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Steven Posnack, Director
Federal Policy Division, Office of Policy and Planning
Office of the National Coordinator for Health Information Technology
Hubert H. Humphrey Building, Suite 729D
200 Independence Avenue, SW
Washington, DC 20201

RE: Comments on PCAST Report

Dear Mr. Posnack:

The American Health Information Management Association (AHIMA) has read and discussed with great interest the President's Council of Advisors on Science and technology (PCAST) Report "Realizing the Full Potential of Health Information Technology" (the Report) and is pleased to respond to questions published by the Office of the National Coordinator (ONC) as requested by the National Coordinator, Dr. David Blumenthal in the December 10, 2010 *Federal Register* (75FR76986).

AHIMA is a not-for-profit professional association made up of more than 60,000 members who are educated, certified, and engaged in the health information management (HIM) profession. The PCAST report highlights the importance of healthcare data, a subject and the center of focus for the HIM profession no matter where it resides. HIM professionals are involved with the collection; storage; use; analysis; coding; exchange; and privacy and security of health information.

Key principles of HIM data processes include maintaining the accuracy and integrity of the data. Likewise, HIM professionals ensure responsible stewardship over health information to maintain the trust of the individuals/patients, the clinicians who depend on the data to treat patients, and institutions that use secondary health data for research, quality measurement, and other population health purposes, as well as public policy and the reimbursement.

The PCAST Report not only draws attention to the role of healthcare data, but also to the direction the government and industry have been taking to reach the goals of electronic health record systems (EHRs) and electronic health information exchange (HIE) including the infrastructure and interoperability standards that support achieving these goals. In actuality, the real goal is the continued improvement of both consumer and population health. The HIM profession shares these goals as noted by our Vision to "...lead the advancement and ethical use of quality health information and wellness worldwide."

The PCAST Report and the technical innovation it presents has captured the attention of the healthcare industry and the release of this report is necessitating the White House, the Department of Health and Human Services (HHS), and ONC to reconsider the direction and approach currently underway as a result of the ARRA-HITECH and Accountable Care Act (ACA) legislation and direction by Congress.

AHIMA sees the Report acknowledging the goals expressed above, and we agree with many of the PCAST's assessment of the problems at hand, the cause of these problems and the current environment of the healthcare industry. AHIMA especially appreciates the attention the Report has placed on healthcare data and how it should be used for the delivery of healthcare as well as the secondary uses of this data for research, quality measurement, population health, and other uses ignored by the Report.

Need for a National Forum on Healthcare Data, EHRs, and HIE

AHIMA agrees that the implementation of EHRs and HIE are crucial for the health of this nation and while we also agree that time is crucial in this regard, we find that both the detail of this Report and the PCAST recommendations deserve much more discussion by the healthcare industry's stakeholders which includes consumers. As AHIMA has noted on previous occasions, we believe the HIT Policy and Standards Committees, established by HITECH are the appropriate forum for such discussion; however, these committees and their workgroups are consumed with the implementation of HITECH. **AHIMA calls upon ONC and HHS to convene an open and transparent national forum for discussion on the directions recommended in this Report as well as the ONC draft road map.** Our comments below highlight some of the areas that should be considered in the Report.

In our review considerable questions were raised that called for additional information regarding the Report's technical recommendations especially in light of current standards and ONC activities related to the national goals. We believe that introduction of the Report's recommendation could delay the current progress to advance health information adoption and exchange. Initiating a national forum to assess the PCAST Report recommendation would both educate all stakeholders as well as provide for a transparent decision making process.

Complexities of Healthcare and Healthcare Data

AHIMA takes issue with the Report's suggestion that other industries have faced the same data issues and successfully developed a solution that is easily transferable and fully compatible with the direction currently being taken. We have identified library science as a potential candidate for examination of metadata use, but we question which industries of healthcare's size, economic impact (17 percent GNP), and complexity have used these recommendations.

We agree that the various healthcare delivery and reimbursement systems, along with multiple governance created by a variety of state and federal rules and regulations for structure and compliance have created serious barriers to adoption of EHRs and facilitation of HIE. To our knowledge, other industries have not faced the extent of multiple compliance issues as in the

healthcare industry. This environment not only affects the delivery of healthcare, but also the implementation of clinical and business systems, and the capital to pay for them. Healthcare is unique among industries for the amount of detailed data it collects and the information it shares for care delivery, reporting and research. The detail varies by the site of service, but it would be inappropriate to assume that primary practices should be the base for changing the structure especially as we implement programs such as “accountable care organizations” and “medical homes.” Healthcare entities even share significant data with competitors, unlike most industries.

