

# **The Effectiveness of Consumer and Provider Education and Outreach: A Content Analysis**

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## **ABSTRACT**

The focus of this research is to measure the effectiveness of outreach related to public understanding and opinions regarding electronic health information exchange (HIE) within and across various states.

The Health Information Security and Privacy Collaboration (HISPC), established in January 2008 by RTI International through a contract with the U.S. Department of Health and Human Services (HHS), assembled 42 states and territories to address the privacy and security challenges presented by electronic HIE through multi-state collaborative workgroups. Two of these multi-state collaboratives focused on developing tools and strategies to educate stakeholders about HIE; one to engage consumers and another to develop a toolkit to educate providers. Between April and July 2009, states participating in the HISPC were challenged to test the effectiveness of the consumer and provider education materials these two collaboratives developed by adapting and disseminating them within their communities.

To measure effectiveness of this outreach across the various states, we performed a content analysis of final reports from each state using qualitative analysis. The information is separated into two major categories: accomplishments and limitations. Within these categories data are coded to indicate differing outreach methods, number of organizations/individuals involved in each separate initiative, and number of commitments to officially disseminate the materials. Within the coded data, we determined how widely materials were adapted and disseminated both within and across states.

Most participating states achieved significant success in adapting and disseminating the tools originally created by the multi-state workgroups for both provider and consumer education. However, some states reported limitations that present important lessons and indicate future directions for creating materials intended to shift public opinion using a multi-component workgroup methodology.

## INTRODUCTION

While the use of computers within most major industries to manage data and communication needs is nearly universal in the United States, attempts to electronicize personal health record information have been largely unsuccessful. In a world where almost every aspect of our daily life is managed via computers, the adoption of a fully functional electronic health record (EHR) system within physician practices in the US is estimated at approximately 4% nationwide (DesRoches 2008). To say that the use of health information technology (Health IT) in the United States has experienced a slow start is an understatement. The potential value of information technology for health systems has been frequently estimated and recognized (see General Accountability Office reports GAO-07-238 and GAO-08-1138) but a number of complex and interrelated factors, including fierce disputes about privacy, fragmentation of the current paper-based system, a lack of common languages and standards, and significant concerns about patient safety during the transition, just to name a few, have made the process extremely difficult. Nevertheless, the Federal government has grown increasingly supportive of initiatives that will “push” the widespread adoption of health IT and health information exchange (HIE). In April 2004, then President Bush called for widespread adoption of interoperable electronic health records within 10 years in an executive order which also established the Office of the National Coordinator for Health IT (ONC) within HHS with the charge of meeting that goal (Executive Order 13335).

Due in part to the foundational efforts that have been ongoing since that time, in early 2009 the American Recovery and Reinvestment Act (ARRA) included an unprecedented investment in health IT via the Health Information Technology for Economic and Clinical Health Act (HITECH). This act requires the Federal government to take an increased role in developing the framework needed to realize nationwide electronic exchange and provides \$20 Billion dollars in infrastructure incentives to do so. HITECH also increased the budget of ONC considerably to continue to support, guide, and evaluate these efforts. Working in conjunction, the resulting initiatives are expected to lead to the long-anticipated conversion of the health care system from paper-based to electronic data storage, retrieval, and exchange.

This paper is focused specifically on data collected through a series of projects funded by the Agency for Healthcare Research and Quality (AHRQ) and ONC beginning in 2005, prior to HITECH, which provide important lessons learned for these new initiatives. The purpose of the initial project, the Privacy and Security Solutions for Interoperable Health Information Exchange project, was to assess variation in organization-level business practices, policies, and state laws, to help policymakers identify common practices and reduce variation. The project had three additional objectives:

- Support the preservation of local/individual privacy and security protections in an environment conducive to electronic interoperable health information exchange;
- Promote stakeholder identification of practical solutions and implementation strategies through an open and transparent consensus-building process; and

- Create a knowledge base about privacy and security issues in electronic health information exchange in states and communities that will inform future state and federal HIE activities.

