

E-hibitions: What Iowa Consumers Think about Electronic HIE



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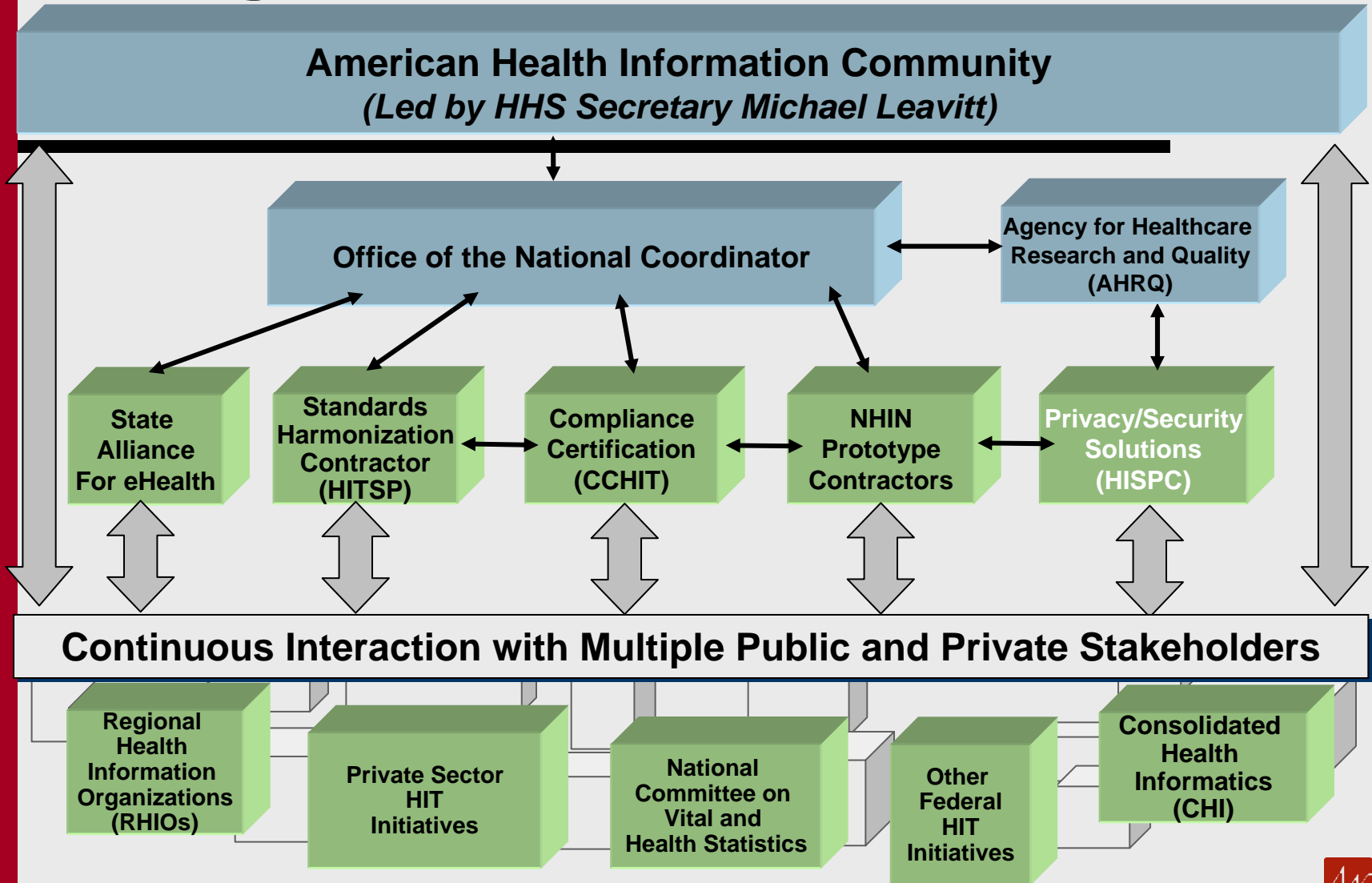
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Outline

- Background
- Focus Group Snippet
- Research Design
- Key Findings
- Using the Findings
- Closing



Background: The National Context



Background: Iowa HISPC

- Iowa one of 34 states
- Led by Iowa Foundation for Medical Care (Iowa's Medicare QIO) as designated by the Governor's office
- Original timeframe: June 2006 – April 2007
- Goal: address privacy and security issues associated with eHIE



Background: Iowa HISPC

- Special emphasis on consumers up front
- Five consumer focus groups
- Purpose: assess awareness and perceptions of privacy and security issues related to eHIE



Research Design

- Three focus groups in urban locations
- Two focus groups in rural locations
- Used professional research/marketing firm
- 50 total participants included mix of:
 - Gender
 - Age (21+ years of age)
 - Healthcare utilization
 - Heavy healthcare users/3+ times in the past 12 months
 - Light healthcare users/1 time in the past 12 months
 - Randomly recruited



Focus Group Snippet

Assuming technology cooperates 😊



Key Findings: General Health IT

- Growing use of technology is apparent
 - Electronic health records
 - Automated visit reminders
 - Computers to record information during visits
 - Electronic prescriptions direct to pharmacy
 - Computerized tests (x-rays, stress tests, etc.)