The Report calls into question the use of transaction and data standards. It fails to note that use of many of these standards was essentially voluntary up until this decade. Even then while the Health Insurance Portability and Accountability Act (HIPAA) dictated the use of standards for administrative transaction, regulators never dictated a consistent use of these standards – something that occurs in other industries. Only now, due to legislation in ACA, is the federal government working to develop uniform guides for the implementation and use of standards. The HIPAA standards including their code sets have been frequently ignored even by federal agencies.

Data Integrity and Use

As the healthcare industry has begun to recognize the value of healthcare data, both administrative as well as clinical, the need for uniformity is more essential. The Report confirms this but ignores the crucial need for data integrity both within individual healthcare entities as well as among entities while we maintain data through the exchange infrastructure.

AHIMA believes that for any interoperability technology, including the metadata tagging recommended by the Report, **maintenance of data integrity must be a key requirement.** To ensure preservation of integrity and privacy practices there must be a health data stewardship infrastructure for both primary and secondary data throughout its lifecycle. Without effective data, we are moving data but we are not necessarily gaining accurate knowledge. **HHS through its HIT Committees and the National Committee on Vital and Health Statistics (NCVHS) must lead efforts to ensure effective stewardship over healthcare data and information in the United States.**

The Report also suggests that the current standards process is perhaps part of the problem in the healthcare industry’s use of electronic data systems. We agree in part because in the US and international data standards organizations have typically been run by “volunteers” chosen by their interest and ability to afford the travel, time, and other expenses associated with the development and maintenance of standard. It is only in the last decade that the federal government has overseen public-private mechanisms to both identify where standards are needed and how they should be harmonized. Other industries have typically accomplished this through industry councils – the same groups that determine the use of the standards. The HITECH HIT Policy and Standards Committees are as close as the healthcare care community has come to such an industry council, but as noted they have not yet undertaken to look at industry-wide issues.

Since the bulk of the standards adopted in the US have been developed on a voluntary basis, there has been limited funding from the federal government for these efforts until very recently, unlike standards development groups in other countries. Lack of funding to ensure stakeholders are involved in the development and maintenance of standard also slows the process down.

The Report ignores data standards that have been developed over time to stratify the health record data for purposes like history and physical, operating reports, and so forth. These standards provide context to the data which are also governed by data standards. We mention this because while the report recognizes the value of data, it fails to note the context that also identifies data and must be represented in the metadata tag.

Metadata Recommendation

AHIMA agrees with the PCAST that metadata tags are both useful and necessary as the industry advances health information exchange. AHIMA's support of metadata tags, however, is not necessarily for the same functions as the Report suggests. We agree with the Report's requirements for a uniform language for the metadata tags, but having many years of standards experience we recognize that this is a huge undertaking. Along with developing a universal language to describe the tags themselves, there must also be a governance process to manage further development, revisions, and other management functions. We are also concerned that given metadata tags are a language they cannot necessarily be initiated incrementally.

In recent years AHIMA has recommended such a governance process for terminologies and classifications and we are guardedly pleased that the HIT Standards Committee has recommend a limited version of this concept applied to only the classifications and terminologies covered under Meaningful Use requirements. **If the Report's recommendations are to move forward, AHIMA recommends that the National Library of Medicine (NLM) be engaged in the development and maintenance of a universal language for tags. We also continue to recommend that the NLM develop and facilitate a public-private process for not only the tag language, but also to govern in a transparent process the standards associated with the US implementation.**

Finally, AHIMA noted the discussion in the Report regarding the HL7 Clinical Document Architecture (CDA). We believe that this and other key standards are critical to the advancement of EHR adoption and health information exchange. We believe the industry should continue to build upon this and other industry-vetted and approved standards in a manner that promotes clinician usability and efficient health information and should be discussed in the industry forum we have suggested.

Implementation of PCAST Recommendations

The PCAST Report reminds us of an ocean vessel moving steadily ahead at 20-some knots when the captain receives orders to change course. Changing course under this circumstance is not that easy. A significant amount of valuable work has been accomplished in the industry and the government to advance considerable progress in the adoption and implementation of EHR

systems and information exchange. **AHIMA urges ONC to consider the beneficial work that has occurred in the industry and facilitate an open discussion on any changes in course.** We believe some of the Report's content will be very helpful; however, significant changes at this juncture could harm the progress accomplished to date. We are concerned that attempting to incorporate these PCAST recommendations into Meaningful Use – Stage 2 (scheduled to begin January 1, 2013) would be more than the industry could bear at this point.

