HISPC and Privacy Survey

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The Consumer Education & Engagement Collaborative
HISPC

Harmonizing State Privacy Law

Intrastate and Interstate Consent Policy Options

Interstate Disclosure and Patient Consent Requirements

Consumer Education and Engagement

Provider Education Toolkit

Adoption of Standard Policies

Inter Organizational Agreements

State Law Analysis

Health Information Security & Privacy

Collaboration
The Health Information Security & Privacy Collaboration (HISPC)

Consumer Education & Engagement Collaborative

WASHINGTON
OREGON
COLORADO
KANSAS
NEW YORK
MASSACHUSETTS
WEST VIRGINIA
GEORGIA
Philosophy of the Collaborative

The use and sharing of protected health information is largely based on consumer trust and understanding.

Goal: We sought to improve trust and understanding

How? By increasing awareness and understanding of privacy and security challenges, requirements, and patient rights

Strategy? Multi-modal educational approaches, targeted audiences, and literacy and language considerations
We Learned:

- The need for, and use of, targeted audiences
- The importance of literacy control
- To avoid re-inventing the wheel using:
  - Templates
  - Strategies
  - Guidelines
- The importance of collaborative/multi-state views
- The importance of iterative looping
  - Content
  - Legal and literacy expertise
  - Consumer testing and feedback
- The importance of central or easily-available repository for resources/tools
The Consumer Education & Engagement Collaborative

The Challenge: Leveraging Diversity

TARGET POPULATIONS:
- RURAL/URBAN
- ETHNIC
- CHRONIC CARE CONDITIONS

GOALS

RESOURCES

PLACE IN HEALTH INFORMATION

TECHNOLOGY EVOLUTION

LEGAL REQUIREMENTS

STRATEGIES

PHILOSOPHIES

TARGET POPULATIONS:
- RURAL/URBAN
- ETHNIC
- CHRONIC CARE CONDITIONS
Collaborative Structure

Major Focus on:

- Libraries/Inventories/Glossaries
- Developing Policy
- Targeted Populations: Chronic care, Rural/Urban, Behavioral health, Ethnic groups
- Website creation & design
- Communication & Outreach via media
- Video
Libraries
Inventories
Glossaries
Inventory Matrix

• **Purpose:**
  – Aggregate consumer materials from various sources into one place so that interested organizations and individuals have a quick look-up resource

• **Goals:**
  – Reduce the amount of time organizations need to look up information
  – Reduce incidences of “re-creating the wheel”
## Tips for State Adaptation and Examples - Washington

<table>
<thead>
<tr>
<th>Brief Description of Resource</th>
<th>Key Word(s)</th>
<th>Targeted Audience</th>
<th>Resource Creator</th>
<th>Description of Resource Creator</th>
<th>Subject area</th>
<th>Media Type</th>
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</thead>
<tbody>
<tr>
<td>Provides an overview of HIT</td>
<td>HIT, health plan</td>
<td>consumers, health plan members, providers, health plans</td>
<td>Aetna</td>
<td>Aetna is a health care benefits company serving members with information and resources to help them make better informed decisions about their health care.</td>
<td>HIT</td>
<td>Website</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Website Link</th>
<th>Last Updated</th>
<th>Tools found in the resource</th>
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<tbody>
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<td><a href="http://www.aetna.com/about/aotl/aetna_perspective/health_information_technology.html">http://www.aetna.com/about/aotl/aetna_perspective/health_information_technology.html</a></td>
<td>2008</td>
<td>consumer health care tools, survey results, brief paragraphs on: FAQs, background and why HIT is necessary</td>
</tr>
</tbody>
</table>
Glossary

• The glossary was developed as a reference document for consumers needing to know the definition of health IT and HIE-related privacy and security terms.

