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Health Information Security and Privacy Collaboration

Consumer Education and Engagement Collaboration Mechanisms for Evaluating Effectiveness of Consumer Processes and Products

Prepared for

RTI International

230 W Monroe, Suite 2100
Chicago, IL 60606

Jodi Daniel, JD, MPH, Director

Steven Posnack, MHS, MS, Policy Analyst

Office of Policy and Research

Office of the National Coordinator of Health IT

200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

Prepared by

Consumer Education and Engagement Collaborative
Colorado HISPC Phase III Consumer Education and Engagement Team

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Office of Policy and Research
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200 Independence Avenue, SW, Suite 729D
Washington, DC 20201

Prepared by

Phyllis Albritton, Colorado
Dawn Bonder, Oregon
Ellen Flink, New York
Jerilyn Heinold, Massachusetts
Victoria Wangia, Kansas

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1. INTRODUCTION

As organizations work toward increased use of health information exchange (HIE) in health care, a better understanding of patients' privacy and security is paramount. The perspectives of consumers must be taken into account to ensure that organizations are successfully improving the health of those that are served.

As states and organizations reach out to consumers, ongoing dialogue and conversation can improve the organization's approach to health information exchange on behalf of consumers, and ensure that consumers understand what is and what is not occurring as part of an electronic HIE.

In many instances, by default, measurement tools tend to address how many items have been distributed and/or how many media outlets are responding to a particular invitation. Although these measurements are important to collect, they do not always adequately demonstrate the success of a process or product in helping consumers better understand privacy and security issues, act on their own behalf in the context of health information exchange, or change their behavior. This document offers mechanisms for organizations to consider that can help discern the success of various processes and products in addressing consumer education and engagement.

The Health Information Security and Privacy Collaboration (HISPC) Consumer Education and Engagement (CEE) Collaborative has used this past year to plan, produce, and distribute both process documents and products that can be used with consumers. These process documents and correlated materials provide multimedia approaches to addressing consumer concerns, as well as educating consumers about health information exchange. To take these outputs to a higher level, it is important to measure the efficacy of these processes and correlated materials. This document offers different mechanisms by which the effect of these materials can be utilized and measured.

2. WHAT TO MEASURE?

To properly evaluate these processes and products, it is important to first determine what is most helpful to include in the measurement tool. Questions and measurements should focus on what information is being sought. Some measures that might be useful in addressing or understanding the needs of consumers' perspectives on privacy and security are:

- Did the consumers learn what was being presented?
- Did the consumers act on information provided?
- Did consumers gain a different perspective than they had previously?

- Were consumers more or less likely to understand privacy and security benefits and risks related to health information exchange?
- Was information presented clearly?

Before developing the processes and products that will be used for consumer education, it is very useful to determine what measures should be expected. This helps keep consumers focused on the results rather than on other aesthetic and esoteric elements that may distract from the message.

3. PRODUCTS

Some products that have been developed through the HISPC CEE Collaborative include:

- websites (West Virginia, Georgia, Colorado, Kansas),
- brochures (West Virginia, New York),
- fact sheets (Kansas),
- frequently asked questions (FAQs) for behavioral health (Massachusetts),
- FAQs on health information exchange (Collaborative),
- guide to consumer rights and tips for protecting health information (Collaborative),
- HIE benefit/risk template (Collaborative),
- glossary (Kansas, Georgia),
- public service announcements—PSAs (New York),
- radio spots (New York), and
- general video (Colorado).

Any and all of these items can be used in a group discussion where a direct correlation can be assessed between the item and the measurements. They can also be addressed in the context of outreach tools such as websites, online venues, and distribution channels. By broadening the venue beyond a simple meeting, the direct correlation of the product to the outcome becomes more difficult to discern because of other factors that may influence consumers. On the other hand, broader dissemination offers a broader opportunity to reach consumers, so it should not be discounted.

4. PROCESSES

Some processes that have been outlined in previous deliverables created through the HISPC CEE Collaboration include:

- guide for working with consumers (New York, West Virginia),

- town hall meeting guide for using a video introduction (Oregon), and
- online tutorial for behavioral health (Massachusetts).

In these guides, advice and experience are offered based on real-world experiences working with communities. So how will creators of consumer education materials know if they are succeeding in their goal?

4.1 Pre- and Post-Interviews/Surveys

The purpose of these efforts is to discern what is known both before the discussion as well as what might have been learned through the discussion.