The Report recommends upgrading systems at CMS. AHIMA fully agrees with this recommendation; however, necessary and appropriate upgrades will require funding from Congress and conceivably could take considerable time that will directly impact work in Stage 2 and probably Stage 3 of Meaningful Use. This situation needs to be discussed in the context of how Stage 2 moves forward, given that the industry also faces a number of systems changes to meet current Medicare, Medicaid, and ACA requirements over the next three to four years.

The Report notes that ONC might have to regulate the use of the recommended metadata tag standards, suggesting further that only through a carrot/stick approach will healthcare providers adopt and implement EHRs or the metadata approach it suggests. The report, while briefly addressing usability of systems, drops the system usability issue and does not look at other factors that affect acceptance, adoption, and use. Cost is a factor. We agree that lack of reimbursement and the fact that EHR system benefits may not be directed at the investor discourages adoption. But other factors such as time, workflow, data flow, and efficiencies also affect the providers' decisions to purchase and use an EHR system(s). Some components of vendors' products can be customized even while using transaction and data standards. The Report suggests addressing just data storage and tags will resolve many of the barriers to adoption. AHIMA believes that more work and a better approach is needed to improve usability and workflow surrounding systems not just the plucking of data, and not all these features can be mandated.

The ability to implement HIT systems, from a data stewardship perspective, requires a workforce of individuals trained in IT or HIM. HITECH has recognized this with its workforce funding components. AHIMA works with almost 300 HIM programs at the associate, bachelors, and masters degree levels to not only address today's management of information systems, data, and issues they entail, but also the healthcare information environment of tomorrow. The Report's recommendations raise concern on whether a sufficient workforce currently exists to implement the systems and achieve the indexing and mapping suggested. While HIM programs address these activities, there is a shortage of HIM and IT professionals, and a new direction suggested by use of the metadata tagging process may not be easy to address in the industry as these limited professionals will be in considerable demand by vendors as well as providers of healthcare. Whether or not ONC accepts the Report's recommendations, **AHIMA urges HHS to consider the workforce needs post HITECH funding and look to Congress to increase Title VII funding to cover HIM programs. Further, HHS should consider developing a permanent office for Allied Health which would include HIM and IT to ensure an on-going workforce for the future.**

Management of Data and Metadata

We begin this discussion by noting that AHIMA promoted the concept of *collect once – use many times* in the context of the effective use of EHR systems and HIE. Likewise, the need for data integrity is a mantra of the HIM profession, so we look to the PCAST innovative recommendations with great interest.

We believe the Report ignores the necessary specificity for healthcare data which challenges the use of the metadata tags for multiple purposes as suggested, at least in the short term (including Meaningful Use – Stage 2). We believe this concept needs testing which unfortunately also means developing a pilot data set. Unfortunately, applying a small data set will not satisfy the potential problems that could occur for data flowing from specialty to primary practices, such as in a medical home situation, or data in a tertiary care organization. **AHIMA is concerned that the recommended innovations cannot be implemented without development and testing across the variety of healthcare industry, especially if the industry is to turn from the direction it is currently heading.**

The Report also highlights data transfer, but seems to assume high quality data exists. The ability to categorize data – to actually record the data into the system (or record) – is not addressed by the Report nor are the issues surrounding data when at rest. Projects such as the Health Story Project are addressing patient centric needs as the Report suggests are necessary in ensuring that data is in the record correctly. HITECH requirements also address patient access to data both in the Meaningful Use requirements and the anticipated privacy rules.

It is unclear also how **data flows into the provider's database** that will then contain the tagged data – in other words how the **middleware** will map the data as described in the Report. (As an aside, if middleware must be purchased for this purpose, it will have to be developed in accord with the universal language, and there will be a cost to the provider.) Data quality issues occur with systems that attempt to structure data entry. It is clearly recognized that there must be both structured and unstructured (e.g. notes) data collection to achieve flexibility and the capture of all the documentation involved in the encounter. The integrity of data collected in the provider system is crucial for the delivery of healthcare, but we believe this is just as important for secondary users of data. To this end the Report also does not describe how the tagged data must be segmented in the data base.

