

Consumer Empowerment & Privacy: What Do Healthcare Consumers Really Know & Want? Healthcare Consumers Understanding of EHR and HIE

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Overview

- A review of consumer literature of the past 10 years
- Overview of focus group design and methods
- Key findings
- Conclusions and Recommendations

Current state of the literature

- In general, previous surveys have found:
 - Majority of respondents are unaware of the general concepts around EHR
 - Very few respondents track their personal health information online/electronically
 - Majority of respondents believe EHRs would significantly decrease medical errors and costs
 - Majority of respondents express concerns about privacy and security

Current state of the literature

- **Survey results to date vary widely depending on**
 - mode (online, RDD),
 - types of questions asked (PHR, medical errors, paper vs. electronic efficiency, security/privacy breaches)
- **Examples:**
 - The range in the percentage of respondents reporting privacy/security concerns is between 25% and 69%
 - Consumer concerns about unauthorized use of their data ranges from 67% to 80%, depending on the survey
 - Anywhere from between 57% and 69% of respondents have not heard about EHRs
 - Little participation in PHR with surveys reporting anywhere from 5% to 13%
 - 70% believe benefits of EHR outweigh risks vs. 42% believe the risks outweigh the benefits

Methodology: Group Composition

Residence	Site	Race/Ethnicity or Countries of Origin
Rural	Raleigh-Durham	Black
	Raleigh-Durham	White
	Minneapolis	All races/ethnicities
Urban/mid	Minneapolis	White
	Phoenix	Hispanic, English
	Phoenix	All races/ethnicities, including at least five Hispanics
Urban/high	Chicago	Black
	Chicago	Hispanic, Spanish-speaking
	New York	White
	New York	All races/ethnicities
	Los Angeles	Hispanic, Spanish-speaking
	Los Angeles	Chinese Mandarin-speaking

Methodology (continued)

- Moderator's Guide
- Focus Group Data Supplemented with short survey
 - Administered at the end of the group discussion
 - 18 statements
 - 5 point scale Strongly Agree/ Strongly Disagree
- Topics
 - Nationwide Health Information Network
 - EHR and Security
 - Electronic Health Records and Patient/Consumer Control
 - Electronic Health Records, and Medical Research

Highlights from the Groups

- Concerns about security of electronic health records are more common than concerns about privacy
- Privacy concerns focus mostly on access to information by health plans and employers (concerns about discrimination)
- Groups suggested a system of role-based access to information (minimum necessary to accomplish tasks and with providers having the highest level of access) would protect privacy

More Highlights

- Spanish-speaking and Chinese-speaking groups struggled with the term “healthcare provider.”
- Spanish-speaking and Chinese-speaking groups would permit access to all types of health data to doctors, including specially protected data such as HIV, STD, Mental health, drug and alcohol and genetic data
- Spanish-speaking groups split on whether paper or electronic records are safer or more accurate
- Chinese-speaking group felt paper records are more accurate

Conclusions

- Need for representative national survey of consumers attitudes and beliefs about electronic health information exchange
- Need to better understand how Health IT impacts the way consumers interact with the health care system
- Need for more multicultural research

Q & A

Thank you!

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