mechanisms for transmitting and receiving it have to be standard so no one can question the integrity of the data or finds themselves is a position of not being able to send or receive the data.

The HITSP entity and process provide great promise. For the first time we have a body that can be seen as providing public/private involvement in the harmonization and guideline processes, but HITSP has its barriers as well.

I have suggested the need for financial support and staffing for coordination and harmonization. Without this staffing and the financial support needed to provide the staffing, the move to identify, adopt, guide, and see consistent standards being used will lag. Other nations, and industries have addressed this issue and the US must address it as well. Perhaps a small fee can be associated with each claim or some other mechanism that will allow the industry and its consumers to spread the cost of the work that needs to be done. First, we need funding to establish the processes and standards, and then later maintain the system to keep it refreshed and consistent with medical practice and knowledge. Similar funding needs to be examined for the groups we suggest for terminologies and classifications and data stewardship. While we must maintain industry oversight through some inclusive public/private entity or entities, we must also move from a volunteer to a full-time mechanism to keep the process progressing. The benefits of the standard EHR and systems we are discussing are too valuable to wait on a disjointed volunteer effort.

If we have the funding and the standards and guides, how do we compel there use? This is a question I hear very often. Standards have been around for many years, yet the healthcare industry or market has not been able to sit down and achieve universal compliance seen in other industries and countries. HIPAA was an attempt, but it did not have industry involvement and buy-in at the level needed and there is no industry pressure to make covered entities abide by the few rules it has, including the federal government.

If we cannot develop some entity or mechanism that has the power to not only oversee the choice standards and guidelines we have been discussing, then we will see a very slow achievement of the steps necessary for full interoperability. This is a somber statement, and I want to acknowledge the work of the Secretary, ONC, and AHIC who are trying an approach based on the Medicare market and the assumption that the federal government will adopt and abide by the selected standards and guidelines. Essentially, this is an industry-wide voluntary system that suggests that others will be as compliant as the federal government says it will be. We have not seen the results of this effort yet and much has to be done. If we do not have the actual upfront buy-in and then demonstrated compliance from all parties, including the federal agencies, even at maximum capacity it will take many more years before we get to the exchange of information we are all seeking under the current system,. Today, it is not clear who will lead this charge.

The last barrier related to standards I want to mention is reimbursement. Unfortunately, reimbursement runs the show.

Many physicians indicate they will not even consider adoption of HIT and standards until the Medicare and Medicaid reimbursement formulas are corrected and they are paid adequately. I understand Congress is addressing this concern, but with the federal government paying such a big portion of the healthcare bill, reimbursement, especially physician reimbursement is a barrier to adoption.

It is more than the amount of reimbursement. The reimbursement process controls other aspects of standards use that affect the achievement of interoperability. The US use of classification systems that reflect 21st century medicine have been thwarted continually because many health plans and payers do not want to convert to a contemporary system. In the US, our ICD-9-CM classification system is seen as part of the reimbursement system. Quality measurements are similarly fast becoming viewed this way as well – administrative data, rather than information something that can be accurately used to actually describe our care, diagnoses, and treatment.

As we build processes like quality measurements and data repositories like the personal health record, the reliance on healthcare claims data raises questions regarding the completeness and accuracy of the information for clinical use or analysis. We must keep our clinical data free from manipulation for reimbursement purposes, and require our reimbursement processes to find another way to develop their payment mechanisms rather than to appropriately control or impact our collection of clinical data. If we cannot rely on the integrity of clinical data any interoperability benefit will be greatly diminished.

As we build the system to adopt and harmonize standards and design guidelines and implementation, we have to build it as intended to provide data that accurately describes the patient and medical encounter. Yes, payers or health plans need to be involved in these processes, but lets build our EHRs and information systems to maximize our health information and ensure data integrity.

Security and Privacy

HIM professionals have been deeply involved in the need for confidentiality and security, and committed to implementing and enforcing laws, regulations, and best practices to assure maximum data and individual protections. We see our role as to provide maximum protection for the consumer and the information. HIM professionals are often the privacy officer in healthcare institutions, and are usually involved in the process of releasing an individual's health information for its intended use. I have attached to my testimony a recent statement on the issue of confidentiality that we produced jointly with AMIA.

AHIMA and its members have been involved in the recent process of reviewing laws, regulations, and practices associated with confidentiality, privacy, and security across the states and the federal government. Many of these laws and regulations go back decades and are intertwined with purposes now forgotten. It will take time to unravel these relationships and allow the states and the federal government to develop uniform laws that protect health information. I can assure the committee that we are engaged in and see a tremendous amount of effort directed as developing maximum uniform protection and developing the security mechanisms necessary to secure our data and networks

HIM professionals believe that use of standard electric health records will permit more secure protections for personal health information than what exists for the current paper record. We are in a transition period, moving from a paper-based system to an electronic record. This change is not

without confusion and gaps that must be addressed are being addressed. I want to note our support for HR 2406's approach to having NIST assist in the identification of potential security standards that should be considered under the HITSP process. NIST has a demonstrated expertise in this arena that can benefit and accelerate the industry's efforts considerably.