• The glossary can be used in a variety of ways – embedded in other documents, used on web portals, used as a stand-alone document.
Website Creation & Design
Consumer Toolkit Materials Online

From this general toolkit, consumers can access an external state consumer health website with HISPC materials re-formatted for consumers.

http://www2.kumc.edu/healthinformatics/HISPC/Toolkit.htm

http://ehealth.kansashealthonline.org/

- 7,370 Page views and 1,751 visits to ehealthwv.org
- Media releases, educational tools for both providers and consumers
- Targeted rural population, seniors, and chronic disease
Tips for State Adaptation and Examples – Georgia and Kansas

Introduces Electronic Health Information to health care consumers

Re-formatted WV brochure for KS consumers
Communication & Outreach via Media
Fact
Sheets/Brochures/Posters

• Washington:
  – Posters/Brochures for Health Record Banking model

• Colorado
  – Language & Literacy in Fact Sheets

• West Virginia
  – Content developed through partnership with WVHIN
  – Tested with collaborative, consumers and literacy expert
  – Posters/Brochures used by physician champions

• Georgia
  – Pharmacy Bag Insert for provider champions
  – HTML Email for consumers

• New York
  – Posters/Brochure/Radio PSAs
Tips for State Adaptation and Examples

- Washington:
  - Posters/Brochures for Health Record Banking model
Tips for State Adaptation and Examples

- Colorado
  - Language & Literacy in Fact Sheets
Tips for State Adaptation and Examples

- Provider Guidelines for Engaging Consumers in Electronic Health Records and Health Information Exchange: What Your Patients Need to Know
  - Outlines main points for physicians to keep in mind when discussing topic with patients

- Electronic Health Records: What You Need to Know
  - Takes the physician guidelines and transfers them into language and graphics that can be directly provided to patients.

- Both can be used:
  - Copied and pasted into physician educational materials
  - Used as a discussion guide
  - Presented in their entirety, in graphic form
Tips for State Adaptation and Examples

**HTML Email**

Introduces consumers to security and privacy of Electronic Health Information and directs them to georgiahealthinfo.gov for additional information.
Tips for State Adaptation and Examples

• Messages based on two themes:
  – Emergency
  – Convenience

• Both can be used:
  – As print ads
  – Posters
  – Radio messages
  – For consumers and providers
NY Brochure - Better Information Means Better Care

**ABOUT YOUR PRIVACY**

Many people are worried about privacy and security when it comes to eHealth. Information can never be completely secure. This is true whether it’s on paper or in a computer. But New York State is doing everything it can to make eHealth private and secure:

- Federal and state laws strictly protect the privacy and confidentiality of health information about you. New York State is requiring eHealth networks and everyone who uses them to follow the same rules to protect the privacy and security of records shared through this system.
- Only the people (such as doctors, nurses, and their staff) who are involved in your health care are allowed to access your health records using eHealth, and only if you sign a consent form. Others, such as employers and immigration agencies, won’t have access to your information.
- Safeguards like passwords and other protections keep your records from being accessed without proper permission.
- You can request a list of everyone who has accessed your records using eHealth.
- If improper access does occur, you will be told, and New York State will make sure steps are taken to correct the problem so it won’t happen again.

**Q: Can I get access to my own medical records through eHealth?**

**A:** By law you already have the right to get a copy of your medical records from the healthcare organizations that made them. Some doctors, hospitals, and other healthcare organizations in New York can give you access to your medical records online or on a computer, not just on paper — but not all of them have that capability today. New York State is working to make it possible for everyone to get access to their medical records through eHealth networks.

In addition, many public and private organizations are developing eHealth tools that you may be able to use to keep and share your health information on a computer.

**Q: Where can I get more information about eHealth in New York?**

**A:**
- www.ehealth4ny.org
  - A web site developed for the public by the Legal Action Center
  - www.health.state.ny.us/technology
  - The New York State Department of Health’s Office of Health Information Technology Transformation
  - www.nyhealth.org
  - The New York eHealth Collaborative
  - Or call 877-690-2211

www.ehealth4ny.org

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*State of New York
  Department of Health*
FAQs

• FAQs are part of “just-in-time’ training.

• When consumers need information fast, a first step is to see if their question has already been asked.

• FAQs were chosen by the Collaborative participants after a ranking process.
Benefits & Risks

• Inventory as baseline information
• Most common questions and concerns
• Replicable & scalable based on local needs
Tips to Protect Your Privacy

• Intended to cultivate and increase consumer confidence
• Modeled on information already being used by HHS
• Easily replicable and adapted to individual state campaigns

What Information Is Protected?
- Information your doctors, nurses, and other health care providers put in your medical record.
- Conversations your doctor has about your care or treatment with nurses and others.
- Information about you in your health insurer’s computer system.
- Billing information about you at your clinic.
- Most other health information about you held by those who provide your health care.