The Report pays a glancing attention to **legacy data** and suggests that data resides in a provider's data base, but does not contemplate the retention of data which is governed by state and federal law as well as the entity's capacity to hold the information in a data base over time (years). We are concerned that tagged data recommended by the Report will take up even more capacity over time even with improved storage methodologies. Some have suggested the use of separate registries for metadata that could negate the use of some tags, however, this has not been tested. Any system built on the assumption that all data is retained could find the availability of data over time affected negatively unless this issue is addressed.

Legal Health Record and Retention

Issues such as **retention of a legal health record** are also ignored by the Report. AHIMA is aware from our annual Legal EHR Summits that address the importance of a legal enterprise record which is becoming even more important with the impact of **e-Discovery** and **data or record auditing**. Again structure is needed to address these issues and there are state and federal laws that regulate in this arena. In addition to the legal aspects of this data, providers are also under scrutiny by government and health plans which audit clinical and administrative data on a regular basis, and need structure to identify services and charges. **The concept of a legal health record must be considered in any system development including one using metadata tags as suggested by the Report.**

Privacy Metadata Tags

The Report suggests that the metadata tag is the answer to **granular privacy directives** by patients. The Report suggests that patients will have to be educated as to the impact of their decisions and interrogated as to their choices; however, it does not suggest how or who might assume this task. Our experience has demonstrated individuals change their mind over time so ONC must also consider how an individual or organization might update the privacy tag and convey this change to others who have collected the data. This will be a costly process and providers and other entities are probably going to seek some reimbursement for the effort.

Privacy tags will also be another code set in need of development in the proposed exchange language. While not a data issue per se, the process of **consents** which is of major concern to the industry must also be addressed in the context suggested by the Report. We realize many are trying to make their systems simple – opt in or opt out – but a tagged system will increase complexity for providers and consumers alike taking decisions to the more granular level.

HIE

AHIMA has been a supporter of the HIE concept since its inception with the NCVHS report on a national infrastructure and recommendations in 2001. We agree with the concerns raised by the PCAST Report regarding exchange, but must point out that the rules and structures of HIE have continually changed over the last several years; and now, many HIEs are subject to both federal and state regulation and support factors. We understand the DEAS concept put forward in the Report, however, we do not believe the Report addresses all the concerns associated with HIEs and the protection of provider data warehouses and systems. We are also not clear on the options for use of the DEAS. There are a number of security issues to consider and these must be discussed to address standardization within the industry. While we recognize the suggestions of the Report are an attempt to streamline the exchange process some of the structure currently in place provides a trust factor not addressed in the Report.

RESPONSE TO ONC QUESTIONS

The December 10 request from ONC raised several questions which are responded to in order below.

ONC Questions and Response

1. What standards, implementation specifications, certification criteria, and certification processes for electronic health record (EHR) technology and other HIT would be required to implement the following specific recommendations from the PCAST report:

1. a. That ONC establish minimal standards for the metadata associated with tagged data elements:

Given the extensive amount of metadata tagging that will be needed even to begin a basic program or pilot, ONC will need to establish a body for metadata tag development, maintenance, and governance. This process might best be handled by the National Library of Medicine (NLM) whose Unified Medical Language Systems® (UMLS®) is already engaged in similar work. NLM is also ideal for the harmonization of terminologies and classifications that will also need to be integrated into this metadata tagging exchange language. Given our experience, we must note that the development of terminologies is very time and resource intensive so moving in this direction could cause an enormous delay.

While the report calls for minimal metadata standards, we do not see how this can be accomplished at a minimal level without addressing all the necessary tagging. In addition, maps must be created and maintained. **To accomplish this work and maintenance, a governance process will also be necessary and we believe legislation must address the governance issues associated with standards and guidelines to maintain data integrity.**

As demonstrated by other standards, there must be a means of testing the metadata to ensure that in use the integrity of the data is maintained.

1.b. That ONC facilitate the rapid mapping of existing semantic taxonomies into tagged data elements.

