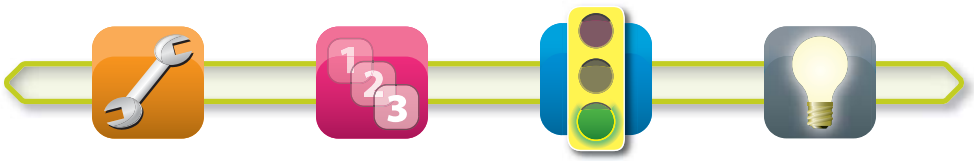
June 2009

Health Information Security and Privacy Collaboration

Action and Implementation Manual



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Health Information Security & Privacy
COLLABORATION

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Contents

Introduction

HISPC RELEVANT RESOURCES

- Assessment of Variation and Analysis of Solutions, June 2007
- Final Implementation Plans, June 2007
- Nationwide Summary, July 2007
- Impact Analysis, December 2007
- Phase III Executive Summary
- http://healthit.hhs.gov/HISPC

Between April 2008 and April 2009, the Health Information Security and Privacy Collaboration (HISPC) completed its third phase to develop state-level solutions to the privacy and security challenges presented by electronic health information exchange. The third phase focused on multistate collaboration, which resulted in the formation of seven multistate privacy and security teams focused on developing tools and strategies to educate and engage consumers; developing a toolkit to educate providers; developing tools to help harmonize state privacy laws; studying intrastate and interstate consent policies; analyzing consent data elements in state law; developing interorganizational agreements; and recommending basic security policy requirements. Each multistate collaborative was charged with developing common, replicable solutions that have the potential to reduce variation in and harmonize privacy and security practices, policies, and laws.

The AIM's purpose is to serve as a guide to the use of all of the tools, materials, and processes developed as part of HISPC Phase III. Many products discussed in this guide are the result of 3 years' worth of participation in HISPC and represent the collective effort and wisdom of 42 participating states and territories. For details on prior phases of the HISPC project, refer to the materials listed in the callout box on the left-hand side of the page.

The AIM is organized by multistate collaborative and is presented in a format that seeks to both educate and promote the use of this work. The AIM is structured around the following sections:

Tools: Provides a list of all tools the collaboratives developed.

Steps to Success: Provides a step-by-step guide to using the tools and processes that each collaborative developed and tested.

Make It Happen: Provides a more in-depth description of the products the collaboratives developed and how to use them.

Implementation Tips: Provides useful tips and lessons learned from the collaboratives.

References to relevant resources throughout the AIM can be found in the callout boxes on the left-hand side of the page, and all materials and references can be found at http://healthit.hhs.gov/HISPC.

1

Consumer Education and Engagement Collaborative

PARTICIPANTS

- Colorado
- Georgia
- Kansas
- Massachusetts
- New York
- Oregon
- Washington
- West Virginia

ABOUT ...

The Consumer Education and Engagement (CEE) Collaborative was formed to develop an array of materials to help consumers better understand health information technology (IT) and electronic health information exchange. The Collaborative focused its efforts on reaching out to a wide range of health care consumers through multimodal, targeted approaches, with the intent to improve trust and understanding by increasing their privacy and security awareness and literacy.

TOOLS DEVELOPED

The CEE Collaborative developed the following tools:

- Health Information Technology Consumer Education and Engagement Inventory Matrix
- Inventory Matrix Gap Analysis Report
- Consumer-Focused Glossary of Health IT/Health Information Exchange Terms
- Planning for Consumer Communication and Education
- Toolkit Materials
  - A Guide to Literacy and Language Considerations
  - Fact Sheets
  - FAQs about Health IT/Electronic Health Information Exchange Privacy and Security
  - Health Information Exchange and Health Information Technology Benefits and Risks
  - Tips to Protect Your Privacy
  - Videos
  - Brochures/Posters/E-mails/Public Service Announcements (PSAs)
  - Press Kit Materials
- Targeted Toolkits
  - Rural Populations
  - Sensitive Information
  - Education through Providers
- Implementation Guides
  - Town Hall Meetings/Public Forums
  - Guidelines for Physicians to Engage Consumers
  - Guidance for Developing Consent Policies for Health IT
- Evaluation and Measurement Guides

Steps for Success

The tools created by the CEE Collaborative can be modified and adapted easily to meet your specific requirements. To make the best use of these tools, it is recommended that you follow the steps outlined below:

STEP 1: Conduct a needs assessment.

STEP 2: Identify available resources.

STEP 3: Create a plan.

STEP 4: Create toolkit materials.

STEP 5: Specify toolkit materials for special populations.

STEP 6: Implement and establish outreach partnerships.

STEP 7: Measure your materials.

Make it Happen

For consumers to engage in the planning, development, or implementation of an initiative, they need to understand the purpose and impact that the initiative will have on their day-to-day lives. To be effective, health care consumers and consumer advocates should understand the risks and benefits of health IT and HIE initiatives. Issues of language and literacy and access to information also present barriers to the education and engagement process.

Based on the experience of the CEE Collaborative, the detail provided below provides helpful assistance in planning and executing a consumer education and engagement campaign.

Review or Conduct a Needs Assessment

Establish a baseline for your state or local community with respect to its knowledge of and exposure to health IT and electronic health information exchange by conducting either a formal or informal needs assessment. The results of this needs assessment will help identify your target audience. An organization should ask the following key questions when planning an education and outreach campaign:

- What message do you want to convey?
- Who makes up your target audience?
- Do you have a communication plan?
- Does the target audience have special needs or interests (i.e., literacy level, language translation, closed captioning)?
- How can you make the information accessible to your target audience?

If you decide to conduct a formal needs assessment, the following activities should be included:

1. Research previous efforts to gauge the needs of the consumers within your state related to education on health IT and health information exchange.
2. Identify or convene a leadership team with sufficient consumer representation to steer and advise the project.
3. Engage the leadership of consumer education groups and educators, consumer representatives, and others to facilitate and assist with reaching consumers and stakeholders.
4. Collaborate with states or regions that have similar populations and other relevant partners to seek feedback on privacy and security educational needs and preferred dissemination methods.
5. Document findings in a report that will be used to provide guidance for additional activities.

Identify Available Resources

A wealth of information already exists that is designed to increase how much consumers understand about their role and participation in the health care system. Modifying existing materials is much easier than developing them from scratch. For this reason, the CEE Collaborative developed the "Health Information Technology Consumer Education and Engagement Inventory" in conjunction with the National Partnership for Women & Families. The inventory includes websites, PowerPoint presentations, videos, consumer forum scripts, handouts, and other relevant materials. It also includes a list of national health IT organizations that maintain consumer engagement materials.

Although the inventory is a handy resource, some of the materials may have been altered, updated, or replaced since they were collected by the CEE Collaborative. Also, many of the documents reflect high-level information and should not take the place of information that reflects the local or regional status of health IT and electronic health information exchange. An environmental scan of local resources should supplement the use of the inventory. Finally, the majority of current resources included in the inventory may not have taken into account literacy issues or other issues that are relevant for the selected target audience.

The CEE Collaborative found that there was no readily available source for definitions that are both accurate and targeted to consumers. In an attempt to standardize definitions across the eight participating states and to create a lasting resource that others would find useful, the CEE Collaborative created the "Health Information Technology/Health Information Exchange Privacy and Security Glossary." This resource provides 45 literacy-processed definitions that were specifically developed for the general consumer population. The glossary, focused on privacy and security terms, provides a concise resource for definitions that are easy to read and understand.

RELEVANT RESOURCES

- Health Information Technology Consumer Education and Engagement Inventory
- Inventory Matrix Gap Analysis
- Health Information Technology/ Health Information Exchange Privacy and Security Glossary

Create a Plan

Some CEE Collaborative states already had ongoing health IT or electronic health information exchange initiatives, and those initiatives emerged as natural partnerships to leverage the CEE Collaborative's work. It is helpful to coordinate an education and engagement campaign with an established or emerging health IT initiative. If there are no major centralized initiatives in your state or region, or if you are the entity charged with creating the initiative, then your next step should be to develop a detailed plan. At a minimum, this plan should clearly define the following:

- goal
- audience
- core messages
- objectives
- specific strategies for each objective
- budget
- timeline/schedule
- evaluation/metrics

RELEVANT RESOURCES

- Lessons from AccessMyHealth
- Kansas Communication Plan
- Education and Public Awareness Campaign (Georgia)

Create Toolkit Materials

While the creation of even one highly effective, targeted consumer education tool is a positive step forward, almost every state in the CEE Collaborative created a "toolkit" of materials. This toolkit typically contained a number of different documents (a combination of pamphlets, posters, brochures, tutorials, forum/town hall meeting materials, e-mails, PSAs, videos, and websites), all created to build on and complement each other. States in the CEE Collaborative found toolkits to be an effective strategy to reach different populations and, in many cases, to relay the same or similar information to multiple audiences. The following sections describe tools created by the CEE Collaborative that are available for local adaptation and use.

Fact Sheet

The purpose of a fact sheet is to orient consumers to a specific issue in an easy-to-digest format. Fact sheets are typically organized around a set of questions or similar headings that provide basic information about the "who, what, when, where, why, and how" of the issue.

RELEVANT RESOURCES

- Georgia Fact Sheet
- CoRHIO Fact Sheets (in six languages)

Depending on the type of the initiative and the level of complexity, you may choose to include just general information about issues related to health IT and electronic health information exchange, or you may want to add information specific to your initiative. Appropriate questions to answer on a fact sheet might be "Is my health information kept safe and secure?" and "What are my rights?"

