



U.S. Department of Health and Human Services



Agency for Healthcare Research and Quality

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# A National Web Conference on Assessing Patient Health Information Needs for Developing Consumer Health IT Tools

## **Presented By:**

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James Ralston, M.D., M.P.H.

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## **Moderated By:**

Teresa Zayas Cabán, Ph.D.

Agency for Healthcare Research and Quality

May 7, 2015



# Agenda

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- Welcome and Introductions
- Presentations
- Q&A Session With Presenters
- Instructions for Obtaining CME Credits

**Note:** After today's Webinar, a copy of the slides will be emailed to all participants.



# Presenters and Moderator Disclosures

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The following presenters and moderator have no financial interest to disclose:

- Wanda Pratt, Ph.D., FACMI
- James Ralston, M.D., M.P.H.
- Patricia Flatley Brennan, R.N., Ph.D.
- Teresa Zayas Cabán, Ph.D.

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- Please address your questions to “All Panelists” in the dropdown menu.
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# Learning Objectives

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At the conclusion of this activity, the participant will be able to:

1. Explain the information needs of hospitalized patients and their caregivers for informing the development of health IT tools to improve communication of safety concerns to their providers.
2. Describe key patient preferences related to the quality, context, and methods of receiving care notifications and reminders within two populations: patients with type 2 diabetes and mothers of children with asthma.
3. Identify three physical features of patients' homes that affect personal health information management (PHIM) among adults with diabetes.



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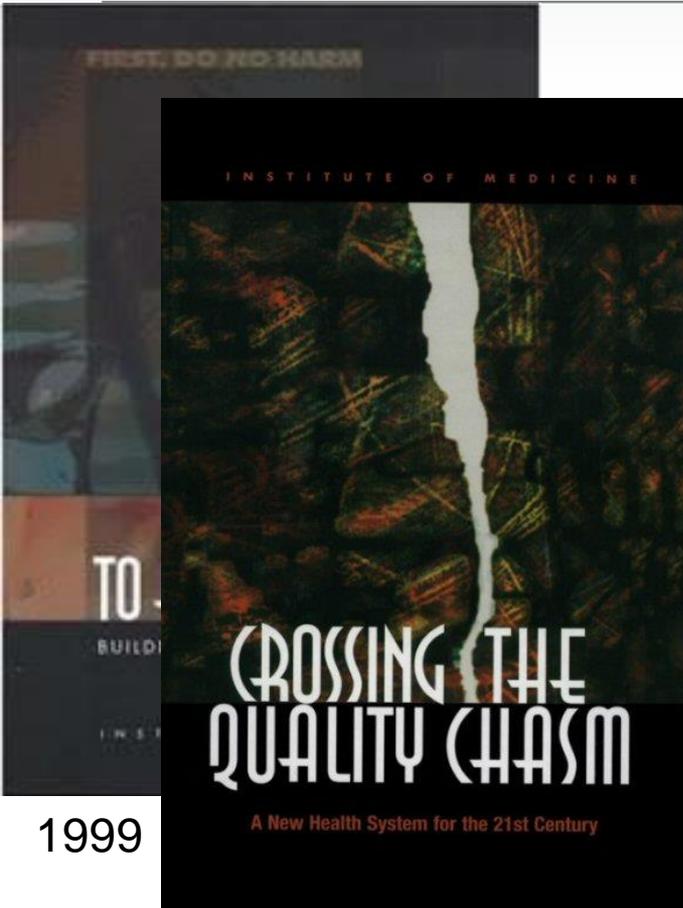
# Patients as Safeguards: Understanding the Information Needs of Hospitalized Patients in Voicing Safety Concerns