Phase 1 of the project engaged organizations in thirty-four states and territories (hereafter referred to as state teams) in performing the initial stakeholder outreach and business process and policy collection activity. As the data were analyzed, it became clear that a number of challenges were shared among participating states. Therefore, funds were allotted for a second phase of the project which provided support to begin the implementation of state-level solutions. This phase also required individual states to develop “collaboratives” to work toward shared solutions to common challenges. At the outset of Phase 3, the project became officially housed under ONC and seven multi-state collaborative projects were selected for execution. This collaborative work is known as the Health Information Security and Privacy Collaboration (HISPC) and expanded funding to forty-two state participants.

At the end of Phase 3, state teams were given 4 months to engage in a set of two “challenges”. The Consumer Challenge required each of the participating states to attempt to adapt and distribute at least three of the consumer outreach materials that the Consumer Education and Engagement collaborative had created. Similarly, the Provider Challenge asked all states to disseminate the Provider Education Toolkit materials through at least two appropriate channels. At the end of the Challenge phase, all state teams were asked to report on their process for meeting each challenge, including the number of organizations approached, outcomes achieved, and lessons learned. *These reports provide the basis for our research statement investigating the effectiveness of the collaborative process to produce tools and resources that are widely replicable and useful by health information exchange initiatives looking for privacy and security related outreach materials.* This analysis is centered on the following hypotheses:

**Hypothesis 1:** Educational materials created by a smaller sub-group of participating states working in conjunction throughout phase 3 were found useful to other states asked to adopt and disseminate them;

**Hypothesis 2:** States outside of the original multi-state group which created the set of materials found them appropriate for replication and adaptable for use in their local environment; and,

**Hypothesis 3:** Materials used during the challenge phase of the project led to effective outreach campaigns for each of the intended targeted groups in the majority of states.

The research findings of this paper are important at this time given the unprecedented Federal investment in health IT implementation and adoption through the HITECH provisions. A significant portion of these Federal funds are allocated to provider incentives to defray the cost of adopting EHRs. However, the incentives come with strings attached, most notably the requirement to use a “certified” EHR and demonstrate the “meaningful use” of the technology, both of which have been defined by new Federal statutes (see 45 CFR Part 170 and 42 CFR Parts 412). These requirements are intended

to ensure that the adoption of electronic records also includes the foundational components necessary to enable necessary and proper exchange of that information.

Large-scale system changes of this nature do not occur without concern, rumor, and often fear—factors that can be mitigated by proper education and engagement with the affected parties. As the HISPC project challenge phase tackled education with two of the most directly affected stakeholders in this change, providers and consumers, much can be learned from the project. Moreover, the massive initiative to support this widespread EHR adoption, the Regional Extension Center (REC) program led by ONC, is currently undertaking the task of outreach and education to these same stakeholders on very similar topics. These RECs, over 60 in number spread across the country, are all charged with the same scope of work, and are expected to be able to draw from similar core sources of information about best practices and lessons learned. However, the question about how these materials are created by centralized entities, adapted for use in local contexts, and disseminated among various stakeholders to accomplish widespread acceptance of health information technology and health information exchange is still a major issue. If done incorrectly, large amounts of money may be wasted by each REC in trying to adapt materials and replicate dissemination procedures that simply cannot be adapted or replicated. If done correctly, the process could lead to a smooth transition, with a common understanding of the various roles and responsibilities of each stakeholder.

## **BACKGROUND AND APPROACH**

The development of the collaborative materials emerged over the course of the HISPC project. In Phase 1, each state team was required to establish a series of committees and work groups to engage relevant stakeholders. These included a state-level steering committee to ensure that key players and initiatives were involved and knowledgeable about the project, and a set of working groups charged with various phases of the Assessment of Variation and Development of Solutions activities. Each state was required to vet potential solutions with stakeholders to ensure specific local concerns were taken into account and incorporated. Data were collected in response to a set of 18 scenarios which described various exchange situations including for example, emergent treatment, non-emergent treatment, research use, bioterrorism, and public health. At the end of Phase 1, RTI researchers conducted an analysis to summarize the information collected, which included over 8000 business practices and over 1000 potential solutions.