As a rule of thumb, a fact sheet should be no longer than two pages and should have short, concise answers. Two or three sentences are ideal, and bullet lists can also be effective in presenting major points. If you find yourself wanting to describe a certain concept in more detail, it is time to think about developing additional materials!

Frequently Asked Questions

A set of frequently asked questions (FAQs) is another handy way to communicate the details of a complicated initiative. A set of FAQs is an extremely effective way to expand on or add to the topics provided in a fact sheet. The CEE Collaborative created a set of 20 FAQs about privacy and security issues related to health IT and electronic health information exchange. The FAQ is offered as a resource that entities can use in whole or in part and offers clear answers to important questions such as "What is 'consent'?"

RELEVANT RESOURCES

- FAQs about health IT/HIE privacy and security

RELEVANT RESOURCES

- Health Information Exchange and Health Information Technology Benefits and Risks

Health Information Exchange and Health Information Technology Benefits and Risks

Another component of the CEE Collaborative's toolkit is an open and accurate discussion of the risks and benefits of electronic health information exchange. The Collaborative created a summary document that can easily be worked into other materials, such as brochures and pamphlets. It can also be used as a separate, standalone handout.

RELEVANT RESOURCES

- Tips to Protect Your Privacy

Privacy Protection Tips

Based on earlier HISPC work, it was identified that many consumers did not understand the protections provided to them by the HIPAA Privacy Rule. The "Tips to Protect Your Privacy" document was developed by the members of the CEE Collaborative for individuals in their states and was tested and processed for low literacy levels. It provides a thorough but easy-to-follow summary of some of the HIPAA Privacy Rule's major provisions directly related to individuals and tips and pointers on what to do if consumers believe their rights might have been violated.

RELEVANT RESOURCES

- Oregon video: "Sharing Health Information Nationwide... and Doing it Right"
- Massachusetts, Colorado, New York, and West Virginia versions of the video

Videos

Videos are an effective communication tool. Oregon developed the first video under the HISPC project entitled "Sharing Health Information Nationwide...and Doing it Right." Two versions of this original documentary were created: a full-length, 16-minute version and a 6-minute summary version. The video contains basic information about electronic health information exchange, interviews with national-level privacy experts, and "people on the street" interviews.

This video can be used in two ways. In HISPC Phase III, four of the states involved in the CEE Collaborative (Colorado, Massachusetts, New York, and West Virginia) adapted components of the video footage to create a similar film that spoke to issues specific to their local environment. In Massachusetts, the film was refocused specifically on behavioral health information. While far less expensive than shooting a similar video from scratch, this alternative can require a significant commitment of time and financial resources.

A second option is to use the video (either full or summary length) as is to jump-start a discussion of privacy and security and electronic health information exchange within your target communities. Along with the video, Oregon has produced a short and simple guide to organize successful town hall meetings around the video.

RELEVANT RESOURCES

- All of these materials can be found at http://healthit.hhs.gov/HISPC

RELEVANT RESOURCES

- Press Backgrounder
- Website press release
- Newsletter/Op-ed articles
- Full toolkit press release
- TV PSA script
- Radio PSA script
- FAQs specific to toolkit materials

Posters/Brochures/E-mails/Public Service Announcements

Each of the states created a number of documents that were developed for the local community or to fit in with the materials of the local initiative and yet shared similar messages. Many of these materials are available through the project website and can be accessed both in finished format and in raw text format. The latter allows your organization to use the text from these materials, in whole or in part, and to place them into documents that already bear the format and design specific to your initiative.

Georgia Toolkit:

- Risks and Benefits brochure
- Easy as 1-2-3 brochure
- Secure-Private-Accessible brochure
- BuckSlip for Pharmacy Bags
- Poster for physician offices
- Two HTML e-mails for consumer outreach

New York Toolkit:

- E-Health brochure
- Two posters
- Two radio PSAs
- Official New York RHIO Consent Form
- Consumer video

West Virginia Toolkit:

- Benefits of EHR/HIE brochure
- Physicians/Providers brochure
- Provider poster
- Seniors brochure
- Privacy and Security brochure
- General brochure

Press Kit Materials

Along with the creation of toolkit materials, there should be a concurrent effort to create press kit materials that appropriately highlight and announce the commencement of the initiative. West Virginia has supplied a full spectrum of materials that can be used in conjunction with the release of the toolkit materials. These materials include not only press releases, but specific TV and radio PSAs highlighting the toolkit materials, FAQs and background information specific to the items contained in the toolkit, and an unconventional form of using the press—an article written by an expert that can be used as an op-ed piece or in a newsletter.

RELEVANT RESOURCES

- Methods for translating documents into different literacy levels and languages
- FAQs for sensitive information
- Self-directed tutorial on sensitive information
- Video covering issues related to sensitive information
- Inventory analysis of PHR characteristics and corresponding PHR consumer guide
- Inventory of laws for sensitive information
- Consumer/Provider information sheets for sensitive information

Specify Toolkit Materials for Special Populations

While the core components of your toolkit are important to a successful education and engagement campaign, entities frequently find that specific materials also need to be developed for subpopulation concerns that must be taken into account in order to be effective.

One CEE Collaborative product, "Methods for Translating Documents into Different Literacy Levels and Languages," provides easy-to-follow tips and guidelines to ensure that the language you are using in your documents is at the appropriate literacy level. This step is important, because consumers often receive materials that are too complicated or too simplistic to be effective. It is best to consult a communications expert to determine whether your materials are written at an appropriate literacy level. If that is not possible, resources are available on the Internet to help. This document provides a number of specific steps to ensure that you are communicating accurately to your target audience.

During the course of the Collaborative's work, two states determined that specific subgroups—rural populations and those concerned with behavioral health information—deserved targeted attention as part of their education and engagement campaign.

Behavioral Health Information

Massachusetts focused on materials targeted to the storage and exchange of behavioral health information. In addition to FAQs and videos, a PowerPoint presentation that serves as a self-directed tutorial is available to explain issues of privacy and security related to behavioral health information, along with a corresponding report that provides a guide to the creation and use of the tutorial. There is also an extensive inventory of laws related to sensitive information found in both federal and Massachusetts state law. Contained within this report is a chapter that provides corresponding "plain language" consumer guides for each of the major areas of law. Finally, an extensive collection of personal health record (PHR) software applications and services and their characteristics is available, as well as a corresponding "Plain Language Consumer Guide" to understanding and choosing a PHR.

Rural Populations

Kansas developed a toolkit around the needs of rural health care consumers. Special care was taken to target specific topic areas that held significant interest to the rural population of Kansas.

RELEVANT RESOURCES

- EHealth Fact Sheet
- ePrescribing Fact Sheet
- Glossary of health IT/HIE terms
- Privacy and Security Fact Sheet
- "Why HIT?" Brochure

Implement and Establish Outreach Partnerships

Once your materials have been created and vetted to ensure that they are accurate, timely, and appropriate for your target population, it is time to push the education initiative forward. The states in the CEE Collaborative undertook a variety of methods for accomplishing the actual use and distribution of their toolkit components, and many of them used multiple methods in tandem.

The underlying theme of all of these methods is the need to balance grassroots outreach with established support within the community. While the initiative must be driven by the needs of consumer stakeholders, it is more likely that an initiative will be sustainable if it is supported by established partners who will carry the outreach effort forward. Some examples of successful implementation and outreach methods used by the CEE Collaborative are discussed below.

Town Hall Meetings/Forums

Oregon detailed its experiences engaging consumers in local, small-group settings. The documentary discussed above served as the centerpiece for a series of town hall meetings, and the team developed a step-by-step guide for planning and executing these meetings to lay a foundation of knowledge that would allow attendees to have an informed discussion on privacy and security issues. The major sections of this guide focus on planning and conducting the meetings, as well as lessons learned.

A significant item contained in the overall Georgia toolkit is the "Consumer Outreach Forum" PowerPoint template. Along with support from the Georgia Department of Community Health (DCH), this presentation guided a number of community forum discussions throughout the state to promote awareness about the security and privacy of electronic health information. It also served as the basis for an internal DCH lunch-and-learn session to promote understanding of the problem between agencies within the department.

Provider Outreach

West Virginia focused the delivery of its consumer materials through physicians. Working with another local initiative, the West Virginia Health Information Network (WVHIN), the project set out to learn more about the consumer population. While this activity provided some information about how consumers felt about health IT, it also revealed consumers' preferred sources of information about electronic health records (EHRs). The project team learned that consumers have a great deal of confidence in their physicians and that consumers, especially seniors, want their doctors to educate them about EHRs.

This information suggested that the best way to engage consumers in a conversation about the privacy and security of EHRs was to have their physicians initiate the discussion in their offices. The West Virginia team developed two documents for this purpose:

- Provider Guidelines for Engaging Consumers in Electronic Health Records and Health Information Exchange: What Your Patients Need to Know
- Electronic Health Records: What You Need to Know

Both pamphlets are available in the report "Provider Guidelines for Engaging Consumers in EHRs and HIE: What Your Patients Need to Know."