Based on our previous answer, we believe that the NLM would have to be involved in this effort as well as potentially the data standards groups such as ICD-9-CM, ICD-10-CM, SNOMED-CT®, LOINC®, CPT®, and so forth, as well as the work of HL7, HITSP, and UMLS. We do not believe this can adequately be accomplished rapidly since mapping is an extremely detailed process and there has been little work in the development of metadata for the purposes described. Mapping carries risks, such as loss of meaning between the source and target concepts. We must also note that multiple maps would likely need to be built, since maps must be developed according to their purpose and there would be many purposes for data exchange. Small sets of data and the process using taxonomies would need to be piloted to determine what it will take to expand this process to metadata standards. Whatever process is developed and used, it must be open and transparent or potential users or stakeholders will not want to implement or use the system or trust the system.

1.c. That certification of EHR technology and other HIT should focus on interoperability with reference implementations developed by ONC.

AHIMA cannot respond to this PCAST recommendation without commenting that one of the problems with the Report's recommendations is its limited focus on interoperability without acknowledging the day- to-day use of EHRs by clinicians, the need for data integrity, the

initial collection of data within the facility, and the other goals of the ARRA-HITECH program. The use of metadata tags would also have to be addressed industry-wide and not just for organizations that are eligible for incentive payments.

Interoperability, as described by PCAST appears not to understand the need for structure in the record even to assign metadata. Therefore the middleware described will have to be tested across the various EHRs and EHR modules. While healthcare providers understand and support the need for secondary uses of data, if the EHR does not meet their needs and if the suggested middleware system does not address these needs as well as needed interoperability then the EHR systems will not be adopted.

Vendors must ensure their EHR systems and modules are certified and the window is limited to make such significant changes in existing EHR systems and modules; and with a limited workforce that understand the concepts and needs the reality of achieving these changes is nominal. Again involvement and transparency would be one of the requirements needed to meet the requirements of the PCAST recommendations.

2. What processes and approaches would facilitate the rapid development and use of these standards, implementation specifications, certification criteria and certification processes?

As noted above, we believe these recommendations need vetting by the healthcare industry and we are concerned with any unilateral movement by ONC to adopt the Report's recommendations and needed standards without such a discussion could derail the existing Meaningful Use program.

Strictly in terms of the recommendations, ONC needs to first work with the various users, stakeholders, and standards bodies as well as groups including the NCVHS and associated federal data groups; AHIMA professionals and informatics experts who are experienced in terminologies and classifications from an administrative, reporting, integrity, mapping, and security perspective; and groups involved in data mining. There are other industries that use metadata, although we believe that healthcare's long term use will be considerably more detailed and extensive. Data used in healthcare is continually expanding.

AHIMA believes that the NLM would have to be a key partner in this process given its experience with UMLS. Even so, we don't believe there can be a rapid development with existing resources and without the piloting of the process and use of metadata.

3. Given currently implemented information technology (IT) architectures and enterprises, what challenges will the industry face with respect to transitioning to the approach discussed in the PCAST report?

Transitioning to the approach discussed in the Report will create significant challenges for the industry particularly now as the movement toward adoption and implementation of electronic health records (EHR) has been harnessed by the meaningful use program. Unlike any other program, the meaningful use program has provided focus for the industry and is creating the foundation from which future systems can build upon through the creation of a consistent

approach for certification and use of EHRs. Below, we have outlined for you some of the critical challenges and barriers the industry will expect to face if the force is shifted toward the opposite direction:

- **Financial** – Implementing EHR systems requires a significant amount of financial resources for total cost of ownership. In order to set up a well functioning system it could take millions of dollars over the lifecycle and maintenance of a system to keep it running. For those providers and hospitals that have chosen to participate in the meaningful use program, they have or will expect to invest in significant financial resources for updated or new system solutions, training, workflow changes, additional resources, and other components that require funding.
- **Time** – For those providers and hospitals working toward meaningful use, they have and will expect to invest a substantial amount of time preparing for and implementing the systems to achieve meaningful use. Although this is a voluntary program to some degree, many have chosen to apply for the incentive payments. This requires time for planning, meeting with other disciplines in the facility, meeting with vendors to review the changes, etc. This time is critical and much needed for other regulatory programs such as ICD-10-CM/PCS, other reporting programs, recovery audit contractor (RAC) programs.
- **Vendor development** – It has been stated from many vendors during the HIT Policy and Standards Committee meetings that vendors need to time develop, test, deploy, and train on new or updated systems. Vendors have devoted much time and resources to developing systems in accordance with the former CCHIT organization and more recently the certification criteria established by ONC. Vendors have stated there should be a minimum time of 18 months to allow for completion of the systems, and this timeframe could be more depending upon the type of system that is developed.
- **Standards development** – In spite of all the years of work on standards, we now are only beginning to see standards harmonized together to produce an electronic health record system. The standards currently in place must be harmonized to some degree with those suggested by the Report and the process of standard – transactions – data and metadata need a reconciliation and governance as suggested above. This has to be across the industry, it can't be just for MU entities and affected standards. There also needs to be a road map for the industry to direct the various standards groups in their development and maintenance.
- **Workforce** – We noted above a concern on workforce especially in areas of information technology and health information management. The tasks that are associated with health data are many and yet there is a limited supply of individuals that understand and can manage the entire system as well as the specialists that are needed. The industry lags behind in