Through this analysis, a number of common themes emerged, including:

- Variations in the Interpretation and Application of Consent,
- Misunderstandings and Differing Applications of the HIPAA Privacy and Security Rules,
- Variations in the Application of Security Policies (Authentication, Authorization, Access, Audit, and Transmission),
- Variation in State Laws,
- Patient Identification, including issues around Consumer Communication and Education, and

- Interpretations of Redisclosure, Ownership, and Public Health Reporting Requirements.<sup>1</sup>

As common issues that created the largest challenges to health information exchange emerged, the RTI team began to support the formation of multi-state working groups as part of the implementation of solutions process. Phase 2 began with an in-person meeting of state team leaders, which established a set of potential cross-state projects. RTI staff facilitated a number of brainstorming sessions about key topic areas. All participating states became engaged in one or more of the groups, and a separate initiative engaged interested participants from a number of states that were not a part of Phase 1 activities to join in these meetings. RTI provided templates and guidelines to support the teams as they developed proposals to form collaborative work groups and complete projects.

Seven of the nine projects submitted to RTI and ONC were approved for completion in Phase 3, each with specific products and outcomes that sought to develop common, replicable solutions to a key privacy and security challenge to interoperable health information exchange. The Collaboratives and participating states are provided in the table below:

**Table 1. HISPC Phase 3 Collaborative Work Groups**

Collaborative Work Group	Participating States and Territories	
	N	State Abbreviations
Consumer Education and Engagement	8	CO, GA, KS, MA, NY, OR, WA, WV
Provider Education	8	FL, KY, LA, MI, MO, MS, TN, WY
Interstate Disclosure and Patient Consent Requirements	11	IN, ME, MA, MN, NH, NY, OK, RI, UT, VT, WI
Interstate and Intrastate Consent Policy Options	4	CA, IL, NC, OH
Harmonizing State Privacy Law	7	FL, KY, KS, MI, MO, NM, TX
Adoption of Standard Policies for Authentication and Audit	10	AZ, CO, CT, MD, NE, OH, OK, UT, VA,

<sup>1</sup> For a full set of Key Issues, please see Dimitropoulos, Linda et al. "Assessment of Variation and Analysis of Solutions". June 30, 2007.

		WA
Interorganizational Agreements	7	AK, GU, IA, NJ, NC, PR, SD

The products created by these multi-state groups were thoroughly vetted by the participating states' steering committees and various other key stakeholder groups. This ensured that the feedback loop with local communities established in Phase 1 was intact and that all products were approved for use and/or distribution by the various stakeholders within the state. A summary of the major public deliverables created by the seven collaborative groups is included in Appendix A.

ONC approved an extension with the purpose of finalizing and disseminating knowledge gained throughout Phase 3. Part of this extension required states to complete two challenges to test the effectiveness of the consumer and provider education and outreach materials developed in Phase 3. The first challenge required states to identify at least three consumer-oriented stakeholder associations/organizations within their state and adapt 2-4 items developed by the Consumer Education and Engagement Collaborative. Specifically, each state was required to: 1) approach the organizations, 2) review and determine which consumer education tools were appropriate to the local context, and 3) work with the organizations to adapt and disseminate the materials. The second challenge required states to identify and partner with at least two provider associations to promote materials developed by the Provider Education Toolkit Collaborative. In each of the two provider associations they were required to accomplish two of the following objectives:

- Gain support of the association to distribute an announcement via its listserv regarding the tools and resources available.
- Identify a “Physician Champion” within the association who is willing and able to effectively support word-of-mouth dissemination of the toolkit materials.
- Secure a speaking arrangement for at least one regular meeting of association members to present the toolkit materials.
- Distribute press release and journal articles in the leading local newspapers, medical trade press and associations’ journals and newsletters, or any other association printed or web-based member communications.
- Establish affiliations with professional associations by having them provide a link to the project website to promote the toolkit material.

The two original groups had slightly different methods for producing their materials. In the Consumer Education and Engagement group each participating state took ownership of one of the major tools or resources and developed that within their state during the course of phase 3, at which point they presented their final documents to the full group for comments, edits, and alterations, thus producing a master document. The Provider Education Toolkit group developed each of their materials up front as a group and then tested them individually within their states.

A total of 37 states and territories took park in the challenge, which includes those states that originally created the materials and were now charged with moving from a test/pilot phase to a more widespread distribution. The challenge took place between April and July 2009. At the end of the four month challenge phase, each state submitted a report which included background, contacted entities, methodology, items reviewed and used, descriptions of how materials were adapted and disseminated, and feedback and lessons learned. These reports were delivered to ONC, but not summarized or disseminated. This paper serves to outline some of the major findings reported, to inform major Federal initiatives that are currently underway.