RELEVANT RESOURCES

- The Oregon Documentary and Step-by-Step Guide to Planning a Town Hall Meeting
- Georgia Consumer Outreach Forum PowerPoint template

RELEVANT RESOURCES

- Provider Guidelines for Engaging Consumers in EHRs and HIE: What Your Patients Need to Know

RELEVANT RESOURCES

- Guidance for Developing Consent Policies for Health IT

RELEVANT RESOURCES

- Consumer Education and Engagement Collaborative Mechanisms for Evaluating Effectiveness of Consumer Processes and Products
- Summary Report of Lessons Learned (Kansas)

Building Policy

Although New York created a number of the documents mentioned above, they also worked concurrently to develop state-level policy around consent guidelines. An essential cornerstone of New York State's health IT policy is to ensure that consumers are appropriately educated about how their health information can be shared and to provide consumers with the opportunity to decide whether or not they desire to have their information accessible via a statewide network. If consumers are not informed, they have no way of understanding what they are providing their consent for.

The information included in New York's "Developing Consent Policies for Health IT" report includes discussions around key components of consent policy, such as existing health IT model/infrastructure, legal and regulatory landscape, and overarching governance structure. It then provides a step-by-step guide of considerations for successfully engaging in a consent policy-making process.

Measure Your Materials

Specific constraints in Phase III of the HISPC project did not allow for collection of traditional survey or focus group data, but a number of the projects were able to team with other initiatives to collect various measurements of the tools created. Because measurement and evaluation are important components of a campaign, Colorado created a document that outlines the importance of and various methods for measuring the consumer outreach materials.

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

The final summary report of lessons learned submitted by Kansas provides an excellent resource for understanding what issues emerge throughout the planning and implementation of a consumer education campaign. Many of the points discussed in this report provide a guide for the items that should remain part of the core driving force behind the implementation and evaluation of your campaign.

Implementation Tips

Through their approach, the CEE Collaborative captured a number of key lessons learned:

- It is important to take into account the literacy level of your target audience. Material that is not presented at the appropriate level will not be effective.
- There are cost-effective ways to use the products created by the CEE Collaborative. For example, it is more cost-effective to use the original video footage of the Oregon documentary than to shoot new footage. By making this footage available to all states and territories, it is anticipated that other stakeholders will be able to get more out of their education campaigns.
- Specific keys to remember as you build your consumer education and engagement campaign are as follows:
  - Identify and collaborate with stakeholders throughout the process, not just at the beginning or the end.
  - Involve steering and advisory committees in the work products.
  - Identify people to be "champions" or "ambassadors" for your campaign.
  - Form the foundation for lasting partnerships and share resources.

2 Provider Education Toolkit Collaborative

PARTICIPANTS

- Florida
- Kentucky
- Louisiana
- Michigan
- Mississippi
- Missouri
- Tennessee
- Wyoming

ABOUT ...

The Provider Education Toolkit (PET) Collaborative was formed to improve health care providers' privacy and security awareness and to provide them with information on the benefits of health information technology (IT) and electronic health information exchange.

Over the course of HISPC Phase III, the PET Collaborative developed and tested an educational toolkit and created a website to address frequently asked questions from health care providers about privacy and security and to teach them about why health IT and electronic health information exchange are important tools for improving patient care.

TOOLS DEVELOPED

The PET Collaborative developed the following tools:

- Tagline and Logo
- Physician Champion Videos
- Leading Expert Videos
- Education Website
- EHR Dashboard Demo
- FAQs
- Media Materials
- Educational Conference Material and PowerPoint presentations
- Continuing Medical Education (CME) Credits

Steps for Success

Most of the tools that the PET Collaborative created can be easily modified and adapted to meet your specific requirements. To best use these tools, follow the steps outlined below:

STEP 1: Conduct an environmental scan.

STEP 2: Form a steering committee or advisory group.

STEP 3: Select your target audience and communication channels.

STEP 4: Enlist services of a printing and publishing firm (optional).

STEP 5: Identify provider champions.

STEP 6: Deploy the toolkit material.

Make it Happen

Get to know the provider associations in your area and understand their current perceptions of health IT, privacy and security, and readiness to participate in electronic health information exchange. An environmental scan provides an opportunity to gauge how receptive providers will be to your message. The environmental scan will help you identify which provider group to target first and will allow you to refine your message content, determine your primary communication channel, and identify organizations that are ready and willing to help deploy the toolkit. Some providers or associations may prefer electronic communications, while others may be more likely to read a printed newsletter or a similar communication. Choosing the right communication channel can make a big difference in your program's effectiveness.

It is easiest to begin your environmental scan by identifying and contacting state and local chapters of professional organizations. Most organizations can be found through general Internet searches. When you contact organizations, it is important to get a better understanding of their priorities and those of the members they represent, such as the following:

- type of organization
- number of members
- members' privacy and security concerns
- members' use of health IT
- possible barriers to adoption of health IT
- educational resources and activities
- preferred communication channels
- referrals to other organizations
- contact information for early adopters and potential physician champions within the organization

Based on the outcomes of the environmental scan, the PET Collaborative selected primary care physicians as its target audience. The secondary audience was medical group management associations or other secondary decision makers within the primary care clinical practice setting. The preferred communication channels for all the groups were (1) e-mail/listserv, (2) newsletters, and (3) in–person conferences and meetings.

The PET Collaborative found that the most effective communication method for its target audience was peer-to-peer discussion in face-to-face settings using members of the provider community who have already gone through the process of "going electronic." Enlisting provider champions and keeping them actively engaged can boost your potential for success. The PET Collaborative validated its conclusions from conversations with associations and others with a target audience member expert. (For a detailed account of how the Collaborative conducted the environmental scan and the associations that were approached, refer to the PET Collaborative's final report.)

Once you have selected the materials you want to use and you have secured buy-in from your partner associations, enlist their help in disseminating the material to their members. Possible approaches include the following:

- Adapt e-mail blasts and use your partners' e-mail lists to introduce and draw attention to the website.
- Add a link to the national site on their websites.
- Have them print your newsletter, editorial article, or other earned media in their regular publications.
- Exhibit at upcoming conferences and events that they organize or support.

Additional detail about the PET website tools:

- The ***PET tagline*** "It's Safe. It's Secure. It's Time" is highly effective and reinforces the PET Collaborative's main message to the health care provider community. The secondary tagline "Get Connected" provides an actionable message: connect to information, connect to peers, and connect to networks for electronic health information exchange.
- The toolkit includes ***PowerPoint presentations*** for physician champions or subject matter experts to use at conferences, physician breakfast gatherings, and other professional meetings. These components facilitate logo recognition and provide peer-to-peer presentation support.
- The toolkit contains two ***Physician Champion Videos*** featuring Dr. David Kibbe, Senior Advisor, American Academy of Family Physicians, and Kentucky's Lt. Governor, Dr. Daniel Mongiardo, talking about the advantages of health IT and electronic health information exchange and encouraging fellow physicians to adopt EHRs. Two additional ***Leading Expert Videos*** were created featuring Dr. Mark Leavitt, Chair, Certification Commission for Healthcare Information Technology (CCHIT), and Dr. John Halamka, Chair, Healthcare Information Technology Standards Panel (HITSP), on the benefits of health IT and electronic health information exchange.
- The ***Dashboard Demo*** page walks website users through a simulated EHR to provide a sense of what an EHR looks like. This tool is specifically designed for health care providers who have limited experience with EHRs.
- The ***FAQs*** page addresses some of the questions providers have regarding health IT and electronic health information exchange. Twenty-six FAQs were videotaped by the physician champions. Answers to the top eight questions are provided in audiovisual form on the FAQ page at any given time.

RELEVANT RESOURCES

- Tagline and Logo
- Educational Conference Materials and PowerPoint Presentations
- EHR Dashboard Demo
- Physician Champion Videos
- Leading Expert Videos
- FAQs
- Media Materials
- Education Website
- CME Credits

- The *Media* page includes news releases, e-blasts (primarily used for announcing the launch of the pilot, but can be made generic and used by any state), an editorial column, a newsletter article, and journal articles outlining easy steps to security and privacy compliance, carried by national and local associations known to be content experts or respected conduits. Brochures and a generic PowerPoint presentation outlining the goals of the project have also been developed.
- The website also provides links to two *CME courses:*
  - HIPAA Basics: Privacy and Security Issues Self-Study Module
  - Electronic Health Records: Implementing a System in Your Practice

A majority of the material the PET Collaborative developed is available at http://www.secure4health.org and can be easily adapted to meet your organization's specific requirements. However, if you plan to create new educational materials or significantly customize the PET Collaborative's materials, consider getting help from a public relations firm. The PET Collaborative's state-level websites provide some excellent examples of how the participating states modified some of the national materials (logo, brochures, videos, etc.) and customized them for their specific audiences.

RELEVANT RESOURCES

- Material developed by the PET Collaborative is available at http://www.secure4health.org

Implementation Tips

The toolkit can be launched either through professional medical associations (as done by the PET Collaborative) or directly to individual provider communities and practices. The PET Collaborative chose to enlist the endorsement and support of professional associations for the following reasons:

- More credibility accrues to the message if it is being disseminated by a recognized professional health care organization.
- The associations will review and vet the materials and provide feedback on the approach of the dissemination effort, thus ensuring acceptability and success of the toolkit.
- Active stakeholder engagement from the outset ensures buy-in and sustainability of the project for years to come.
- Larger number of providers can be reached through these associations, whose memberships may run into thousands.

