

March 31, 2009

Health Information Security and Privacy Collaboration

Inventory Matrix Gap Analysis

Prepared for

RTI International

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Chicago, IL 60606

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1. INTRODUCTION

The current process for most health care organizations and individuals in creating health information exchange (HIE) and health information technology (health IT) consumer materials is to look online for information and/or create resources from scratch. This process suggests that organizations and individuals are finding and creating materials in silos, often recreating materials or doubling the efforts needed to search out existing materials. The purpose of creating the Consumer Engagement and Education (CEE) Collaborative Health Information Technology Consumer Education and Engagement Inventory is to aggregate into one place the consumer education and engagement materials currently in existence so that interested organizations and individuals have a quick look-up resource in locating information.

The CEE Collaborative is one of the workgroups created from the national Health Information Security and Privacy Collaboration (HISPC), funded through the Office of the National Coordinator for Health Information Technology (ONC). The CEE Collaborative is comprised of eight different states, including Colorado, Georgia, Kansas, Massachusetts, New York, Oregon, Washington, and West Virginia. Additional to the state-level projects, members of the CEE Collaborative are developing an educational resource toolkit as a template for general use by other states and organizations in educating and engaging consumer about HIE and health IT. The Inventory is one of the educational resources developed for the toolkit and this particular project was lead by Washington State.

Corresponding to the goal of the CEE Collaborative to develop an educational toolkit as a general resource for states and organizations, the targeted audience for the Inventory is the organization, individual, or HIE stakeholder that is seeking to educate and engage consumers about an HIE project. Additionally, the consumer resources that are included in the Inventory are directed toward the patient consumer rather than the provider consumer. This decision was made because of the presumption that the HISPC Provider Education and Engagement Collaborative will create a resource document targeting physicians and other health care providers.

1.1 Process of Creating the Inventory

The first task for the Inventory workgroup was to agree on inclusion/exclusion criteria. Among the list of criteria, the group decided that we would only include a resource if it was related to consumer HIE and health IT with special consideration for resources addressing privacy and security issues; has recent updates (April 2005–2008); in final form versus a beta or draft version; has an author or producer (i.e., not anonymous); free to use; and would be understandable to the user upon visiting the website. Additionally, the group chose not to include websites that promoted any specific businesses and/or the inclusion of

such websites could be considered free advertisement for the businesses. For example, some personal health record (PHR) vendors describe the usefulness of PHRs on their websites, but the information is very much related to the use of the vendor's specific PHR. These types of resources were excluded from the Inventory. Only materials with website links were included because this is the easiest way for organizations/individuals/HIE stakeholders to access the information (for a full list of inclusion criteria, please look at the "Inclusion Criteria" tab on the Inventory).

The Inventory group formed an alliance with the National Partnership for Women & Families at the beginning of the project. Like the CEE, the National Partnership recognized the redundancies of HIE stakeholders recreating consumer materials and were, thus, also working on a project to aggregate consumer HIE/health IT resources. The National Partnership was further along in assembling consumer materials and graciously shared their website links and findings with the Inventory group, which were then included in the CEE Inventory.

All of the HISPC states were then contacted and asked to send any materials that they have used to engage consumers in the health IT/HIE efforts. In response, about one-third of HISPC states sent their consumer materials for inclusion in the Inventory. These resources included websites, PowerPoint presentations, videos, consumer forum scripts, handouts, and other relevant materials.

Finally, a list of national health IT organizations was created. This list included groups from government (e.g., Agency for Healthcare Research and Quality [AHRQ], VA [Veteran's Affairs]), trade/industry groups (e.g., American Health Information Management Association [AHIMA], American Medical Informatics Associations [AMIA], Healthcare Information & Management Systems Society [HIMSS]), vendors who have name recognition (e.g., Microsoft HealthVault, GoogleHealth), consultant groups (e.g., Deloitte, Harris Interactive), foundations (e.g., Markle Foundation, California HealthCare Foundation), consumer advocacy groups (e.g., Advanced Association for Retired Persons [AARP]), and state-level efforts (e.g., Regenstrief, State-Level HIE Consensus Project). The websites of each of these health IT organizations were examined for consumer engagement materials.

Upon nearing completion of constructing the Inventory matrix, members of HISPC states were asked to review the tool for readability, completeness, and to provide general feedback. The Inventory incorporated many of the suggestions in anticipation that the final product would be a functional resource to our HISPC peers and other HIE organizations.

1.2 Gaps in the Inventory

Two types of gaps in the Inventory were identified. The first type of gap relates to the extent of consumer resources found in the Inventory: some potentially important consumer

resources that are missing from the highlighted websites. The second type of gap relates specifically to the Inventory project and the resulting matrix product.

Consumer Resource Gaps

The search for consumer materials to include in the Inventory resulted in a wide array of resources. Despite the diverse set of materials, however, there are a few items missing that would be of value to the consumer. These items are listed below.

Community Health IT and HIE Environment Scan

Although much information was collated about defining HIE and different types of health IT (e.g., electronic health records (EHR), personal health records (PHR), and so on), consumers do not have a website or document that tells them about the current status of HIE and health IT adoption in their region. The wealth of daily technology usage in our world may lead consumers to believe that the norm in health care is to use technology, when, in fact, the adoption of health IT and HIE is in its infancy. Consumers may read about all of the health IT and HIE progress being made nationally and assume that their health care system is also moving towards technology, not realizing that it is mostly the larger health care systems that have adopted technology at this time. It would be helpful if organizations engaging their communities in health IT and HIE could post an environmental scan to indicate which health care systems have adopted technology so that consumers can gauge the relevance of the health IT information in their geographic location.