## METHODS

To begin the analysis of the data reported, we uploaded all of the report files to a qualitative analysis software product called NVIVO. This software allows for the development of a coding scheme in the form of “nodes”, which can be broken into multiple major analysis categories, and can contain various sub-categories under each major category. Two master nodes were established for each of the major challenge activities: Consumer education and engagement and Provider education. Under each of these challenge activities, nodes were created for 1) number of organizations contacted, 2) Outreach methods, 3) Specific materials targeted, 4) Accomplishments (Positive Lessons Learned), 5) Limitations (Negative Lessons Learned).

The text of each challenge memo was loaded into the program and reviewed according to these five analysis categories. The co-authors then split the coding duties evenly, each coding 37 reports. Each piece of text relevant to the analysis categories was associated with the relevant category. During this process, subcategories emerged and were built around the major analysis categories, specifically within the categories of Outreach Methods, Accomplishments, and Limitations. The outcomes of this coding are discussed in the following section.

## OUTCOMES

This section outlines the findings of our qualitative analysis regarding the effectiveness of the materials developed by the Consumer Education and Engagement and the Provider Education Toolkit collaboratives to provide a foundation for outreach in other states which did not participate in their creation. Due to the potentially political nature of the responses, individual states are not identified in the text.

## **CONSUMER CHALLENGE**

Across the 37 states that participated in the challenge, a total of 111 organizations or 3 per state were initially approached to review, adapt, and disseminate the Consumer Education and Engagement materials. Although not all 111 organizations were able to participate, a large number agreed to distribute the materials either during the performance period, or committed to distribution as part of a longer term education and outreach plan. This number of approached organizations indicates that the objective to identify and approach at least three consumer-oriented stakeholder associations/organizations was met in all states.

### **Outreach Methods**

As outlined in table 2, the majority of states were able to distribute materials developed by the Consumer Education and Engagement collaborative through web or print media, and in a number of cases, both methods were used. A number of states also focused their efforts on presenting to stakeholders at various organizations to inform them of the availability of the different resources and to discuss options for incorporating them into strategic and future outreach and education plans. Only four states reported that they were unable to distribute any of the consumer challenge materials through the organizations they approached during the given timeframe.

**Table 2: Specific Outreach Methods for Consumer Challenge**

<b>Method</b>	<b>Sources (States)</b>
Materials Distributed via Web	N=19
Print materials distributed	N=19
Other (organization-level commitments or strategic meetings)	N=11
Focus Groups	N=1
Did not Distribute	N=4

### **Successes**

Overall, the majority (n=25) of states had positive feedback to relate, as well as a number of successes. One success was that the tools were well-received, clear, concise, useful, and easy to read. (n=7). In addition, states reported that the HISPC work products were favorably received by consumer organizations (n=6). States also found that organizations were supportive of the work being done through HISPC; organizations were appreciative of the quality and quantity of information and resources developed; and organizations appreciated having these educational tools for adoption and use.

Furthermore, several states (n=7) found that many organizations appreciated not having to “re-invent the wheel”. Having the tools and materials to build on, rather than author them from scratch not only saves money, but also provides an excellent starting point and foundation for additional efforts.

Some examples of positive comments include:

- “consumer organizations are eager to know more about electronic health records and to understand their impact on their constituents.”
- “organizations were pleased to be included in this process.”
- “They were enthusiastic about the opportunity to provide educational material to their constituents.”
- “Organizations liked what they saw and were eager to share the information.” and
- “Willingly committed themselves to disseminate the material to their members.”

## **Limitations**

Several states (n=12) expressed limitations to the materials/products. The two most recurring limitations were: the materials were too general or complex (n=6); and literacy issues (n=6). Literacy issues included, but were not limited to, difficult language, language hard to understand, the need to accommodate a lower reading/grade level, and material “too full of technical terms and jargon”. Reports noted that some organizations felt “the format and structure of some of the material made it difficult to understand the content and visualize the value of the material.”. In addition, some organizations felt the material would be difficult to adapt in such a short time frame; comprehensive material may not be useful to consumers; and the material would raise concern rather than provide reassurance.