In-person, face-to-face communication was determined to be the best means to communicate with physicians. If you intend to disseminate the toolkit using the PET Collaborative's approach, keep the following lessons in mind:

- Form a steering committee or advisory group that represents a broad array of stakeholders in your community. The group can provide valuable insight and feedback from the provider perspective.
- To have the most impact, enlist support of local physicians who are dynamic and credible. Physicians want to hear from other physicians because they trust their peers.
- Keep the message "vendor neutral."
- Include extended staff such as office managers and IT staff.

- Contact partner associations frequently and convey your objectives clearly to ensure that they understand their roles and responsibilities. Some partners may be enthusiastic when first committing to participate and later realize they cannot follow through with their commitment due to Board concerns, other pressing activities, or lack of interest in promoting the message to their members.
- Build flexible, reasonable timelines using long-range planning tools. Unrealistic deadlines restrict choices and affect quality of work.
- Use tools such as project management software and matrices to stay on track and evaluate progress consistently.
- Talk to a target audience member first and discuss your ideas with an advisor from that group.
- Be aware of the content approval process if you intend to develop new content, and plan accordingly. This process can be time-intensive and involve several layers of approval.
- Understand that professional organizations have varying staff levels, and some may not have the capacity for the type of partnership you envision.
- Research partnering association agendas for the year and piggyback whenever possible on their conferences and meetings.
- Realize that working with multiple associations requires tact and political awareness.
- Allow sufficient time for testing the tools.

3 Harmonizing State Privacy Law Collaborative

PARTICIPANTS

- Florida
- Kansas
- Kentucky
- Michigan
- Missouri
- New Mexico
- Texas

ABOUT ...

The Harmonizing State Privacy Law (HSPL) Collaborative was formed to develop tools to assist state-level stakeholders identify, analyze, and propose solutions to reduce variation in state privacy laws. The HSPL Collaborative identified best practices for the categorization and evaluation of these types of state laws and designed its set of tools to enable states to better understand their privacy law landscape and potential challenges to interstate electronic health information exchange.

TOOLS DEVELOPED

The HSPL Collaborative developed the following tools:

- The Roadmap and Analytical Framework
- The Comparative Analysis Matrix (CAM)
- The Assessment Tool

Steps for Success

The tools that the HSPL Collaborative created can be easily used to conduct an analysis of state privacy law. To best use these tools, it is recommended that you follow the steps outlined below:

STEP 1: Convene stakeholders and experts.

STEP 2: Use the analytical framework and populate the Comparative Analysis Matrix (CAM).

STEP 3: Review the populated CAM for completeness.

STEP 4: Assess the benefits and feasibility of making legislative changes.

STEP 5: Engage stakeholders in the legislative process (optional).

Make it Happen

Convene Stakeholders and Experts

You should involve a large number of stakeholders as you identify and analyze state privacy law. Doing so will help you establish common goals across a number of disparate and sometimes contentious groups. It is also likely to increase your potential for success if stakeholders recommend a legislative change to reduce variation and facilitate the exchange of electronic health information. In this circumstance, you should engage resources and coordinate efforts with other initiatives within the state that are paving the way to promote electronic health information exchange. The process of convening stakeholders will be unique for each state and should include public and private entities, local and regional providers, payers, and advocacy groups, among others. The process of consensus building during the legal analysis can be straightforward and relatively short, or protracted.

Working through the process outlined by the HSPL Collaborative requires a lot of group work. Effective techniques for successful group work include developing a stated mission and vision to remind everyone of the agreed-upon goals, working to develop cooperation and trust, and providing strong leadership. It helps to realize that consensus among a critical mass is realistic, although unanimous support is unlikely. In the end, the legal analysis you perform will provide a basis for any potential legislative recommendations or potential alternatives and may also provide an educational resource for health care providers and other stakeholders.

Use the Analytical Framework and Comparative Analysis Matrix (CAM)

The Comparative Analysis Matrix (CAM), available in the Roadmap report, is a tool that provides a consistent and structured way to identify state laws governing the use or disclosure of health information. The CAM is a collection of almost 150 subject matter areas that are typically addressed by state law related to health information exchange (e.g., treatment disclosures, public health disclosures, payment-related disclosures). The subject matter areas serve as a "map" of the topics to consider when conducting the state law survey. The CAM also provides the organizational framework for grouping identified laws for comparison and analysis purposes. Key to populating the CAM is becoming familiar with its organizational structure and definitions. The definitions of patient-focused health care and population health are from the Office of the National Coordinator for Health Information Technology's *Coordinated Federal Health IT Strategic Plan: 2008–2012*.

RELEVANT RESOURCES

- The Roadmap and Analytical Framework
- The Comparative Analysis Matrix (CAM)

Review the Populated CAM for Completeness

Populating the CAM involves adding each applicable state law to the matrix, comparing it to HIPAA or other relevant federal or state laws, and identifying any gaps in the law. Certain subject matter categories may not have an applicable state law, which creates a potential gap.[1]

Once the CAM is relatively complete, it is time to consult with health law experts and other stakeholders and revise the content of the CAM, including the identification of gaps, as necessary. It is also important to agree on which laws are more stringent than HIPAA or other relevant federal laws, because these laws relate to patient-focused health care. Focus on questions or differences of opinion and bring these issues to resolution through additional research or clarification of the applicable law. This step is crucial, because differences may exist in the interpretation of some privacy laws among stakeholders in the group. Before you can develop solutions, it will be necessary to ensure that everyone is working from the same baseline.

For more detailed information and instructions on how to populate the CAM, please refer to the Roadmap.

Assess the Benefits and Feasibility of Making Legislative Changes

Once the CAM is complete, the Assessment Tool can be used to assess the costs, benefits, and feasibility of making legislative changes. The Assessment Tool can assist stakeholders to identify and reach consensus on priority recommendations that may include legislative and nonlegislative solutions. The Assessment Tool may be used exactly as contained in the Roadmap or it may be modified as agreed by stakeholders. Modification could include adding, deleting, or revising the review or assessment criteria; changes to the scoring process; or other changes the group views as beneficial in encouraging participation and reaching a consensus. Two alternate formats of the Assessment Tool are provided:

- ***Multi-Score Format:*** This format focuses on the scoring factors that relate to the feasibility and significance of making a change in the law.
- ***Single-Score Format:*** This format focuses on discussion of the relative importance of the criteria. This format may encourage greater participation in the process, because stakeholders are not required to submit and, possibly later, defend multiple individual scores.

For specific instructions on how to use the Assessment Tool, please refer to the Roadmap.

RELEVANT RESOURCES

- The Assessment Tool

[1] As used by the HSPL Collaborative in this process, a gap is an area of the law that is silent or otherwise ambiguous with respect to health information exchange and that results in a barrier to the implementation or use of health information exchange within the state.

Engage Stakeholders in the Legislative Process (Optional)

If a priority recommendation is for legislative change, you will need to gain a solid understanding of how the legislature operates and how to reach out to supporters. Working through the legislative process is a long and sometimes difficult journey. It requires active participation and identification of strong partners. Having a dedicated group of advocates on your side will be an invaluable asset to achieving legislative reform.

Understand the legislative process in your state.

- Find out when the legislature is in session, its schedule, how each chamber is run, whether there are key legislative leaders whose support will be critical, and how a bill is drafted. You will need these essential pieces of information before you plan a trip to the state capitol.
- Review basic website information on deadlines for bill filing and significant legislative dates.
- Consider the roles of the governor, the governor's office, and state agencies, such as the department of health, in the legislative process.
- Communicate with the governor's office and determine what role, if any, the governor's office can take in facilitating successful adoption of the bill. If state agencies are responsible for implementation, they will likely take their lead from the governor's office.

Review key personnel in your legislature.

- You must know how bills are assigned to committees and which committees may hear your bill. Generally, health information technology (IT) bills go through health-related committees, but other committees may also review them.
- Research how bills are set to be heard in committee and before each chamber. The people who make those decisions must be informed and educated about your idea.

Identify potential sponsors for proposed legislative changes.

- Potential sponsors will include members of leadership, committee members, other members with a strong history of policy interest in health IT-related areas, and members whose districts will be most impacted should the bill pass, such as a member whose district contains a large hospital.
- Before you approach potential sponsors, learn more about the politics in your legislature.
- In some states, it may be appropriate to see members of leadership or the committee chair first, regardless of whether those individuals are likely to sponsor your bill.
- Those members also may have recommendations about potential sponsors who could help ease the bill's passage.
- Look for members who are active in state or national task forces on health IT, active participants in the National Conference of State Legislatures' health committee, and those involved in other similar organizations.

Inform and educate.

- Notify the leadership and each member of the committees that will hear the bill: educate them on what the bill does and how it will help health care in the state.
- Go to these meetings with the following information in hand: a one-page list of groups that support the bill (these endorsements should be gained through meetings

with the relevant professional associations and similar groups), a one-page memo with bullet points of the bill's key provisions, a one-page memo of talking points on the bill, and a sense of how much the bill may cost and who may oppose it.

- If you do not know the answer to a question, respond that you will research the issue and provide a response to staff in the member's office.
- Meet with employees of the state agencies likely to be involved in implementing the bill—generally health and human services agencies, health care licensing agencies, and information technology agencies.

For detailed background information, please refer to the Final Report.

To find out more about best practices the HSPL Collaborative identified, please see the Best Practices Report.

For specific information on the variation in state privacy laws, please refer to the 50-State Legislative Analysis.

RELEVANT RESOURCES

- Final Report
- Best Practices Report
- 50-State Legislative Analysis

Implementation Tips

State-specific reports, which can be found in Appendix A of the Final Report, provide informative guidance based on the experiences of individual states. Below are some helpful tips for using the HSPL Collaborative tools.