With the adoption of electronic health records we have the technology to provide confidentiality or privacy through a variety of security processes. Just how we adopt and use security processes or standards is under considerable and appropriate debate. Identified health information flows throughout the healthcare industry, and other industries, as well as to consumers themselves, and in some cases employers. This flow is through consumer request, reimbursement systems, government reporting requirements, school requirements, and so on. The process is complex and some of the uses of technology just as complex. Therefore, we must be careful to use technology wisely or we could impede the movement of information when it is most needed.

Surveys indicate that most individuals want their health information where it is most needed for their own clinical care and for the benefit of the population. What consumers do not want is to have their health information misused. They do not want to be inappropriately discriminated against because of their health status or information.

In addition to uniform rules, regulations and technology to achieve health information confidentiality and security, AHIMA believes in essentially three basic principles for over all protection:

1. Personal health information should be protected wherever it lays or is transported – whether or not the entity or person accessing, transferring, storing, or holding the information is a healthcare entity or covered by HIPAA.
2. Individuals should be protected against inappropriate discrimination on the basis of their health information – this would include situations of employment and insurance.
3. Individuals should be protected against the intentional misuse of their health information.

There are two caveats to these three principles. To be effective laws and regulations related to discrimination and misuse must include provisions for active prosecution and penalties, and the public must see active prosecution and penalties.

There are and probably never will be absolute secure systems that will provide the confidentiality or privacy sought by some of the public and expected by all of the public. But interoperability will be a failure if we cannot build trust in the system of EHRs, PHRs, and health information exchange. We can never undue an actual disclosure of an individual's health information, but we can take steps to ensure that any one intentionally discriminating against an individual or misusing health information will know that they face severe penalties for doing so.

Global Harmonization

My comments on terminologies and classifications gave a glimpse of international collaboration. Many of the classifications used in the US are actually either international standards, or a US version of an international standard. The SNOMED terminology, for instance has recently moved from a US-based standard to an international standard. The HL7 standards are international standards. There are other standards as well. Disease and public health are not controlled by state or international borders.

So we have to consider the global harmonization of some of the standards we use in US healthcare, especially terminology and classification standards used for clinical care.

I am sorry to report that the US is behind in this matter. I alluded to the restraints in some of our classification systems. While most of the world is using the current WHO ICD-10 classification standard for disease or a modification of it, the US remains over 10 years behind, still using ICD-9-CM for morbidity reporting, a version developed in the 1970's. While US uses ICD-10 for reporting mortality information, we run into situation s such that, currently, until the next change in codes, the US can report that you died of avian flu, but cannot report that you survived avian flu. Similar delays have occurred with other outbreaks since the ICD-9-CM numeric classification cannot accommodate the WHO ICD-10 alpha-numeric codes, making it necessary for the US to manufacture an alternative code when needed and when possible. When we exchange information with most other countries, the codes must be converted, and information coming from outside the US, has to be maintained in a separate database.

WHO has begun the process to update ICD-10 to the next version ICD-11. A final ICD-11 classification is expected in eight or nine years. ICD-11 is based on the ICD-10 structure, and its development will be based on the use of ICD-10, which limits US input. We are concerned that the failure to move our national terminologies and classification forward in sync with international progression leaves our healthcare industry behind and exposes our public health system to additional barriers and costs because we have not kept up with public health in the rest of the world.

We believe our recommendations related to terminologies and classifications will help change our role in the international community. Groups like the HL7 should continue to be encouraged to develop standards for clinical care information exchange that are international in flavor. While our reimbursement systems might differ, our ability to share data for clinical care, research, and public health should not be restrained. The US is a world leader in health research and technology and a move to insure international standards can only help make our role internationally stronger.

Mr. Chairman, Mr. Hall, this concludes my responses to the Committee's questions. There has been remarkable progress in the last 4 years to move healthcare from paper to a technology enabled interoperable system. Developing and deploying standards is fundamental prerequisite. But so is sound policy and sound governance to ensure that technology and policy are aligned and are being advanced over time. This is an effort that requires the full engagement of all three sectors of our society, government, industry and the private non-profit. It is not a project like Y2K that has an end point. It is a process that requires a long term view and a public and private commitment to the public good. Federal and state funding is required as is the authority that can only come through intelligent government action. The HIM profession and AHIMA stand ready to work with Congress, the administration, and our healthcare colleagues to continue on a path that becomes ever more critical.

I thank you for your invitation, your time, and your attention, and I am ready to answerer any questions you might have.

Thank you again.

Contact