Sixteen states expressed limitations related to timing. A majority of them (n=9) felt the timeline was too short, which made it difficult to build relationships, engage organizations, and adapt and vet the material. Furthermore, some states (n=3) were challenged because this effort “took place during the summer months when a lot of people are out of the office.” Interestingly, the timing of the H1N1 outbreak also impacted 2 states in carrying out their work with consumer organizations. In addition, the consumer challenge set forth by HISPC had to compete with the existing agendas within consumer organizations, other HIE efforts, and sometimes even lobbying priorities due to active legislative sessions.

In carrying out the consumer challenge, some states (n=3) found that staff at many of the consumer organizations did not have significant knowledge or experience with Health Information Technology. In addition, a couple of states discovered that consumer knowledge is highly limited. Related to this, one state noted that “audiences are not making the connection among EHR references, privacy requirements, and ARRA forthcoming programs.” In fact, this state found that “the Federal Stimulus Package (ARRA) was not well understood.”

In addition to the above mentioned limitations, some states expressed other challenges they faced. These included, but were not limited to, a lack of interest; budget cuts; lack of adequate funding to produce/adapt/disseminate materials; difficulty garnering support for the needed local customization; and difficulty convincing organizations that education is a higher priority than other issues.

## **PROVIDER CHALLENGE**

Across the 37 states that participated in the challenge, a total of 114 unique organizations (3 per state) were reported as approached for review and potential dissemination of the Provider Education Toolkit Materials. While not every organization that was approached was able to fully participate in the distribution of materials, the vast majority either participated during the period of performance, or committed to plans that involved participation just outside the period of performance. While the average of 3 organizations approached per state exceeded the contractual requirement of two and indicates that the materials were disseminated to more organizations than expected when the challenge was first issued, it also speaks to the value of one of the project's initial objectives, which was to maintain a stakeholder base within each state of various groups (including provider associations) that were involved and engaged in issues of privacy and security related to health information exchange.

### **Outreach Methods**

Outreach methods were suggested as part of the official challenge; the use of the various methods by the state teams is shown in Table 3. The most frequently used method was to disseminate the toolkit materials via the web, which was accomplished by linking to the central site and sending notices about the toolkit out via listserv. Most states also conducted various meetings, or asked to present at previously scheduled meetings held by provider associations. A number of states also disseminated print versions of materials (brochures, news releases, etc.). Only four states reported that they were unable to disseminate the materials with any of the organizations that were approached at the outset of the challenge task.

**Table 3: Specific Outreach Methods for Provider Challenge**

<b>Method</b>	<b>Sources (States)</b>
Materials Distributed via Web-based methods	N=22
Meetings/Focus Groups	N=18
Materials Distributed via Print Media	N=11
Other	N=7
Physician Champion Identified	N=6
No Outreach	N=4

### **Successes**

The majority of successes reported through the challenge memos fell into four major categories: Reception, Quality, Reach, and Other. In total, 15 states reported that the materials were received with strong support by the organizations that were approached. Many reports mentioned a deep appreciation for how useful the materials were to their

provider education efforts. These reports also noted that organizations were happy that they did not have to “start from scratch” to develop the materials available in the toolkit and that they were able to fill a gap that had previously existed in their health information exchange and health IT education efforts. One state reported that the materials were “well received and the response exceeded expectations”. These states also reported that the materials seemed to encourage and engage the providers that reviewed them and many noted specifically that the neutrality of the information provided was of extreme value to the physician user.

A total of nine states reported specifically on the quality of the toolkit, noting that it was a great resource that clearly communicated the benefits of health information exchange and the adoption of health IT. A number of states noted situations where the physician participants noted that they felt the materials advanced their awareness of the topic and provided direct compliments about the high quality of the toolkit package. One physician group noted that they thought “the toolkit materials [were] excellent.” These states also felt that the materials were valuable resources that could be customized to address local providers.

Three states give specific examples of how far the toolkit materials were able reach into the provider stakeholder community. One state reported that through their outreach efforts, the provider education materials were integrated into a larger privacy and security toolkit that has become the basis for a regular course that will be taught to medical students going forward. Another state estimated that through their outreach efforts, state associations “disseminated the toolkit information to approximately 10,000 association providers”. Another state noted that the dissemination of the provider education materials had proven a successful test of their network of provider stakeholders developed during the course of the HISPC project.