- The Assessment Tool is not designed for individual self-administration. It requires a carefully designed process involving preparatory meetings or communications to the group, facilitated discussion, and opportunities to follow up about specific issues or concerns. Stakeholders using the tool should have the opportunity to discuss their views of key concepts. More than one meeting is probably necessary to work through the process.
- Having a Legal Working Group (LWG) meet face to face proved to be a critical part of the process and also led to a more effective process.
- To assemble a shared legislative agenda, a leadership group must build communication, relationships, and trust. Members of this group may represent various constituencies, each with its own agenda. It takes time for the individuals involved to recognize that while they may vary on some issues, a set of goals will be developed that they can champion collectively.
- An educational process is needed for legislation that impacts or creates barriers to electronic health information exchange or EHRs.

In addition, the following elements are critical to state-specific legal assessments:

- Include a range of stakeholders whose interests might be affected by legislative changes and include participants experienced in the legislative process. Legal expertise is required to populate the CAM and review the group's analysis for completeness.
- Strive to maintain a core objective. A facilitator may be necessary to maintain neutrality and independence during group considerations of the CAM and Assessment Tool. Develop a mission and vision that all state stakeholders can share. Strive for consensus rather than unanimity and take small steps initially to build trust.
- Be prepared to identify and address knowledge gaps and review and assess progress periodically.

4 Intrastate and Interstate Consent Policy Options Collaborative

PARTICIPANTS

- California
- Illinois
- North Carolina
- Ohio

ABOUT ...

The Intrastate and Interstate Consent Policy Options Collaborative was formed to examine two policy issues related to consent. One part of the Collaborative's work focused on the development of tools and resources that states and health care stakeholders could use to determine what level of choice is appropriate for individuals regarding the electronic access, use, and disclosure of their health information. To accomplish this objective, the Collaborative examined a variety of consent policy alternatives ("No Consent," "Opt Out," "Opt In," and two alternatives offering more granularity of choice, "Opt In with Restrictions" and "Opt Out with Exceptions"). The other part of the Collaborative's work included an examination of the utility of select legal mechanisms (Uniform Law, Choice of Law, Interstate Compact, and Model Act) that states might be able to leverage to facilitate interstate electronic health information exchange. The Collaborative also developed tools and resources that states can use to evaluate which, if any, of the mechanisms they could successfully employ.

TOOLS DEVELOPED

The Collaborative developed the following tools:

- Guide to the Development and Use of *Intrastate* Consent Policy Alternatives Analysis Templates, which includes the following templates:
  - Summary of Pertinent Facts Template
  - Executive Summary of Pertinent Facts Template
  - Developing Consent Policy Stakeholder Issues for Analysis Template
  - Alternative Solution Analysis Template
  - Comparative Summary Analysis (CSA) Template
  - Summary CSA Specific to a Health Care Scenario Template
  - Health Care Scenario Steps Template
  - Comparative Summary Analysis Modified Template
  - Summary of Laws Template
  - Public Mental Health Template
  - Summary of Pros and Cons Template
  - Summary of Findings Template
  - Issue Recommendation Template
- *Interstate* Guidebook, which includes the following templates:
  - Interstate Compact Analysis Template
  - Choice of Law Analysis Template
  - Uniform Law Analysis Template
  - Model Act Analysis Template

Steps for Success

Most of the tools created by the Intrastate and Interstate Consent Policy Options Collaborative can be easily modified and adapted to meet your specific requirements. To make the best use of these tools, we recommend that you follow the steps outlined below:

Intrastate Analysis

The intrastate analysis process can be divided into three major steps:

STEP 1: Do your homework.

STEP 2: Conduct the analysis.

STEP 3: Draft the summary and recommendations.

Interstate Analysis

The interstate analysis process can be divided into six major steps:

STEP 1: Establish a legal review work group to conduct research and analysis.

STEP 2: Reach consensus on the legal mechanisms to be reviewed.

STEP 3: Develop a research agenda, definitions, and assumptions, as well as expectations regarding the review criteria, in consultation with the steering or governing committee and the legal review work group.

STEP 4: Analyze each legal mechanism against the review criteria. If developed by a subgroup, submit the analysis to the entire work group for input, questions, and comments, as well as guidance in the preparation of the conclusion of each of the selected mechanisms.

STEP 5: Compile all comments from the analysis of each mechanism into a single template to eliminate redundancies and to leave a unique set of considerations for each legal mechanism.

STEP 6: Present the reviews to the steering committee or other oversight group for approval, if applicable.

Make it Happen

Intrastate Analysis Process and Templates

The Guide to the Development and Use of Intrastate Consent Policy Alternatives Analysis Templates describes the process of engaging stakeholders in a structured analysis of the level of choice individuals should have with respect to the access, acquisition, disclosure, or use of their health information in an electronic health information exchange environment. The process and templates can assist your organization in pursuing a deliberative and objective analysis of the complex issues surrounding consent.

RELEVANT RESOURCES

- Guide to the Development and Use of Intrastate Consent Policy Alternatives Analysis Templates

THE FIVE CONSENT POLICY ALTERNATIVES

- No Consent: Patient's records are automatically placed into the HIE system, regardless of patient preferences. Assumes that all records of participating entities will be available to the system.
- Opt Out: Patient's records are automatically placed into the HIE system, and exchange is allowed for sharing medical information without prior permission provided by the patient. The patient's information remains available for electronic exchange until the patient chooses to opt out of participation in the HIE and revokes permissions.
- Opt In: Patient's records are placed into the HIE system after the patient provides permission. Exchange of medical information is not allowed without prior permission provided by the patient. Assumes fewer records will be available to the system.
- Opt In with Restrictions (granularity of choice): Patient's prescription records are not automatically placed into the HIE system, and exchange is not allowed for sharing medical information without prior permission provided by the patient. Restrictions on which health information may be disclosed, the purpose for the disclosure, or specified health information to be disclosed are allowed under this option.
- Opt Out with Exceptions (granularity of choice): Patient's records are automatically placed into the HIE system, and exchange is allowed for sharing medical information without prior permission provided by the patient. The patient's information remains available for electronic exchange until the patient chooses to opt out of participation in the HIE and revokes permission. Patients also have the right to specify that information be removed from the electronic exchange.

To initiate an analysis of consent alternatives, it is important to develop an understanding of the origins of current policies and stakeholder positions. Your organization could convene a panel of stakeholders that accurately reflects the various views of your community, including consumers, providers, vendors, payers, and health information exchange organizations. This stakeholder panel could then decide which consent alternatives are appropriate to analyze given your local policies.

Conducting a literature review is another important preparatory component. When conducting the literature review, consider applicable federal and state laws, as well as various stakeholder practices regarding the use and disclosure of personal health information (PHI). The two templates described below will allow a subset of your core team to quickly summarize the pertinent facts and information from available literature. After completion, these templates will help participant stakeholders gain a common understanding of the issues surrounding consumer consent.

- ***Summary of Pertinent Facts Template:*** Use this template to create and provide a summary of key information from a single source.
- ***Executive Summary of Pertinent Facts Template:*** Use this template to collect and disseminate a compilation of summaries of pertinent facts on a single topic.

Once you have summarized your findings in these templates and shared them with participating stakeholders, you can solicit input on which issues they find important in order to further refine the direction of your analysis.

To begin your analysis, frame its scope and identify specific issues by completing the Consent Policy Stakeholder Issues for Analysis template. When determining your scope, consider the time and resources available for the effort. Consent is a complex issue, and stakeholders will likely have a broad range of interests and apply them differently to each consent alternative. If you have limited resources, you can use the document to narrow your scope and analysis. Answering the following questions will help provide the basis for selecting the appropriate templates to use or adapt:

- Will you discuss consent alternatives in general or narrow the focus by using specific health care scenarios?
- Will you analyze the five alternatives to consent studied by the Intrastate and Interstate Consent Policy Options Collaborative, or will you explore other alternatives?
- Will you build off the analyses of other states and use their findings to start your state discussion on consent?

At this point, detailed analysis work begins. To guide, document, and analyze stakeholder input for each individual consent alternative under consideration, the Collaborative developed an Alternative Solution Analysis template and found that a majority of stakeholder discussion, time, and effort was focused here. The template captures the pros and cons of *one alternative* in a specific health care scenario. This completed template can be quite lengthy, depending on the size and diversity of your stakeholder group. You may want to capture all major perspectives shared, then go back and edit to remove redundancy and align comments.

Your strategy and the depth and breadth of your planned analysis will help you determine which of these templates fits best. The Comparative Summary Analysis (CSA), Summary CSA Specific to a Health Care Scenario, Health Care Scenario Steps, and Summary Law templates can be used for a more detailed analysis, but are time and labor intensive. The Modified Comparative Summary Analysis template can be used when resources are limited; it includes fewer stakeholder issues or interests but supports covering more health care scenarios.