Sample Quotes

- “It seems like they’re [doctors] not paying attention to you as much because they’re trying to figure out the computer instead.”
- “With all the technology they have, why is it that they are so slow in getting information to the patient or the family doctor?”
- “Why should we have to go through the same rigmarole when you come to the same desk every time? We’ve got all this technology, why don’t they use the computer and pull it [patient information] up?”
- “We guard the information so terribly; we don’t share the information with some of the people who really need to know.”



Key Findings: Paper Files

- Concerns with paper files:
 - Take up lots of storage space
 - Natural disasters
 - Loss/theft of paper files
 - Improper filing
 - Security
 - “How safe is the information in a paper file with a copy machine in every doctor’s office?”
 - “The janitor can look at my records... there is no security.”



Key Findings: Electronic Files

- Positives:
 - Better care (e.g. know all the meds the patient is on)
 - Quicker access to records
 - Save time filling out paperwork over and over
 - Lower costs



Sample Quotes

- “If we can get doctors to communicate with each other through the computer, it’s a win-win for all of us.”
- “You can get a better result out of it [computer files] if you don’t get all of your prescriptions from one facility, somebody has the ability to say ‘we have something on here that is not going to work with these other five things you are taking.’”
- “... the electronic file could save your life someday...if you had an accident or something and were in a strange place, they could get the records so much faster than...pulling out a file or faxing.”
- “I’m more confident in the electronic transfer of information than I am of...some girl in the file department pulling part of my file to send to Dr. XYZ and making sure she gets the right information to the right fax number.”



Key Findings: Electronic Files

- Concerns:
 - Privacy and security
 - Back-up for crashes
 - Accuracy/data entry errors
 - Costs
 - System compatibility



Key Findings: Privacy/security

- Privacy/security concerns:
 - Who has access
 - Data accuracy to ensure security
 - e.g., incorrect patient ID leading to medical mistakes
 - Who oversees the system
 - e.g. government vs. private
 - Lack of time for staff training on security features
 - Lack of consequences for breaches



Sample Quotes

- “If someone gets my SSN, can they access my files?”
- “There are only so many things in our lives we can’t keep private, we can be extra guarded about our finances and our health.”
- “Do we know who is accessing it?”
- “To me, this is just an opportunity to use my information.”



Key Findings: Privacy/Security

- In terms of who has access, consumers are especially concerned about:
 - Employers
 - Insurance companies
 - Telemarketers
 - Government
 - Schools



Sample Quotes

- “If it’s some type of mental condition or depression, they could keep from hiring you.”
- “I wouldn’t want to be denied insurance because of the possibility of a genetic disease in my family.”
- “If there was something serious that would keep me from getting a job or keep me from getting insurance, I wouldn’t want that to be common knowledge for somebody to find out.”



Key Findings: Summary

Consumers see the benefits of eHIE but want reassurance about privacy and security.

- Biggest concern: who can access their records
- Many “e-hibitions” are due to the unknown, not actual experience
- Most would trade some privacy for access
 - “I’m willing to trade-off the privacy part of it...if I was 500 miles away and had an accident, it would be nice for someone to access my information back in Des Moines.”
- Rural vs. urban: rural had more general HIE concerns
- Most skeptical: those who have experienced privacy/security breaches or are more private by nature



Key Findings: Summary

What would help with buy-in?

- Seeing and knowing what's in my electronic records
- Authorizing who can have access
- Ability to opt-in/opt-out
- Assurances that technology is robust (e.g., comparable to banking industry)
- Assurances of staff training on privacy/security
- Demonstration pilots for HIE
- Knowing other countries experiences
- Public/private partnerships to oversee (e.g., not just government)
- Seeing penalties enforced for breaches



Using the Findings

- ✓ Create messages that address these concerns
- ✓ Determine best way to communicate
- ✓ Stress value of HIE in terms of health care quality
- ✓ Offer opt-in/opt-out
- ✓ Conduct demonstration pilots
- ✓ Engage consumer groups in eHIE efforts
- ✓ Cite successful examples of private/secure eHIE
- ✓ Use banking/finance in examples
- ✓ Recognize current system is not 100% secure
- ✓ Encourage stricter rules around negligence/breaches



Using the Findings

- ✓ Communication tool kit – Iowa HISPC project
- ✓ HISPC Collaborative: Communication
- ✓ Other state's examples: Louisiana, Indiana
- ✓ Lots of consumer work to pull from:
 - Markle Foundation (www.markle.org)
 - California Health Care Foundation (CHCF.org)
 - Dr. Alan Westin studies



Closing

Improving patient care is the focus, not HIT.

HIT and electronic HIE are tools to help.

Consumer buy-in and participation in eHIE is vital!

Note: a full copy of the IA Consumer Focus Group report can be obtained from the Iowa Foundation for Medical Care (email: sbrown@ifmc.org)

