

PATIENT PERCEPTIONS OF HEALTH INFORMATION EXCHANGE AND IMPLICATIONS FOR SUCCESSFUL IMPLEMENTATION*

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Structure of Presentation

1. **SAFE Health**-a local Health Information Exchange (HIE)
2. Objectives of assessing patient perceptions of SAFE Health
3. Description of focus groups
4. Findings
5. Implications



SAFE HEALTH

- **SAFE Health, or Secure Architecture For Exchanging Health information**, is a local health information exchange (HIE) being implemented in Central Massachusetts.
- SAFE Health involves a medical group (Fallon Clinic), a HMO (Fallon Community Health Plan - FCHP), a medical school (UMass Medical School), & a teaching hospital (UMass Memorial Health Care).
- SAFE Health uses a federated, decentralized approach to authentication, master patient index, and repositories
- Goal is to create a secure, scalable, and sustainable model that can be replicated and interfaced with other HIE



OBJECTIVES OF ASSESSING PATIENT PERCEPTIONS OF SAFE HEALTH

1. Assess patients' overall perception of the SAFE Health concept (benefits or advantages versus risks or disadvantages)
2. Obtain patients' opinions about access to SAFE Health information:
 - Who should have access and the levels of access?
 - Would patients like to access their SAFE Health record?
 - Who would patients trust to maintain their SAFE Health record?
3. Understand the features and functionality of SAFE Health desired by patients:
 - Emailing providers
 - Downloading record on a CD or DVD
 - Accessing and printing forms
 - Log of access



FOCUS GROUP APPROACH

SELECTION OF FOCUS GROUPS

1. Respondents:
 - 21 years of age or older and English speaking
 - Enrolled in FCHP with full medical and prescription benefits for at least 1 year

2. Six focus groups:
 - Acute illness
 - Healthy adults (2 groups)
 - Chronic illness (2 groups: less than 65 years, and 65 and older)
 - Caregivers

3. Discussion guide with a TV news story on SAFE Health.

4. Groups were moderated by a professional moderator



CHARACTERISTICS OF FOCUS GROUPS

- 48 participants
- 7-9 participants per group
- 26 women and 21 men. Caregiver group was entirely women
- Age: 21-72 years.
- 85% college educated or some college education
- 96% White (reflects FCHP membership)



OVERALL FINDINGS OF FOCUS GROUPS

PERCEPTIONS AND CONCERNS OF SAFE HEALTH

CATEGORY	PERCEPTIONS/CONCERNS
OVERALL PERCEPTIONS	Positive; however, 1 participant in each group expressed concerns about the concept
SECURITY	Serious concerns, especially hacking
BACK UP OF DATA	Questions raised in all groups
ACCURACY AND ERROR	Concerns, especially with data input and record retrieval
IMPLEMENTATION	Implementation glitches, but considered inevitable
LOSING PERSONAL TOUCH	Patients reduced to a number in the health care system

FEATURES AND FUNCTIONALITY OF SAFE HEALTH

CATEGORY	FINDING
WHO SHOULD HAVE ACCESS TO THE RECORD?	Everyone who treats patients, <u>as long as patients give consent</u> ; Blanket access for ER
WHO SHOULD <u>NOT</u> HAVE ACCESS	Government, employers, insurance companies
ROLE-BASED ACCESS	Limit administrative staff access
LOG OF ACCESS	All patients agreed that this was a good idea

FEATURES AND FUNCTIONALITY OF SAFE HEALTH

CATEGORY	FINDING
PATIENT ACCESSING RECORD	Yes for most patients – ensure accuracy, curiosity, evaluate care, share data
DOWNLOAD RECORD	Only caregiver and chronically ill groups; security concerns for other groups
EMAILING PROVIDERS	Unrealistic for providers given their schedules and time commitments
MAINTENANCE OF RECORD	PCP office

EXAMPLES OF COMMENTS

- Especially in an emergency room situation – they can save your life a lot quicker
- It is a great idea and it would be great if it worked, but we all know that if there is a security system out there, there is a hacker out there that's going to try and get in.
- I really don't want to tell the receptionist my personal what ever is going on with me.
- To make sure that it's all right. It's like checking your credit report, only more important.
- Can you imagine the doctor at the end of the day of a ten-hour day, he goes and has 150 emails? It's unfeasible to think about it really working

IMPLICATIONS FOR SAFE HEALTH

- Acceptable to a significant majority. Concerns of a minority will need to be addressed.
- Develop and implement state-of-the-art security protocols along with public education
- Reliable back-up systems
- Communication strategy to assure patients about confidentiality of data
- Role-based access as mandated by HIPAA security regulations
- Emailing providers not essential at start-up



OVERALL CONCLUSIONS FOR HIE

- Majority of patients feel very positive about HIE; minority have concerns about access, security, and implementation.
- Proponents of HIE must develop an effective communications strategy to address these concerns.
- Communications strategy must address variety of patient health statuses and range of concerns.
- Additional studies involving patients from different ethnic minority groups should be conducted.

Thank you