- ***Comparative Summary Analysis (CSA) Template:*** This template was developed to manage the quantity of information captured by completing the Alternative Solution Analysis templates. It can be used to effectively combine and compare all stakeholder input, including commentary regarding the positive, negative, or neutral impact of each consent alternative on each stakeholder issue or interest for the identified health care scenario. Strive to eliminate redundant or similar statements.
- ***Summary CSA Specific to a Health Care Scenario Template:*** This template is simply a portion of a CSA and includes the top part of the form, the summary row, and the definitions. It can be used as a one-page handout or as an overview to your board or committee. It too was developed to help manage the quantity of information that is compiled as the work progresses.
- ***Health Care Scenario Steps Template:*** This template provides a way to cross-check the analysis in your CSA template. Instead of examining consent alternatives by specific issues, this template leads stakeholders through an analysis of the steps in a health care scenario. This template permits an analysis of how each consent alternative measures up to the original identified health care scenario's electronic health information exchange goal.

- ***Comparative Summary Analysis Modified Template:*** This template is a modified version of the CSA template. It is formatted the same way but contains fewer specific issues or identified interests. Use of this modified version will allow for the analysis of multiple health care scenarios when stakeholder resources and time are limited.
- ***Summary of Laws Template:*** This template arranges the state's applicable laws by steps in the scenario. Federal and state laws are identified and summarized by each step in the scenario, with the citation provided for reference. The obligations column identifies the legal obligations of the parties involved in each specific step of the scenario.

Once you have completed, reviewed, discussed, and documented your analysis, you are ready to move to the final step of formulating a summary of the analysis and recommendations. Use the following templates to compare analyses between health care scenarios and to formulate recommendations.

- ***Summary of Pros and Cons Template:*** This template can be used to compile and report the pros and cons identified in your comparative summary analysis. Pros and cons are listed by consent alternative for each specified issue, across all health care scenarios.
- ***Summary of Findings:*** This template can be used to report the overall summary of findings from your comparative summary analysis. Although structured similarly to the Summary of Pros and Cons template, this template uses a narrative form to summarize each specified issue by consent alternative across all health care scenarios.
- ***Issue Recommendation Template:*** This template can help you develop recommendations to present to an advisory board or steering committee. The template provides for the inclusion of a recommended consent alternative, support for the finding, recommended implementation strategies, and any dissenting opinions.

The Guide to the Development and Use of Intrastate Consent Policy Alternatives Analysis Templates provides additional detail about each of the above steps and includes all templates used by the Collaborative.

Interstate Analysis Process and Templates

The Interstate Guidebook offers a structured analysis regarding the viability of four legal mechanisms that can be used to resolve policy variations that impede interstate electronic health information exchange. The guidebook includes information about the analysis process and four analysis templates (one for each legal mechanism). The templates include a series of review criteria that require an analysis of state law, combined with the identification of the pros and cons for pursuing a specific legal mechanism.

Each state participating in the Collaborative established a legal review work group to conduct the research and analysis. Your work group should include members representing as many stakeholders of the health care delivery system as possible and should include both the public and private sectors. The group will first need to reach consensus on the legal mechanisms that the state will review. The Collaborative identified four possible legal mechanisms; however, your group may identify others. The templates are scalable to any number of alternatives, and the review criteria used for the evaluation should not change.

Your steering committee, legal review work group, and any other team members should work together to develop a research agenda and timeline.

After selecting the legal mechanisms that might align with your state and neighboring states with conflicting laws, first review the "definitions" and "assumptions" sections to agree on a consistent approach to the analyses. Next, agree on the expectations involving the review criteria. It is critical that the group agree on the expectations it has for the outcomes of the review process. Once you have consensus on the expectations, decide on the analysis process.

The Interstate Guidebook describes the review criteria considered by the Collaborative when it analyzed the four mechanisms. Examine the 15 criteria closely, as they provide the foundation for a comprehensive and consistent evaluation and make up the core of the analysis process. You may also wish to revise or add to them to meet the needs of your state. Following are three examples of criteria developed by the Collaborative:

- ***Implementation Requirements:*** Identify the balance between pros and cons for the steps required to implement each mechanism. Completing this section will require a thorough understanding of the existing legislative, political, and legal policy infrastructures, as well as the resources needed to implement each mechanism.
- ***Liability:*** Does the option address liability concerns? Liability issues may be a significant obstacle to interstate agreement on a standard approach to consent. Determine how issues of liability for inappropriate disclosure have been resolved in your state. Identify the merits of each mechanism in resolving liability concerns.
- ***Enforcement:*** How difficult will it be to enforce each proposed mechanism if enacted, and which state agency or organization will assume enforcement responsibilities? How would the implementation of each proposed mechanism alter the current approach to enforcement?

RELEVANT RESOURCES

- The Interstate Guidebook

THE FOUR LEGAL MECHANISMS

- Uniform Law: A legislative proposal approved by the National Conference of Commissioners on Uniform State Laws (NCCUSL) proposed to state legislatures by NCCUSL for adoption, usually in its entirety, to uniformly govern a matter of interest to adopting states. Offers states the option of enacting the same law governing consent, to supersede conflicting laws between adopting states.
- Choice of Law: A provision states can adopt to specify which state's law governs consent when PHI is exchanged between states with conflicting laws.
- Interstate Compact: A voluntary agreement between states that is designed to address their common problems. Usually used to address issues such as conservation, education, water rights, and penal matters. An interstate compact addressing consent to interstate exchange of PHI would supersede conflicting laws between states that join the compact.
- Model Act: A legislative initiative proposed by NCCUSL, an advocacy group, or a trade group for adoption by state legislatures on a matter of interest to all states. Different from a uniform law in that it may or may not be adopted in its entirety. Frequently modified to meet states' needs or adopted in part.

When conducting the analysis of each legal mechanism against the review criteria, weigh the pros and cons of the mechanism, identify any implementation considerations that arise, and document these for the comparative summary analysis. As you complete your analysis, compile the comments into a single analysis template and eliminate redundancies. This approach will yield a unique set of comments for each legal mechanism. Lastly, present the reviews to the steering committee or other oversight group for approval, if applicable.

Implementation Tips

- When using the Alternative Solution Analysis template, encourage participants to strive for objectivity and to complete the form by capturing all identified pros and cons for each consent alternative in relation to the identified stakeholder issues or interests. The template is intended to capture and document all predictable stakeholder polarities that will arise, such as consumer privacy interests versus provider access interests. To avoid long debates over the meaning of terms, ensure that all definitions in the template are clear and understood by all stakeholders before starting the analysis.
- Allow plenty of time for the process. Developing a research and analysis process and templates is challenging and time consuming; several rounds of review and revision will be required.
- Be flexible in terms of the process and templates in order to address the state's specific collaborative processes. For instance, in addition to completing the analysis using the assumption that the *disclosing state* has more stringent consent laws for the release of PHI than the *requesting state*, you may want to complete the analyses using the reverse assumption.
- Create a diverse group of stakeholders. Diverse stakeholder representation is critical to conducting this type of analysis. The diversity will provide a thorough and lively discussion.
- Realize that reaching a consensus is not always possible. However, it is important to provide a process for stakeholders to record dissenting opinions. We recommend that these opinions be submitted in writing.
- Maintain a set schedule of meetings. Meetings can be held via web conference, but in-person meetings can be especially helpful when discussing the analyses. Try to meet in person as often as time and funding allow.

5 Interstate Disclosure and Patient Consent Requirements Collaborative

PARTICIPANTS

- Indiana
- Maine
- Massachusetts
- Minnesota
- New Hampshire
- New York
- Oklahoma
- Rhode Island
- Utah
- Vermont
- Wisconsin

ABOUT ...

The Interstate Disclosure and Patient Consent Requirements Collaborative was formed to document variation in state law as it relates to the consent requirements for, and disclosure of, health information for treatment purposes (emergent and nonemergent) and public health within and across state lines. The current variation that exists in how consent and disclosure requirements are managed has made it difficult for organizations to determine—in the context of interstate electronic health information exchange—when appropriate disclosure requirements have been met at both the requesting and the disclosing organizations. The Collaborative captured detailed information about consent and disclosure requirements from the 11 participating states to better understand this difficulty and to identify solutions for resolving it, where possible.

TOOLS DEVELOPED

The Collaborative developed the following tools to study and analyze state patient consent and disclosure requirements:

- Information Collection Templates
- Project Director's Guide
- Final Report (Analysis and Recommendations)

Steps for Success

STEP 1: Understand each template's scope.

STEP 2: Refer to the Project Director's Guide.

STEP 3: Read the Final Report and compare your results.

Make it Happen

Understand Each Template's Scope to Select Appropriate Templates and Areas of Focus

The information collection templates are designed to collect state law and health information organization (HIO) policy requirements for the consent and disclosure of health information. They include qualitative, open-ended questions, as well as a structured, quantitative matrix of multiple choice answers. The templates are organized around three scenarios: disclosing information for treatment in emergent and nonemergent situations and disclosing public health information for treatment purposes. The template for each scenario includes detailed instructions, definitions, assumptions, and exclusions.

First, determine if a template is appropriate for use in part or whole. Completing all three templates in full will provide a comprehensive view of the laws related to consent and disclosure. However, using selected portions of the template may also be useful and effective for specific inquiries. The templates provide a structured approach to capturing consent and disclosure requirements for exchanging data in precisely defined circumstances.

The templates are organized with the types of protected health information (PHI) along the vertical axis and sources of PHI across the horizontal axis. To guide the process of selecting templates and focus areas, all of the types and sources of information considered in each of the three templates can be found in the Collaborative's Final Report.