- subject areas such as mapping or crosswalks, healthcare data analysis, integration of engines to develop data for internal quality and decision making as well as for external secondary uses of data. The current workforce efforts under HITECH do not put funding in the direction to meet these needs and funding is limited. Employers, often victims of how it was done also are not always aware of the system that is needed for tomorrow if healthcare data is to have the value that AHIMA believes it has.
- **HIE Organizations** – These entities are facing many challenges given the on-going metamorphosis they have been undergoing over the last decade and the different directions or goals given to them by governmental bodies and others. Investment in data exchange is absolutely necessary to achieve many of the goals specified but stakeholders need to achieve a structure and goal across the country and keep to it. The PCAST Report is yet another direction and given the limited funds available on a state and local basis, HIE organizations may have to sit back and let the industry evolve before undergoing yet another metamorphosis.
- **State Regulations** – HIM professionals have been caught in the variation among state regulations and practices as well as with federal regulations for many years. Federal and state legislators are reluctant to give up turf either in the form of federal preemption or a uniform set of state regulations. ONC did undertake some study of this issue with RTI a few years ago, but it is questionable whether the desired results occurred. ONC needs to undertake a study – designed to be presented to federal and state policy makers that demonstrates the current problems, including those identified in the Report, and again meet with federal and state policymakers to see what can be achieved and the problems and costs for not achieving consensus.
- **Governance** – AHIMA has noted the need for governance over vocabularies (terminologies and classifications) for quite some time including the need to have such governance over the entire healthcare sector and not just those associated with Medicare and Medicaid. Likewise, we continue to insist that ARRA-HITECH presents the industry an opportunity for governance over all of our transactions and issues identified in the HITECH language. The HIT committees need to be open to taking on these tasks and developing a transparent process for industry involvement.
- **Crossover** – The question in the minds of HIM professionals, and we are sure many others, is how will ONC handle the crossover from the existing direction to the one suggested in the Report. Unfortunately, when dealing with terminologies it is difficult to go from one to the other without flipping the switch similar to the ICD-10 crossover (and hopefully not in the neighborhood of that change. If there are entities willing to pilot a dual system that would be helpful. Systems could be built to handle the change in such a way as to have the capability

- but not use it until there is full capacity. That said, however, there is also the problem with data of those not covered by HITECH. If data is going to be usable across the industry this will affect all entities just like ICD-10-CM.

3.a. Given currently implemented provider workflows, what are some challenges to populating the metadata that may be necessary to implement the approach discussed in the PCAST report?

There are a number of unanswered questions regarding the Report that requires industry discussion including the entry of information into the EHR systems and the mapping and indexing of information required as well as the impact on workflow. As noted, vendors and users must determine how data will be stored and used for internal purposes as well as external purposes. Privacy and security processes will also have to be developed. Most importantly existing and new workforce will be needed to understand what is needed to make such a change and maintain the systems and data (including integrity) in the future.

3.b. Alternatively, what are proposed solutions, or best practices from other industries, that could be leveraged to expedite these transitions?

We have not found any to date. Again this needs to be part of an industry forum dialogue.

4. What technological development and policy actions would be required to assure the privacy and security of health data in a national infrastructure to HIT that embodies the PCAST vision and recommendations?

As noted in our responses above, there are issues surrounding capturing patient consensus for granular data requests. An education component and process will be needed and the industry must also address the issues of authentication, security and the DEAS system. In addition to all of this, the impacts of federal and state laws also pose challenges. The metadata tags will have to be developed with the means of addressing both changes individual preferences and updating of these preferences in all provider systems containing the information in question.

5. How might a system of Data Element Access Services (DEAS) as described in the report, be established, and what role should the Federal government assume in the oversight and/or governance of such a system?