Finally, at least two states reported that the outreach efforts served to initiate some important discussions with providers about the privacy and security of electronic health information within their stakeholder base. They expressed that these conversations might not have been possible without the toolkit and the underlying challenge task to support them.

## **Limitations**

States also described a number of limitations that they encountered while performing the outreach of the provider toolkit. These included issues with Timeline, Customization, Scope, and Dissemination Problems.

In total, 19 states reported struggling with the amount of time allotted to them to complete the outreach task. In addition to encountering competing priorities and scheduling difficulties within the four month timeframe, many states also reported that the recent passage of the American Recovery and Reinvestment Act (ARRA) was a frequent deterrent from the conversations that the toolkit was intended to cover. Because the tools were created prior to the passage of ARRA, the materials did not cover certain

questions about changes in landscape due to the provisions on health IT and HIE activities.

Three states felt that they were not provided enough time or resources to undergo adequate customization of the toolkit materials. They also noted that for the materials to be truly successful, an ongoing initiative to support them would likely be necessary in their states. Two states suggested that the toolkit's focus on primary care physicians was limiting in terms of reaching out to the full set of providers needing education in their area. They suggested a similar set of materials focused specifically on either pharmacists or nurses would be highly beneficial.

Two states noted that the physicians to whom they presented the toolkit materials did not feel like they were the ones making decisions about HIT and HIE in their organizations and that the materials seemed to surface other concerns about implementation, funding, and liability issues that caused anxiety about the switch to electronic health records. Another two states noted that they had found little use for the materials in general due to high rates of physician adoption in their locations. One state noted that in their specific location, provider education had been fairly widespread but that education for legislators and patients was still sorely lacking.

## **CONCLUSIONS**

The hypothesis underlying the Consumer and Provider challenge task suggested that education and outreach materials developed by a multi-state workgroup could be used by other states with the same outcomes they might have seen if they had created the materials themselves as part of individual initiatives.

### **Usefulness of Materials to other States**

The first hypothesis states that *educational materials created by a smaller sub-group of participating states working in conjunction throughout phase 3 were found useful to other states asked to adopt and disseminate them.*

The majority of participating states (n=25) reported that materials developed by the eight original Consumer Education and Engagement Collaborative were useful, which we defined as well-received, clear, concise, useful, easy to read, and well-received by the consumer organizations approached. The largest limitation reported related to this hypothesis was the general lack of enthusiasm or interest by their consumer stakeholder organizations (n=3).

Fewer states (n=9) specifically noted the usefulness and quality of the materials related to the Provider Education Toolkit, however, the materials do seem to have been distributed among a larger number of organizations and through a larger number of methods than were reported for the consumer materials. Specific feedback about the experience of attempting to disseminate these materials indicated strongly that they were well-received

and of high quality. Only four states noted that they found little or no use for the materials within their provider stakeholder community.

Based on these facts, we find that the majority of states that participated in the consumer and provider education challenges were able to report that the materials were of high quality and useful to them, and/or that the materials were well received and disseminated widely among the various organizations that were approached.

### **Ability to Replicate and Adapt Materials**

The second hypothesis stated that *states outside of the original multi-state group which created the set of materials found them appropriate for replication and adaptable for use in their local environment.*

Seven states provided feedback about the ability to replicate and adapt materials, noting a general feeling of relief that they did not have to build materials from scratch. A greater proportion--approximately one-third of (n=12)--reported limitations with the consumer education materials that affected their ability to replicate and adapt them for local use. Primarily, these limitations revolved around reports that the materials were either too complex or too simplistic. The duality in this specific subsection of limitation seems to indicate the diversity in advancement and/or prevalence of a discourse about health information exchange within the various participating states. A major lesson emphasized by the original Consumer collaborative group was the importance of ensuring that all materials were created at a 9<sup>th</sup> grade literacy level or lower. However, some states felt that this standard was too high for their target populations and others felt that it degraded the message and quality of materials. This is an important point of reference for future work related to consumer education materials related to HIE and health IT – the consumer audience across the country is extremely varied and should never be treated as one-dimensional. Tools that take into consideration a wide range of literacy and health care knowledge levels have the potential to make the greatest impact.