The Big Picture

There are many resources related to how HIE can generally improve patient quality of care, as well as the specific benefits of EHRs or PHRs or regional health information organizations (RHIOs). However, there are no documents that explain the overall impact of health information technology and how all of the different health IT pieces fit together. Such a document would define EHRs, PHRs, and data reporting to RHIOs, then explain how these types of health IT differ and are similar to one another. Most importantly, the suggested resource would elucidate for consumers how these types of technologies feed into each other. For example, PHRs are completed at the patient level, EHR data is inputted by providers, and aggregated EHR data can be found through RHIO databases, which can then be used by providers and patients for benchmarking purposes. This suggested resource would help consumers better understand the different types of health IT efforts available.

Need to Take Literacy and Languages (Other than English) into Account

Most of the resources were written in English and target the highly literate. Only a handful of posters and brochures could be accessed in Spanish and those resources were found on only one website. The National Institute for Literacy reports that there are 30 million adults that are illiterate to the extent that they cannot read a simple sentence. Additionally, there are 45.5 million (15.1% of the population) Hispanics living in the United States according to

the United States Census. Given the large number of potential health care consumers that are either illiterate or Spanish speaking, it would be beneficial to create health IT consumer education materials that are targeted for low literacy or non-English speakers. It should be noted that there are several literacy resources within the Inventory.

1.3 Inventory Project Gaps

The amount of time and resources devoted to this project only allowed for a cursory aggregation of consumer education materials. The gaps identified with the Inventory Project exist because of scalability issues. As such, there are several opportunities for improvement in the future with additional funding.

Keeping the Inventory Current and Relevant

The major Inventory Project gap that was identified is the (in)ability to keep the matrix current and updated. Currently, the only process to keep the Inventory updated is a manual lookup of the website link that is listed. This is not scalable since this project ended on October 31, 2008. Ideally, the Inventory should become a live document where any user can revise the link or add a new resource as it becomes available, with an agency overseeing the revisions to ensure that the additions complement the purpose of the Inventory. The key is that the user updates the tool (with some oversight) so that the Inventory Project members are not a bottleneck for keeping the resources updated.

A Finer Level of Detail

While the Inventory column entitled "Tools Found in the Resource" lists the types of consumer materials that can be found through the link, it would be more helpful to users if each of those materials were listed out independently with a brief description and its own URL. The Inventory in its current form would probably be the most valuable for users who already have some idea of the types of consumer resources they would like to find because of the lack of granularity. Having a finer level of detail in the Inventory would add value especially for those users who may be newer at accessing consumer education materials. A related point in support of honing the details of the Inventory is that the user can only utilize the Inventory as a starting point to search for consumer materials currently, but would still need to spend the time to surf the website for additional content. This reduces the efficacy of the tool.

Organization Contacts

Initially, the Inventory included the contact names and information of at least one HISPC state representative, as well as a contact from each of the national organizations listed. Contact information would be a helpful resource to users because it would allow them to speak to a person if they have questions about materials or wish to discuss a project further. However, upon further investigation, the contact names and information were

removed from the Inventory because the information was often outdated or incorrect. It takes a great deal of exploration to find the right contact person for each website link, get permissions to post the contact information, and to keep that information current. The issue of keeping the organization contact information updated is related to keeping the inventory links current. Both projects would benefit from additional staffing and resources.

User Access to Non-Website Consumer Materials

Although we received some materials that were not available on a website (e.g., such as videos, focus group scripts, etc.), we were unable to include it in the Inventory because of the inability to either turn the materials into accessible media, or to house the information in a place where all users could access it.

1.4 Suggestions for Future Projects and Opportunities for Improvement

As with any project, there are opportunities for improving the Inventory that should be considered. The most pressing opportunity is keeping the Inventory updated and relevant over time. Because HIE/health IT websites are constantly changing, with revisions to consumer materials, there needs to be a process by which the website links are tested every few months to ensure validity. One suggestion would be to test all of the links in the Inventory in 6 months (i.e., April 2009) as a pilot to see how many links are no longer functional. The results would give evidence as to how often HIE websites change and consequently, an estimation of the shelf-life of the Inventory as well as guidance on whether additional manpower is needed to keep the document updated.

A related point is that the website links should be maintained with as little additional resources as possible. It would be advantageous to use available technology to have users of the Inventory update the information. This could be accomplished by putting the Inventory on a Wikipedia, which would allow users to login and make appropriate changes. The result would be a “live” document that can be accessed and revised by users. A shared knowledge base of users through a medium such as a Wikipedia would expand the list of consumer resources and keep links updated with minimal management needed.

1.5 Summary

Despite some limitations which are discussed in this gap analysis, the Inventory can be a useful resource for organizations, individuals, and HIE stakeholders seeking to find a common place for consumer materials. It is the intention of the Inventory creators that users will be able to find a more complete set of consumer engagement information in less time by using this resource than if they were to look for the information on their own. The major caveat is that the website links included in the Inventory may change or be removed in short time, reflecting the changing nature of the health IT landscape. Upkeep of the

Inventory is highly recommended, whether through the CEE, a Wikipedia, or some other form of administration.