There are patently a variety of options similar to earlier suggestions for locator services by the Markle Connecting for Health project. Until discussion and consensus can be determined for how they will work and interact with providers as well as users it is difficult to pick a model. We also anticipate that there may have to be a decision on what role states might play given the internet approach being taken.

6. How might ONC best integrate the changes envisioned by the PCAST report into its work in preparation for Stage 2 of Meaningful Use?

Presuming that Stage 2 Meaningful Use requirements begin January 1, 2013, we do not believe it will be feasible for ONC and the industry to integrate these recommendations into Stage 2 without appropriate resources and time. As we have noted developing the universal

language, the privacy tags, and the mapping and middleware will take considerable effort and workforce.

As for Stage 3 Meaningful Use, there needs to be an industry agreement and consensus and incentive to achieve all of the necessary work within the four years between now and this final stage. If this cannot be discussed and reasonably planned and agreed to by the industry, then we do not believe ONC should begin these changes.

7. What are the implications of the PCAST Report on HIT programs and activities, specifically, health information exchange and Federal agency activities, and how could ONC address those implications?

As previously suggested we believe ONC needs to convene an industry stakeholder conference to reach a consensus on the future direction of EHR adoption, standards, and HIE. The PCAST recommendations will affect all current stakeholders to health data as well as the vendors and contractors that will be needed to develop the languages and change or build anew the systems to facilitate these changes. Likewise, those building information exchanges, or whatever replacement is agreed to, need to be committed to this plan of action and whatever timetable the industry believes it can meet otherwise we could end up with a mid-1800s railroad system with no real exchange as originally envisioned. Given our needs for interoperability and for data for quality, public health and the other goals mentioned in the report, this cannot be allowed to happen.

8. Are there lessons learned regarding metadata tagging in other industries that ONC should be aware of?

We believe subject matter experts from the NLM and the Library of Congress be queried. The library and information sciences discipline has engaged in metadata tagging for a long time. MARC (machine-readable cataloging) developed in the 1960s was considered a huge success in allowing libraries to share cataloging records, so every library did not have to do original cataloging on every item acquired. It worked out particularly well when the Library of Congress employed tons of top-notch catalogers and other librarians could just copy the records they created and adapt for locally-specific information. Now that LC has scaled back their original cataloging considerably, it involves more effort to identify quality cataloging and, when it can't be found, to create original catalog records. A lesson learned from the library profession is that standards are critical, but data quality should be the driver.

The W3C project and writings about the semantic web are also instructive; however, this one was written in 1996.

A number of search engines are now employing faceted search results, where they take the results and spit them out again according to certain criteria attached to the content. If you use Google, you'll see they've started providing faceted search results off to the left of the screen. This can only be done by some system of tagging or identifying. Whether it is done dynamically or by some other means, Google will have to respond.

9. Are there lessons learned from initiatives to establish information-sharing languages (“universal languages”) in other sectors?

There are many initiatives in the area of establishing languages for describing resources, particularly digital. We have identified:

- LC’s [MARC \(MODS, MADS\)](#),
- ADL’s [SCORM](#),
- W3C’s [RDF](#), [OWL](#),
- Dublin Core’s [DCMI Abstract Model](#), and
- Open Archives Initiative [PMH](#).

It is our understanding that many of these standards work with RDF, however, interoperability remains a problem. All of them seem to create an XML schema, which appears to be the one constant.

In terms of initiatives, UMLS is the largest project we are aware of. It tries to bring together a large number of vocabularies to create a metathesaurus. See, e.g. Betsy Humphries article - <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC225759/pdf/mlab00111-0061.pdf>

Without expertise in these industries except for UMLS, we conclude that these are complicated activities that work best when the process is transparent and the resulting language non-proprietary. For the most part we are not aware of how they integrate into vendor systems.

Again, AHIMA is pleased to respond to ONC on the PCAST Report. We strongly ONC to convene an industry conference to learn more about these recommendations and discuss how they might function, as well as their impact on the industry including EHR system adoption and HIE. In the meantime, you have regarding these comments, of if we can provide any additional information, don’t hesitate to call me at (202) 659-9440 or e-mail dan.rode@ahima.org or in my absence please contact Allison Viola, AHIMA’s director for federal relations at allison.viola@ahima.org.

Thank you for your time and consideration of these comments and recommendations.

Sincerely



Dan Rode, MBA, CHPS, FHFMA
Vice President, Policy and Government Relations

cc. Allison Viola, MBA, RHIA