A total of 15 states reported feedback about the ease of using the provider education materials and they wide ranging appeal the materials had to their stakeholders. The vast majority of states were able to disseminate these materials as requested without any significant local adaptation required. Only three states reported problems with adapting the provider education materials, and the reasons provided were focused primarily on the amount of time provided and a fear that without sustained resources the initiative would be forgotten.

Overall, results for this hypothesis are more difficult to determine. The number of limitations reported related to the consumer materials outweighed the number of successes in this area. However, the majority of participating states did not have any limitations specific to this hypothesis to report, which indicates that they did not have significant problems in adapting the materials. The number of limitations reported regarding replication and adaptation related to the provider materials was extremely low. This leads us to assert that while some issues related to transferring documents created by

a smaller multi-state group to a widespread nationwide campaign are evident, the benefits of having a starting point on which to build educational activities outweigh the limitations to building materials from scratch in most situations and contexts. We also believe that consumers, as a stakeholder group, display far more variability and present more complexities than providers and future efforts to create educational materials for them should be extensive, dynamic, and flexible.

### **Overall Effectiveness of Outreach Campaigns**

The third and final hypothesis stated that *materials used during the challenge phase of the project led to effective outreach campaigns for each of the intended targeted groups in the majority of states.* If limitations due to the externally imposed timeline of the project are removed from the analysis regarding the overall effectiveness of the outreach campaigns, it appears that the successes of the outreach activities outweigh the limitations experienced in both the consumer and provider education challenges. Although not every state was able to accomplish the level of outreach that was set out for them to meet, there were very few reports of this being due solely to the quality of the materials. By analyzing the information reported to us, we believe the provider education challenge was slightly more effective in the overall breadth and depth of the outreach campaign. However, it is also clear that nearly all participating states were able to disseminate all or at least parts of the materials, both from the consumer and the provider challenges, to directly improve the educational resources available to both sets of stakeholders within their state about issues of privacy and security related to electronic health information exchange.

In summary, we find that the primary lessons related to the research objective are that materials created and tested in a small number of states can provide the necessary contextual information to make them successful tools for the vast majority of other states. Our research model did not have a way to incorporate the effects that the differing approaches taken by these two groups in creating their materials may have had on the final outcomes. Although it may seem possible that tight coordination at the outset of the collaborative project with individual entity testing afterwards (as in the Provider Education Toolkit group) leads to slightly more effective adoption outcomes, this is not necessarily the case, given some significant compounding factors such as the vast difference in the range of specialized needs displayed by the Consumer community. Additional research on this subject specifically would need to be done to make any such determinations about the effect of the differing collaborative approaches. Understanding the complexities of these two stakeholder groups, especially the extremely variable and dynamic consumer population, is a factor that must be central to any future efforts.

## APPENDIX A

### **SUMMARY OF MAJOR PUBLIC DELIVERABLES PRODUCED BY THE HISPC MULTI-STATE COLLABORATIVE WORK GROUPS**

#### Consumer Engagement and Education

- Print materials: Glossary, Health IT Fact Sheets, FAQs
- Website materials: Videos, tutorials, model websites
- Marketing Toolkit: Brochures, Posters, radio/TV public service announcements
- Guidelines: Literacy Control, personal health record (PHR) inventory, Guidelines for Materials Adoption, Guidelines for conducting educational forums, Guidelines for initiating physician-patient conversations

#### Provider Education Toolkit

- Online and print materials (videos, posters, brochures, etc)
- Summary Report of provider interest level

#### Interstate Disclosure and Patient Consent Requirements

- Final Analysis of state law requirements across participating states
- State law reference guide
- Blank templates for the analysis of state law requirements
- Recommendations and Guidelines

#### Interstate and IntraState Consent Policy Options

- Central bibliography of consent documents
- Process for evaluating approaches to intraState consent
- Templates for the analysis of consent policy options
- Guidebook to analyzing interstate legal mechanisms

#### Harmonizing State Privacy Law

- Comparative Analytical Matrix (CAM) and Roadmap for action
- Framework for achieving legislative action

#### Adoption of Standard Policies for Authentication and Audit

- Recommended basic policy requirements
- Implementation guide for adoption of basic policy requirements

#### Interorganizational Agreements

- Library of sample data sharing agreements
- Core privacy and security provisions
- Model agreements for data sharing
- Implementation user guide
- Evaluation results of the exchange pilot tests and signed agreements

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