What Should I Do if My Rights Are Denied or I Don’t Believe My Health Information Is Being Protected Properly?
- Contact a privacy officer. Every health care provider and health plan covered by the federal health privacy law must appoint someone on their staff as a privacy officer. If you experience a problem related to the privacy of your medical records or access to them, you might want to contact this individual in an effort to resolve the problem.
- File a federal complaint. You may also choose to file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights, the federal agency charged with enforcing the federal health privacy law. This office has the authority to impose civil and criminal penalties if they find a violation of the law. Your complaint must be filed within 180 days of the incident. You can also go directly to http://www.hhs.gov/ocr/privacy/index.html.
- Seek state-level recourse. There are officials in your state who may be willing to help you address violations of the...
Town Hall Meetings/Forums

- **Massachusetts**
  - Used documentary to begin discussion of risks/benefits

- **Oregon**
  - Used documentary to establish baseline of knowledge for informed discussion on privacy concerns

- **Georgia**
  - Facilitated sessions on the security and privacy of Electronic Health Information

- **West Virginia**
  - Consumers interested in learning about privacy and security in “plain language”
  - Trusted their physician (the most) to give them the facts about EHRs/HIE
Video
Tips for State Adaptation and Examples

Massachusetts focus on Behavioral Health and Sensitive Information

“Balancing Risks & Benefits: the Sharing of Sensitive Health Information”

• Conversations with national and local experts in health IT, mental health, consumer advocacy, and privacy law

• Two themes:
  – Knowledge leading to good analysis and assessment of personal risk/benefit
  – Trusting healthcare providers and asking questions

• Strategy: Begin with the concept of electronic health information and work down to the specifics of what consumers should know and how they can begin to learn it.
Targeted Populations:
Chronic care, Rural/Urban,
Behavioral health, Ethnic groups
Additional Resources and Lessons from the States: Tailoring to Specific Needs/Populations

- Massachusetts
  - Developed a set of resources that focus on *behavioral and sensitive health information*
- Colorado
  - Latino Population
  - Chronic Care Population
- Kansas
  - Rural and Frontier Population
- New York
  - eHealth Brochure and Consent form translated into 14 languages to meet diverse population needs
- WV
  - Rural, seniors and chronic disease
MASSACHUSETTS: Focus on Sensitive Health Information Populations

We learned:

A Multi-modal approach is important—people have different learning styles. To name a few...logical, auditory, kinesthetic and visual learners...

Literacy control is key—people can’t learn what they don’t understand! Language translation alone doesn’t ensure understanding.
MASSACHUSETTS: A multi-modal approach to learning about sensitive health information

- Self-directed electronic tutorial
- Frequently asked questions (FAQs)
- Legal rights of MA consumers with behavioral health/sensitive information health issues
- Documentary: “Balancing the Risks and Benefits: the Sharing of Sensitive Health Information”
- PHR Inventory and companion Consumer Guide for PHR Choice

NOTE: All literacy-controlled
Understanding Sensitive Health Information Sharing

Click to learn more…

Overview of Sensitive Health Information

Mental Health

Genetic Tests

HIV-AIDS

About the HISPC project
What is legally sensitive health information?

- Most people consider their personal health information to be private. Several laws exist to protect this privacy.

- “Sensitive” information is medical information that is protected by law. These laws were passed to help people to seek testing and treatment without fear of discrimination.
How is sensitive information protected?

The main way your sensitive information is protected is with a process called **informed consent**

- You always have the right to be provided with certain information (about what is going to be done and why) before health care services are rendered.

- Your consent may be needed each time your health information is sent from a health care provider at one office to a provider at another office.
What is consent?

“Consent” means permission. In health care, this is permission that is given by either you or an authorized person to use your health information.

Federal or state law may decide several details of the consent process.

Your doctor’s office or hospital may have other consent policies in addition to what is required by law.
You just moved and found new doctors closer to your new home. Before your move, you had seen a psychiatrist. You went for monthly check-ups and to get your prescription medicines. You would like your new psychiatrist to have a copy of your old records. You sign a “release of information” form at your old psychiatrist’s office, giving permission to send your medical record to your new doctor.
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Test your understanding
FAQs

• Questions compiled by the HISPC Staff
• Ranked by Behavioral Health Forum and the HISPC Workgroup
• Selection of high-ranked questions to be answered
• Literacy and legal review
• Refinement of answers
A sample of questions...