Wanda Pratt, Ph.D., FACMI  
University of Washington  
AHRQ grant R01HS022894



# Patient Safety: A Major Problem

- ✧ 440,000 deaths a year
- ✧ 10-20 times that number receive serious harm



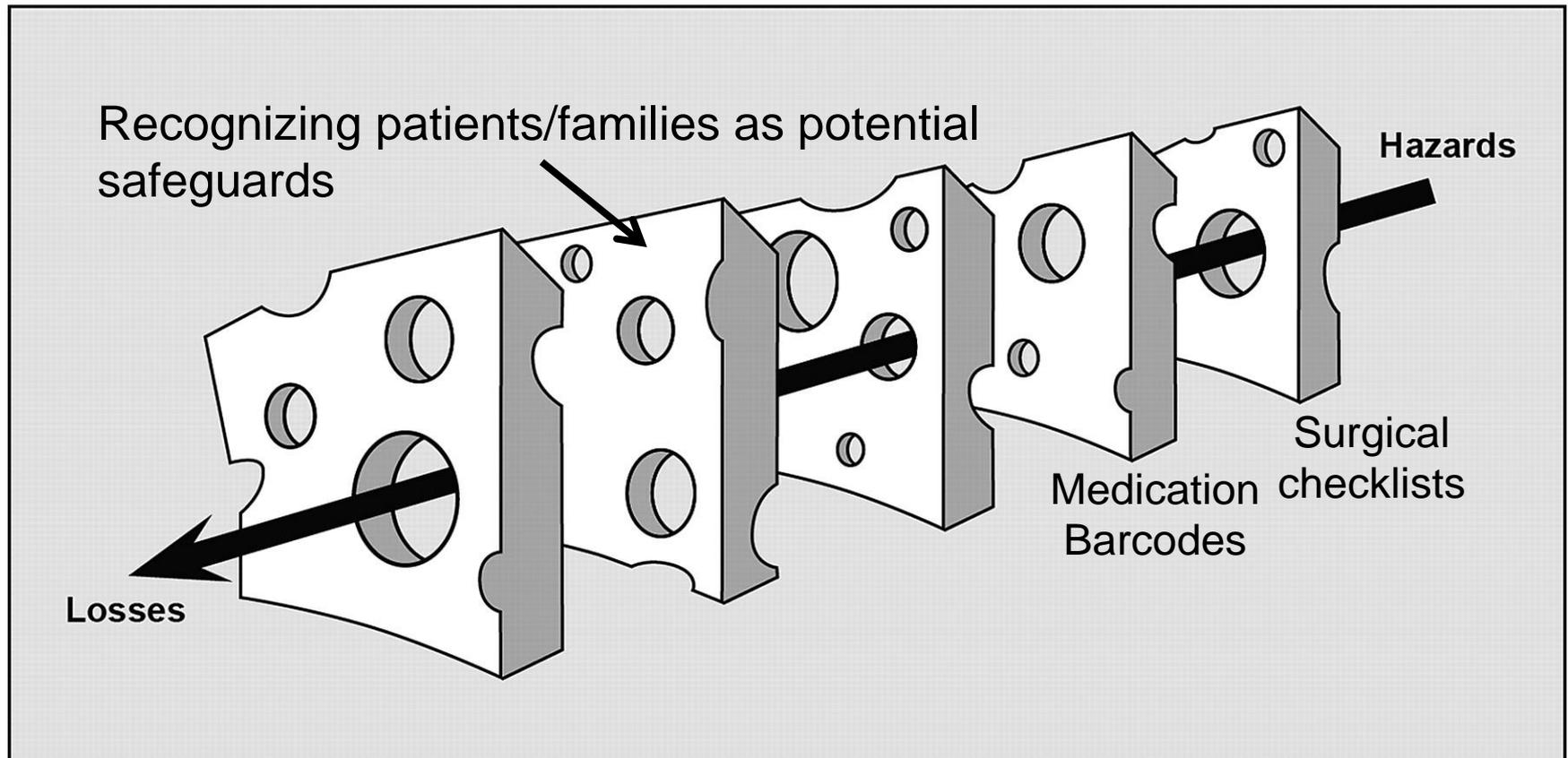
1999

2001



James JT. A new, evidence-based estimate of patient harms associated with hospital care. *Journal of Patient Safety* 2013;9(3):122–8.

# Patients as Safeguards





# Aims

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1. Identify information that would increase patients' and their caregivers' **situational awareness**, and enable them to recognize potential safety concerns.
2. Identify opportunities to support inpatients and their caregivers in **capturing and managing** health information, concerns, questions, and customized care needs.
3. Determine strategies to **support active dialogue** among patients, caregivers, and providers on safety-related concerns and the overall care experience.