Select a Focus Area (Example)

For the emergent and nonemergent treatment scenarios, there are a total of 187 PHI type/data source combinations (17 PHI types × 11 sources = 187 combinations). However, an organization may prefer to examine a subset of PHI type/data source combinations, such as the disclosure of all types of HIV information by a hospital. In addition to considering a subset of PHI types and sources, these combinations could also be compared across the scenarios. That is, you can look at whether differences exist in consent and disclosure requirements for HIV information in an emergent treatment situation, a nonemergent treatment situation, or when a public health agency is disclosing the PHI. Once you have determined which templates and types and sources of PHI are appropriate, develop a process for completing the templates, and begin filling them out.

RELEVANT RESOURCES

- Information Collection Templates

RELEVANT RESOURCES

- Final Report

Refer to the Project Director's Guide to Select the Best Process for Completing Templates

The Project Director's Guide serves as a supplement to the directions provided in the information collection templates and offers additional instructions to the leader of your research effort. The information included may also be useful to those who fill out the template (e.g., legal counsel). The guide also summarizes the steps for completing each template and offers a short description of each worksheet that can be used for reference. Finally, the guide describes the following four preliminary steps that should be completed before you begin completing a template:

1. Determine a process for using the templates (facilitated session or individual respondent). Either process will work well for collecting data. In both instances, the project director should be available to offer guidance and instruction. Factors such as the schedule and availability of respondents and the need for consensus will drive the selection of response mode. For example, if a number of individuals must agree on the interpretation of a certain state law, a facilitated group session may be essential. However, if the document is intended to serve as a reference for planning or policy making, you may prefer to use the individual respondent mode.

2. Identify individuals who will participate in the process. Regardless of the response mode, legal experience and familiarity with state privacy law will greatly expedite the process. The 11 states from the Collaborative discovered while completing the templates that legal citations were located in a wide variety of statutes including
   - general medical records statutes;
   - health care confidentiality statutes;
   - individual data type statutes, such as those for HIV (which may be different from STD, and/or communicable diseases), mental health, substance abuse treatment, genetic tests, and so forth;
   - professional licensing statutes (e.g., pharmacists, physicians, or, more specifically, mental health providers, which may or may not include psychologists);
   - facility licensing statutes (e.g., lab, hospital, inpatient mental health facility, substance abuse treatment facility; public and private); and
   - HIE/HIO specific statutes.

   In addition, if an organization uses the scenario that addressed data held by a public health agency, someone may need to consult staff at the agency. Disclosure of information held by the public health agency either can be a matter of policy or can be defined under state law.

3. Prepare a quality control plan for data entry. Because the spreadsheets are large, this could involve having two individuals key in responses or randomly selecting cells and confirming the responses. Regardless of the method chosen, a data quality control plan should be in place to check and review responses.

4. Develop a process for resolving differences in interpretation. Because the responses can be subject to interpretation, the leader should be prepared to manage disparate responses and determine procedures for resolving discrepancies in advance.

RELEVANT RESOURCES

- Project Director's Guide

Complete the Template and Analyze the Information

The templates include detailed instructions, definitions, and assumptions. As noted previously, the project director will likely need to be involved to explain the process and answer any questions that respondents may have. The logic model for data collection that the Collaborative used for the three scenarios is provided in the Collaborative's Final Report.

You may analyze the data in several different ways once they are compiled. Analysis could include frequency tables showing the number of yes/no/sometimes/unclear responses per scenario or a more qualitative discussion of the open-ended questions. If two or more organizations undertake the project jointly, data can be compared across any of the dimensions included in the template. See "Read the Final Report and Compare Your Results" section below for additional information about how the Collaborative analyzed and presented its data.

RELEVANT RESOURCES

- Templates Final Report

Read the Final Report and Compare Your Results

The Collaborative Final Report details the Collaborative's data analysis and offers recommendations for potential next steps to reconcile consent and disclosure requirements across state lines. The Final Report also offers insight into the level of complexity in consent and disclosure requirements across states. The analysis presented in the report can help individuals determine where their state or organization falls on the spectrum and identify priority areas for action.

RELEVANT RESOURCES

- Final Report

- ***Review your results in the context of the information compiled by the Collaborative.*** As the Final Report indicates, some states have very restrictive requirements, while others have far fewer requirements. Thus, achieving common policy solutions will require either finding a way to accommodate the spectrum of local preferences or identifying common points of convergence to which states can agree.
- ***Convey your results and information to others.*** Graphic representations can be a powerful way to convey information to stakeholders. The graphics found in the Final Report represent two different ways that the Collaborative displayed its information. The graphical displays developed by the Collaborative made it clear that consent is far less likely to be required in an emergency situation. In addition, the degree of restrictiveness in an emergent versus a nonemergent situation is not necessarily correlated. For example, Minnesota requires consent or other disclosure requirements in an overwhelming majority of nonemergent treatment situations. However, in an emergency situation, consent or other disclosure requirements are not at all in play. Understanding how these factors can vary based on a given situation can help organizations understand their own state policy environment and requirements to exchange health information with organizations in other states. Empirical evidence can also be used to develop solutions that will support interstate electronic health information exchange.
- ***Evaluate solutions.*** The options presented in the final report outline potential solutions that could be explored to reconcile state disclosure and consent laws and articulate potential next steps. Options are organized based on whether they are driven by a nationwide approach, a state-based approach, or a current-day approach, meaning the options assume variations in state law and attempt to address and manage them. The options offer starting points from which to plan, design, and implement feasible and practical approaches to protecting health information in an electronic health information exchange environment.

Implementation Tips

You may consider several key points when using the templates and Final Report:

- The templates inherently limit the scope of data collection by precisely defining scenarios and sources and types of PHI. In these instances, the defined options for responding could artificially conceal some of the complexity that exists in practice.
- Variation in interpretation of state laws is inevitable. When you present findings, you should acknowledge this limitation.
- As written, the templates do not request supporting information for "no" answers. If you are sharing the results with a wide audience, you may want to gather this information to justify a "no" response.
- Respondents must be knowledgeable about the full range of statutes that might be relevant when completing the templates. Relevant laws can be found in many different statutes. Consulting a range of statutes, including general medical records, and facility and practitioner licensing statutes will improve the reliability of the data.
- A caveat from this work is that the solutions presented in the Final Report cannot always be implemented at the organizational or state level—in some instances they will require nationwide cooperation to achieve results.

6 Interorganizational Agreements Collaborative

PARTICIPANTS

- Alaska
- Guam
- Iowa
- New Jersey
- North Carolina
- South Dakota

ABOUT ...

The Interorganizational Agreements (IOA) Collaborative was formed to develop model data sharing agreements (DSAs) and to provide participating states, related governmental departments, and health care providers with tools to facilitate electronic health information exchange between states. The IOA Collaborative focused its model DSA work on the development of consistent privacy and security provisions and other core data sharing provisions.

TOOLS DEVELOPED

The IOA Collaborative developed the following tools:

- Model Data Sharing Agreement, Public Health
- Model Data Sharing Agreement, Public Health (American Immunization Registry Association [AIRA] endorsed version)
- Model Data Sharing Agreement, Private Entity
- Public Health Implementation User Guide
- Private Entity Implementation User Guide
- Master Document of Grouped Contract Provisions
- Core Privacy and Security Provisions

Steps for Success

The following steps serve as a guide to implementing the IOA Collaborative's model DSAs:

STEP 1: Review the IOA Collaborative's DSAs and corresponding Implementation User Guide.

STEP 2: Review the Master Document of Grouped Contract Provisions and Core Privacy and Security Provisions.

STEP 3: Plan your approach to the review and approval process.

Make it Happen

Review the IOA Collaborative's DSAs and Corresponding Implementation User Guide

The IOA Collaborative created its model DSAs to reduce the time involved in developing agreements and to jump-start the processes for engaging in electronic health information exchange. To ensure an effective start to the process, first review these materials to determine if one of the IOA Collaborative's DSAs meets your objectives for electronic health information exchange.

The IOA Collaborative initially drafted two model DSAs, one for electronic health information exchange between private health care providers, such as hospitals, clinics, and physician offices, and one for electronic health information exchange in the public health context. The model public health DSA was designed for the electronic exchange of public health records, such as birth records, death records, biosurveillance data, food-borne illness, lead paint, and hearing data. After presenting the model public health DSA to AIRA, the IOA Collaborative modified its original DSA to accommodate cross-state immunization registry exchange and gained AIRA's endorsement. This change resulted in a third model DSA.

The DSAs are legal contracts that cover the purpose and scope of the agreement, use of and access to information, participant requirements, privacy and security safeguards, termination of the agreement, warranties and limitations of liability, compliance with laws and regulations, insurance, notices, governing law, and other areas. The IOA Collaborative developed Implementation User Guides to outline the use and execution of both the public health and the private entity DSAs. Both guides present the background, rationale, and other considerations related to the use of the IOA Collaborative's DSAs. These guides provide a common understanding of the DSAs for organizations and entities to reference at any point during their review and approval process.

RELEVANT RESOURCES

- Model Data Sharing Agreement, Public Health
- Model Data Sharing Agreement, Public Health (AIRA-endorsed version)
- Model Data Sharing Agreement, Private Entity
- Public Health Implementation User Guide
- Private Entity Implementation User Guide

Review the Master Document of Grouped Contract Provisions and Core Privacy and Security Provisions

As you become familiar with the purpose of each DSA and its corresponding Implementation User Guide, it should become clear which agreement is right for your situation. Consider any unique factors that exist among the specific organizations interested in executing the agreement. Additional or alternative provisions may be needed beyond those included in the current DSAs.

