

HISPC Multi-State Consumer Education & Engagement Collaboration: Massachusetts Projects

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Consumer Education & Engagement: Statement of the Problem

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

We sought to improve trust.

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

MASSACHUSETTS

Massachusetts developed a set of resources that focus on behavioral and sensitive health information. A multi-modal approach was used including a self-directed tutorial, FAQs, legal inventory, video and a PHR inventory and consumer choice guide. These tools were literacy controlled and reviewed by MA legal experts.

The Massachusetts Projects: Sensitive Information

- Web based self-directed tutorial
- FAQs
- Legal Inventory & Consumer/Provider Information Sheets
- Video Documentary
- PHR Inventory and Consumer Guidelines

Self-directed tutorial about Sensitive Information

- “Just-in-time” learning for understanding the laws and your rights
- Definitions
- Frequently asked questions
- Questions to ask your healthcare providers
- Self-tests

Understanding Sensitive Health Information Sharing

Click to learn more...

[Overview of Sensitive Health Information](#)

[Mental Health](#)

[Genetic Tests](#)

[HIV-AIDS](#)

[About the HISPC project](#)



Understanding Sensitive Health Information Sharing

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.



Understanding Sensitive Health Information Sharing

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.



Understanding Sensitive Health Information Sharing

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.



Understanding Sensitive Health Information Sharing

What is consent?—*Example*



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.



[Test your understanding](#)



Understanding Sensitive Health Information Sharing

What is consent?—Answer



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 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, that gives your permission to send your medical record to your new doctor.



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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 there 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 Collaboration
- **Steven Locke MD**, Psychiatrist
- **David Szabo JD**, Partner, Nutter, McClennen & Fish LLP

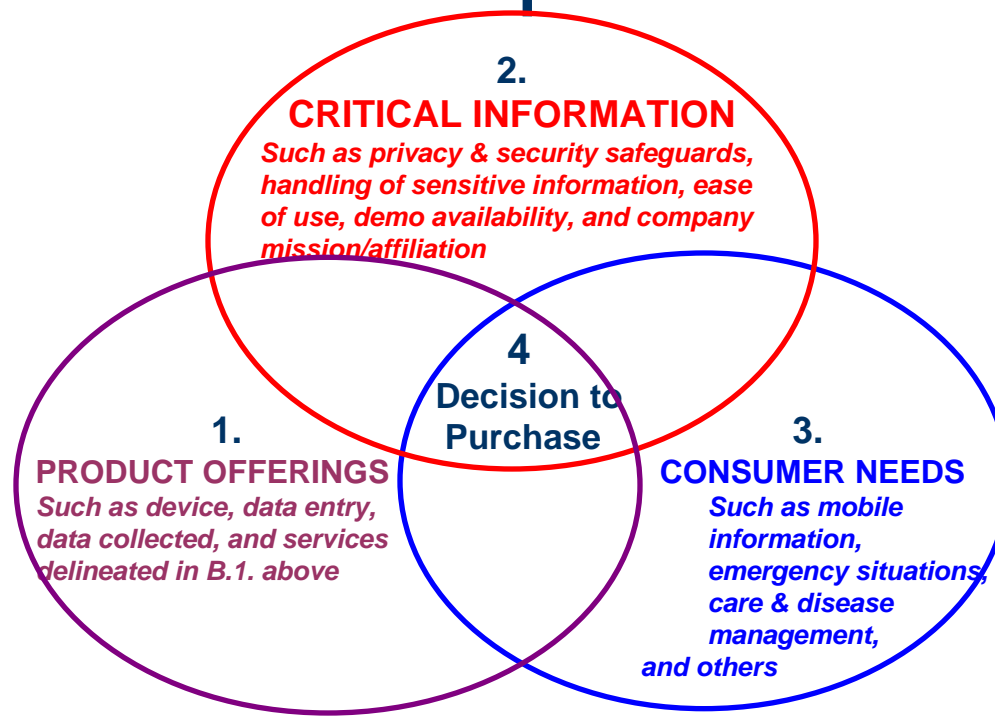


SHOW VIDEO



PHR Inventory, Analysis & Consumer Guidelines

The decision to purchase a PHR



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 information up-to-date
- Automatic updating from other sources
- Accessibility and security
- Privacy
- Portability
- Cost

Last Thoughts...

Need to capitalize on these projects and collaborative work by:

- Dissemination
- Spotlight
- Use
- Refinement
- Re-distribution

Resources:

- <http://privacysecurity.rti.org/>
- <http://www.ahrq.gov/>
- <http://www.myphr.com>
- Heinold J, Allen L, Stone D: EHRs, PHRs, and ePrescribing: How Do the Pieces Fit Together? Patient Safety & Quality Healthcare, July/Aug 2007.

For more information about the MA HISPC projects:

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