• What are the risks and the benefits if I consent to having my sensitive information shared electronically with other providers for treatment? In other words, what can go wrong and what can be better when I allow my sensitive information to be shared?
• Can my employer see my sensitive information?
• Does my health plan/insurer “have” my sensitive information? If yes, how do they protect my privacy? Are Medicaid claims handled differently?
• Can a child’s sensitive information be seen by family members, the health insurance coverage policy holder, parents?
• …and 21 others
Legal Inventory & Consumer Information Sheets

- Type of Information Covered by Statute
- Brief Summary of the Statute
- Legal Citation
- Entities or Persons Regulated by the Statute
- What Disclosures are Expressly Permitted and For What Purposes
- Who is identified as a Permitted Recipient of the Information and for What Purpose or Purposes
- Is the patient’s express permission required for the release of information?
- Are there restrictions in the statute on to whom the information may be disclosed?
- Are there other restrictions stated on the release of information?
- If the patient’s express permission is required, what is the term used to describe that permission?
- Must the patient’s express permission be in writing?
- If there is an express permission requirement, are their exceptions?
- If yes, does the statute require the recipient to obtain permission to disclose to others for the listed purposes (or otherwise)?
- Does the statute expressly address the electronic exchange of health information?
Documentary:
The Sharing of Sensitive Health Information

Themes: Balancing the Risks & Benefits;
The Importance of the “trusted relationship”

Participants:
• Lisa Fenichel MPH, eHealth Consumer Advocate, HCFA
• John Halamka MD, CIO Caregroup, ER physician
• Mark Hauser MD, Psychiatrist & Treasurer, MA Psychiatric Society
• Jerilyn Heinold MPH, Director, HISPC Multi-state Consumer Education & Consumer Engagement Collaborative
• Steven Locke MD, Psychiatrist
• David Szabo JD, Partner, Nutter, McClennen & Fish LLP
The decision to purchase a PHR

1. PRODUCT OFFERINGS
   Such as device, data entry, data collected, and services delineated in B.1. above

2. CRITICAL INFORMATION
   Such as privacy & security safeguards, handling of sensitive information, ease of use, demo availability, and company mission/affiliation

3. CONSUMER NEEDS
   Such as mobile information, emergency situations, care & disease management, and others

4. Decision to Purchase
PHR Project Findings

- Company Affiliation
- Product Description
- Media Used
- Data Origin & Input
- Audience
- Privacy & Security
- Secondary Uses
- Cost
PHR Project Consumer Guidelines & Recommendations

• Ease of keeping info up-to-date
• Automatic updating from other sources
• Accessibility and security
• Privacy
• Portability
• Cost
Colorado

• We learned:
  – Similarities
    • Providers need to share health information electronically
    • Consumers would like to have electronic access to their information
    • Very concerned about employers & insurers misusing information
  – Differences
    • Latino community concerned about cost to consumer
A few key lessons from New York

• An inclusive process takes time
• No one deliverable can fit all needs: need different kinds of media & customizable templates
• Direct consumer testing is essential
• It’s hard to find a balance on extent of detail (and it varies by medium)
• There are limits on lowering literacy levels—especially for a patient consent form to exchange electronic health information
Guide to Common Projects: Translating for Literacy

• The two golden rules of communicating in plain language are:
  – Know your audience—who are you writing for? Take into consideration age, gender, ethnic background, education, etc.
  – Identify your main message and key points—and stick to them!

• Writing in Plain Language—20 Quick Tips
We want you to know...

• The general public assumes we share information & that there will be a breach.
• They are OK with this, but want to know we are doing our best to protect them.
• Different conversations with different audiences require different tools & processes.
• Templates only take you so far, but they are a great start!
• Literacy and Language matter.
Privacy Survey

• 35 questions on healthcare consumer issues including:
  – the use of online information,
  – sensitivity for sharing healthcare information (including mental health),
  – attitudes towards sharing information with a variety of entities,
  – understanding of benefits and concerns regarding HIE,
  – familiarity with/interest in PHRs and other online services.

• Approximately 1000 people (aged 18 or older) participated in the survey.

• Participants were distributed geographically (US) and by age. Other demographics included income, employment status, education, urban/rural, ethnicity and access to the internet.
Resources

• [www.stoneandheinold.com](http://www.stoneandheinold.com) has the most updated MA HISPC project tools and reports as well as some of the consumer materials from other states.

• [http://healthit.hhs.gov/HISPC](http://healthit.hhs.gov/HISPC) for access to other collaborative products