The Master Document of Grouped Contract Provisions is a compilation of documents and tools used by the IOA Collaborative to draft its model DSAs. It contains a list of documents included in the IOA Library of Data Sharing Agreements, an abbreviated classification scheme used to classify provisions from applicable documents in the IOA Library, and a section-by-section categorization of the provisions reviewed by the IOA Collaborative in the process of selecting the core provisions for the model agreements. The Master Document of Grouped Contract Provisions provides alternatives to the provisions contained in the model DSAs that may be more appropriate given the needs and objectives of your exchange initiative.

The Core Privacy and Security Provisions document provides additional provisions, if deemed necessary for your purposes. This document also includes alternative language that can be used to modify the language used by the IOA Collaborative in the existing model agreements.

RELEVANT RESOURCES

- Master Document of Grouped Contract Provisions
- Core Privacy and Security Provisions

Plan Your Approach to the Review and Approval Process

Use of the IOA Collaborative's DSAs should significantly speed up your process for engaging in electronic health information exchange. However, unique conditions may exist relative to your local environment, and you should expect to tailor the agreement to meet your stakeholders' needs. It is essential to plan the appropriate approach for each organization or entity to review the DSA and to obtain approval and required signatures.

The success achieved by the IOA Collaborative provides valuable insights in getting organizations to sign the agreements. Success factors include the following:

- Identify and invite key stakeholders to the process as early as possible (agencies, providers, vendors, etc.).
- Select a point person to manage and walk others through the process (both the agreement signing and the technical completion of data exchange).
- Determine the scope and objectives of the exchange.
- Encourage transparency.
- Obtain approvals for project implementation from senior management, the state commissioner of health, or the organization's board of directors, and sign the agreements.
- Include and inform senior management, legal representatives, and technical representatives throughout the project.

In preparation for the execution of a DSA, make sure that the appropriate representatives from each participating organization have reviewed the provisions and provided feedback on whether any of the provisions will have a negative impact on your ability to conduct electronic health information exchange. To that end, make sure you have considered the following:

- Identify technical and program contacts for each participating entity from the start of the project.
- Coordinate closely with technical experts as the provisions are translated into the "specifications" used to create and transmit the data files. Be prepared and plan accordingly for the time needed for the respective technical teams to communicate.
- Consider error checking as a vital component from the onset. The parties should select the most appropriate method.
- Select values and guidelines that will create consistency in the file exchange (i.e., CDC HL7 specifications for data formats).
- Formalize requirements and technical definitions documents before beginning technical or programming aspects of projects.
- Establish a sign-off procedure or similar method to ensure that data transmissions are reconciled, as appropriate.

For more information on the process and documents used by the IOA Collaborative to develop their model DSAs, see the HISPC Phase III IOA Collaborative Final Report.

Implementation Tips

- Review the IOA Collaborative's model DSA and its respective Implementation User Guide with legal, medical, technical, and administrative representatives.
- Use the IOA Collaborative's DSAs as model legal documents that can be modified as necessary through attachments to the core document to meet a specific organization's legal, medical, or business needs.
- Consider the IOA model DSAs for new electronic health information exchange projects when no agreement exists or when existing agreements need to be updated.
- Set the stage ahead of time. Participants in the IOA Collaborative's public health pilot reported that the preparatory work completed by state departments of health well in advance of the data exchange had a significant effect on the timeliness of getting the document approved. Otherwise, issues related to lean departmental staffing in public health agencies and other priorities within the department of health can delay the process significantly.
- Initially, keep the scope of the data exchange small. Test it, validate it, and then expand the scope after the system for exchange is vetted.

7 Adoption of Standard Policies Collaborative

PARTICIPANTS

- Arizona
- Colorado
- Connecticut
- Maryland
- Nebraska
- Ohio
- Oklahoma
- Utah
- Virginia
- Washington

ABOUT ...

The Adoption of Standard Policies (ASP) Collaborative was formed to create an approach and process to identify and reconcile the variation in how organizational security policies are implemented across different electronic health information exchange models. To reduce the variation in approaches found, the ASP Collaborative created minimum, uniform policies related to authentication and audit.

TOOLS DEVELOPED

The ASP Collaborative developed the following tools:

- "How To" Guide to Adoption of Uniform Security Policy (Adoption Guide)
  - Adoption Process
  - Feasibility Checklist (Appendix A of the Adoption Guide)
  - Uniform Security Policy (Appendix B of the Adoption Guide)
- Final Report: an in-depth look at the process used to develop and vet the uniform security policies

Steps for Success

STEP 1: Review the "How To" Adoption Guide.

STEP 2: Assess the feasibility of adopting the ASP Collaborative's Uniform Security Policy.

STEP 3: Adopt the Uniform Security Policy.

Make it Happen

Review the "How To" Adoption Guide

RELEVANT RESOURCES

- Adoption Guide

To gain a better understanding of how to leverage the work of the ASP Collaborative and seek consensus on minimum policy requirements that facilitate electronic health information exchange, it is best to first review the introductory section of the Adoption Guide. This section outlines the process and framework used by the ASP Collaborative to define and harmonize minimum policy requirements related to authentication and audit.

The purpose of the Adoption Guide, and the main objective of the ASP Collaborative, is to provide organizations with a set of uniform security policies and a well-defined process for adopting them. The section of the Adoption Guide entitled "The Adoption Process" constitutes the main body of the guide and describes seven steps for adopting the policies. Following these steps will help your organization gain stakeholder consensus and help you adapt the security policies, where necessary, to meet the unique needs of your organization.

Appendix A of the Adoption Guide, entitled "Feasibility: Preparing for Change and Process Checklist," is a useful tool if your organization is interested in assessing the feasibility of adopting the Uniform Security Policy. Appendix B of the Adoption Guide contains the Uniform Security Policy, which provides the specific minimum policy requirements for authentication and audit created by the ASP Collaborative.

Assess Feasibility

RELEVANT RESOURCES

- Adoption Guide, Appendices A and B

Section 1 of Appendix A, entitled "Preparing for Change," provides a guide to assessing the feasibility of adopting the Uniform Security Policy. This section includes a series of questions along with a bulleted list of issues to be considered. ASP's framework in Section 1 of Appendix A is taken from E. Rogers' work on diffusion of innovative practices and will help your organization respond to both internal pressures and external influences.[2]

Section 2 of Appendix A, entitled "Checklist," is a summary of steps described in the Adoption Guide. You should use this checklist to track your progress in adopting the Uniform Security Policy, checking off steps as they are completed and noting areas where you will need additional assistance or confirmation.

[2] Rogers, E. (2003). *Diffusion of Innovations*. New York: Free Press.

Adopt the Uniform Security Policy

The Collaborative developed a seven-step process that your organization can follow to adopt the Uniform Security Policy. These steps are described in more detail below:

1. ***Goal and scope:*** Define your scope and establish a set of clear and realistic goals.
2. ***Resources:*** Review what resources your organization will need to undertake this process, such as time and materials, human energy, and activity.
3. ***Desktop review and risk analysis:*** Perform a desktop review of your organization's authentication and audit business processes.
4. ***Consensus building:*** Work to build consensus among your project team, members, and stakeholders with respect to the adoption process.
5. ***Legal assessment:*** Assess which laws should be reviewed and taken into consideration.
6. ***Documentation of policy:*** Document the policy as your organization goes through the adoption process.
7. ***Implementation—testing, training, deployment, and production (including evaluation and maintenance):*** Test your system with respect to the policy; decide how you would train end users on the policy, how your organization should deploy the new policy to end users, and how you would produce post-implementation review, modification, and support.

RELEVANT RESOURCES

- Uniform Security Policy can be found in Appendix B of the Adoption Guide

Implementation Tips

- Keep in mind as you are using the Adoption Guide that policies cannot be static if they are to address the changing landscape of electronic health information exchange. Formulation of policies that conform to current standards also must address the need to evolve with changes across the industry.
- The Adoption Guide incorporates lessons learned by the ASP Collaborative about the consensus adoption of security policies. As you refer to the Adoption Guide, keep in mind that the following elements were critical to the Collaborative's success in developing policy requirements:
  - The Collaborative used a common glossary of terms and definitions to ensure that all team members had a similar understanding of key terms.
  - Each participating state maintained a baseline of existing policies that accurately represented its practices and procedures for reference during negotiation.
- Current common practices and the current level of technological development may fall short of the ideal for effective, reasonably priced, and secure electronic health information exchange. The Collaborative participants consciously established policies to support the present reality while recognizing that those policies must be continually reviewed and updated as electronic health information exchange processes evolve.
- The Collaborative developed the Uniform Security Policy as a best practice solution tool, recognizing that when organizations exchange data, there is a minimum acceptable policy for organizations whose size, available resources, and complexity vary widely.

RELEVANT RESOURCES

- The glossary can be found in Appendix D of the Adoption Guide

- Throughout the process, the Collaborative participants performed outreach to stakeholders responsible for policy implementation. This practice will be instrumental in helping you achieve your goal of adopting policies.
- The Uniform Security Policy is not meant to be used as a standalone document. You should use it in conjunction with the Adoption Guide to properly utilize both tools. As your organization determines what authentication and audit requirements are necessary for electronic health information exchange, make sure to refer to the minimum requirements identified by the Collaborative in the Uniform Security Policy. The Uniform Security Policy describes the authentication and audit requirements that all 10 states in the Collaborative agreed were necessary, as well as what requirements the Collaborative thought were out of scope for the work being done.