A simple, cost-effective way to measure impact through such a process is to interview or survey participants regarding their knowledge about health information exchange privacy and security issues before and after a discussion. In person, surveying can be accomplished through a show of hands. Alternatively, it can be done with short surveys on paper, on the Web, or on a handheld device; the surveys can be conducted before and, again, after the event.

4.2 Show of Hands

One might use *show of hands* in a large group to simply understand what the audience knows before starting, or in a small group to maintain the feel of a more intimate conversation. An advantage to a show of hands is that it is a simple, direct, and inclusive way to discern a community's interest and understanding of the issues. One concern with the show of hands method is the effect of peer pressure. Will a group of participants offer their true opinion or offer the opinion that seems most appropriate? This concern should be considered when deciding whether to use this mechanism.

4.3 Short Survey

In a *town hall meeting*, surveying can be done using either paper surveys or handheld devices that can anonymously tally participants' answers to questions. Although both paper surveys and handheld devices can be more expensive from a time and materials perspective, the anonymity they afford can reduce the peer pressure effect.

In an *online* venue, a short survey can be inserted before and after the tutorial. Using this mode, it will be important for the organization to decide whether it is more or less useful for this to be an anonymous survey. These surveys offer the option of providing contact information if the participant would like to be contacted further.

4.4 Focus Groups

In some circumstances, it is important to understand more detail regarding a consumer's reaction to processes and/or products. In these cases, focus groups are most appropriate.

Focus groups are identified groups of consumers, usually in settings of 8–15 people, for a more intimate discussion that digs deeper into questions and concerns. In many cases, focus group participants are paid for their time. Focus group results can offer more insights than a brief survey about how and why a particular product or process was or was not effective. These insights provide important information for improving the impact of such products or processes. On the other hand, conducting focus groups can be expensive. Also, it is important to ensure sufficient representation from diverse demographic groups to adequately generalize from the limited experience of a smaller number of participants.

4.5 Built-in Surveys

For online items, either full websites or portions of a website, online surveys can be built in. If a consumer accesses a section of a website on which information is presented and measurement is sought, a brief survey can be built into the structure of the website. If the item is an online tutorial, pre- and post-surveys can be incorporated. If a consumer is accessing an item on a website, these surveys may not offer pre- and post-usage information, but can provide insights regarding the usefulness of the information offered. A few short questions can suffice with the option of contact information for further follow-up. Questions may include the viewer's perspective on actions they may take as a result of seeing what is presented. This measurement tool is a relatively low-cost mechanism and can offer direct relational results from particular information. However, the respondents in these surveys are self-selected, which can impact the value of the information offered. If only those who are most driven to reply do so because they are very interested or very concerned, the results of these surveys will be skewed. It is also important to keep in mind that a population, such as the elderly or the indigent, may not be well represented in such a survey because of lower online usage than other demographic groups. These factors must be taken into consideration when reviewing results.

4.6 Phone Surveys

Phone surveys can be used to follow up with the general public and/or targeted populations when PSAs, radio spots, and disseminated videos are used. These surveys can be more expensive to conduct and require more detailed consideration, both before the materials are disseminated and after, to ensure the phone surveyors ask the right questions and that the demographic profile for which the questions are being asked is relevant. The advantage of these surveys is the ability to ask more probing and follow-up questions of people who may not have taken a brief online survey.

4.7 Monitoring Actions

Another way to measure results is to monitor changes in behavior or the ability of a particular product to inspire a consumer to act. For example, a brochure, fact sheet, or PSA may ask consumers to go to a website. During the time the PSA, is shown, the website can

be monitored to see if consumers access it. Increases in website access could be identified and correlated to the PSA time schedule.

Another example is an “ask” in a video. Colorado’s 3-minute introduction to health information exchange requests that the viewer “ask their clinician whether they use health information exchange.” In this case, changes in behavior can be monitored by following up with clinicians to discern whether consumers who viewed the video had asked this question. In addition, consumers known to have viewed the video can be surveyed to determine whether they had asked their clinician.

A concern about these monitoring tools is whether the particular product is the catalyst for action or whether the action takes place based on a series of products and processes. Because of the distance between the consumer and the individual measures, other influencing factors may be at work. While this concern occurs in almost all monitoring scenarios, they are still recommended tools to reach a broader audience.

5. CONCLUSION

Numerous options can be considered when measuring the effectiveness of processes or products related to consumer education and engagement. In all cases, it is important to consider what measurements and processes to use so that the outcomes can be measureable and efforts can continue to improve their effectiveness with consumers.