



West Virginia HISPC Update

WVHIN Board Meeting

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Background

- **Original project:** assessed barriers to implementation of a health information network and proposed solutions.
- **Goal with extension (HISPC 2):** Further understand the general public's knowledge and attitudes related privacy and security issues to EHR and HIE.
- **End result:** Develop a comprehensive, consistent communications plan, a messaging platform and educational materials in conjunction with the WWHIN Board and set the stage for HISPC 3.



Approach

- Conduct a series of focus groups designed to help understand West Virginia consumers' knowledge and attitudes related to HIE and EHR- (WVHIN Sponsored)
- Commission a random-sample telephone survey- (WVHIN Sponsored)
- Work with the Consumer/Employer Committee of the WVHIN to gain insights and ideas into the privacy and security issues with the network
- Establish a speakers' bureau and set up a series of presentations to a variety of consumer groups throughout West Virginia.
 - Provide basic education and, most importantly, hear valuable comments during the question and answer sessions



Approach (cont.)

- Use information from all sources to develop:
 - Long range communications plan
 - Consumer toolkit (for distribution through physician's offices)
 - Media opportunities to raise awareness



Approach (cont.)

- Make materials widely available for the benefit of all states
 - Place on our Web sites (www.wvmi.org)
 - Share with other states
 - Consistent messaging for sustainability and for implementation



Progress/ Findings to Date

- Focus groups
- Phone survey
- Consumer presentations



Focus Groups

- Held in five distinct areas of the state
- Variety of audiences (seniors, professionals, mix)
- August 27 – September 17



Top Line Findings

- People in WV are open to EHR & HIE
- See it as inevitable
- People see it as more convenient (particularly e-prescribing)
- People in VA system love their EHR
- Participants understood HIPAA
- The more people were told the better they felt and privacy and security issues



Top Line Findings

- Concern about hacking
- Concern about who is in charge of data
 - Do not want insurance companies in charge
 - Some big brother concerns in S. W.Va.
 - Computer crashes
 - They want control of who has access



Other Items

- People want to be educated on EHR in plain language
- Katrina factor
 - Records available after disaster
- ER access to records
- A good number of people suggest non-profit or government entity to control data



Phone Survey

- 500 person survey
 - Validate focus group
 - Test message
 - Quantitative as opposed to qualitative
 - Detect demographic differences
 - Determine computer usage and understanding
 - Concern about EHRs



Top Line Numbers

- 41% of West Virginians are very satisfied with their own medical insurance.
- 51% are very satisfied with the quality of their own care.
- 61% are very confident in their own doctor.
- Just 34% believe their own personal medical records are very secure.
- 59% would be at least somewhat interested in having access to their own medical records.
- 29% would be interested in a system that would provide secure access through the internet.



Top Line Numbers (cont.)

On Health Information Exchange:

- 66% support (27% oppose) electronic medical records, also called Health Information Exchange.
- 70% support (25% oppose) e-prescribing.
- Overall, the best reasons in favor of electronic medical records are:
 - Paper records can be lost or destroyed, but electronic records can be backed up and securely stored in several locations
 - Electronic medical records will be available instantly in electronic format, so someone gets the right care in the event of an emergency.



Top Line Numbers (cont.)

- 61% say they would be at least somewhat likely to use secure, password-protected online access to look at their medical records.
- West Virginians are very concerned about security of electronic records, and worry most about identity theft, possible discrimination by employers, and that their information might be shared without their consent.
- **Doctors and hospitals are most trusted to run such a system. Insurance companies and private, for-profit companies are trusted least**



Research Uses

- Research will allow us to develop the message points to use in outreach
- Can be used to convince policy makers on deployment
- Provide insight on how to position EHR and HIE with the WVHIN
- Detect differences with national feelings



WV Consumer Meetings

- Concurrent to the focus groups and survey, WVMI has established a speakers' bureau and set up a series of presentations to a variety of consumer groups throughout West Virginia.
- WVMI's presentations include an overview of electronic health records and exchange and elicit in-depth discussion.
- Completed 21.



Consumer Presentation

- Pros and cons of using computers to store your medical records
- Importance to you:
 - Affects your health care, your privacy and security
 - Know what's coming in health care



Key Findings from Consumer Group

- At least two or three people in every group said their doctor uses an electronic health record
- Almost someone in every group was familiar with the Veterans Health Administration's electronic health record system or with another system that uses EHRs
- While positive overall, all the groups were concerned about records being lost due to a computer crash.
- Some people in every group expressed concern that computer hackers would break into their medical records and steal their identity or that their health care information would be made public on the Internet.



Key Findings, (cont.)

- Participants said they liked:
 - the convenience e-prescribing would offer
 - having their medical records available if they had to go to the emergency room
- Some participants had questions about how e-health would affect billing and insurance.
- Some participants in two groups were dissatisfied with the way their doctors notified them of their test results.



HISPC 2 Deliverables

- Development of “key messages” for consumers
- Development of a long range communications plan
- Development of educational materials for physicians/consumers--including brochures, posters, Web template
- Coordination with the Consumer/Employer Privacy Committee to develop and “shape” the privacy and security issues for the WV Network



Next Steps: HISPC 3

- Two Dimensional Project:
 - 1. Implement and expand on accomplishments of HISPC 2 in WV:**
 - Interface with physicians, trade groups, other stakeholders
 - Educate the public through a variety of channels, including television announcements, media and the launch of a Web site
 - Continue to work with Consumer/Employer Privacy Committee
 - Measure our impact



HISPC 3 (cont.)

- **2. Participate in multi-state educational collaborative with 7 states (CO, KS, MA, NY, OR, WA, GA)**
 - Create inventory of existing consumer education/engagement resources
 - Develop summary documents on risks and benefits of HIE and the privacy and security of HIE
 - Develop a glossary/definition of common terms
 - Create 2 summary guides targeted to consumers on HIPAA and how to protect PHI
 - **Create guidelines on how to engage consumers**
 - Translate all materials into various languages and/or different literacy levels
 - Develop template to educate consumers about consent process



HISPC 3 (cont.)

- ONC has approved our proposal and also has asked us to look at how we would approach future projects (HISPC 4)
- Contract negotiations need to be worked out with ONC and RTI and we should have a contract “soon” to begin HISPC 3