# Population and Setting

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- Hospitalized patients and their caregivers
  - ▶ ≈50% medical
  - ▶ ≈50% surgical
  - ▶ Diversity of Seattle area

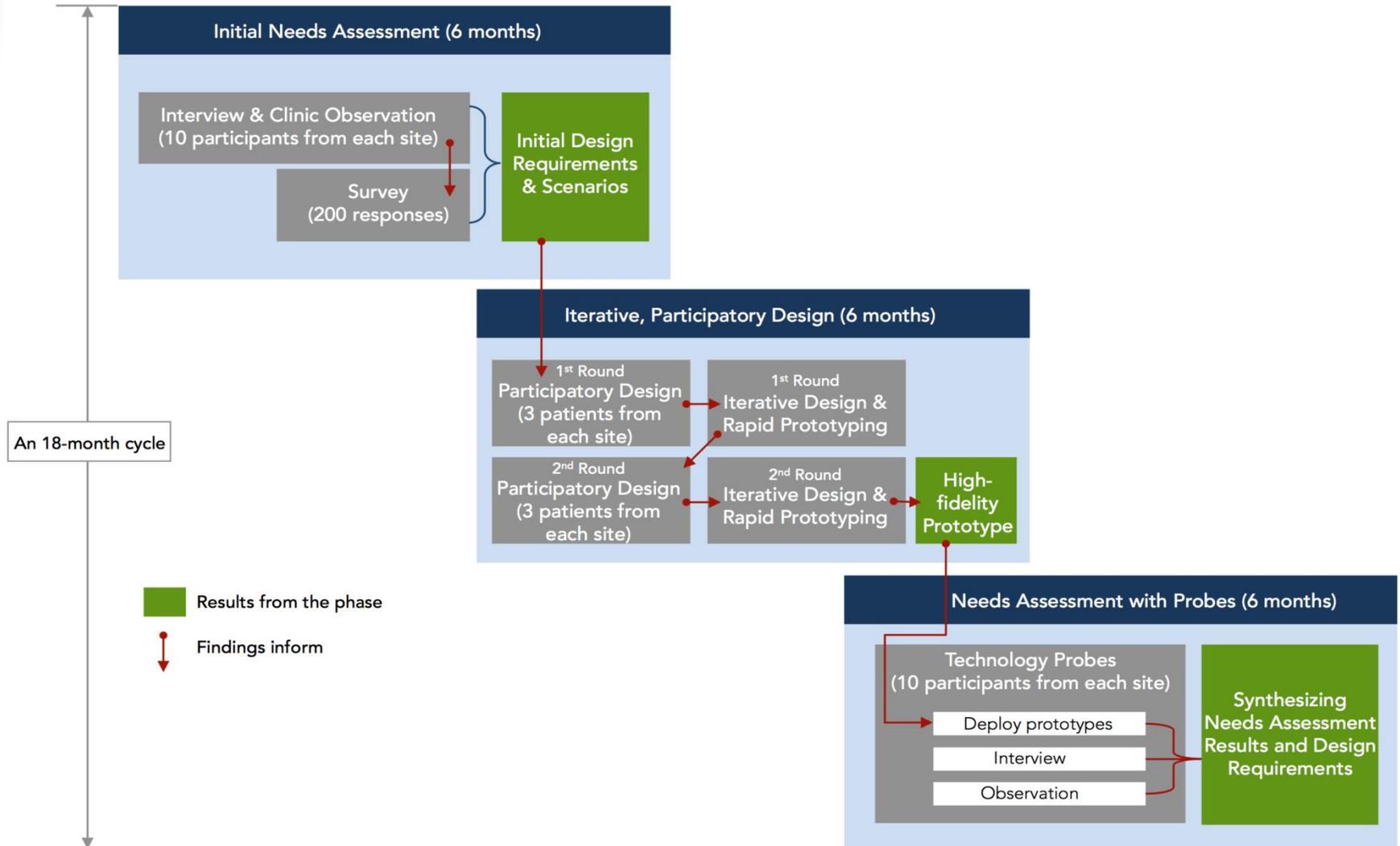
Adults over 18 years old



Children 7–18 years old



# Three-Phase Methodology





# Phase 1, Aim 1

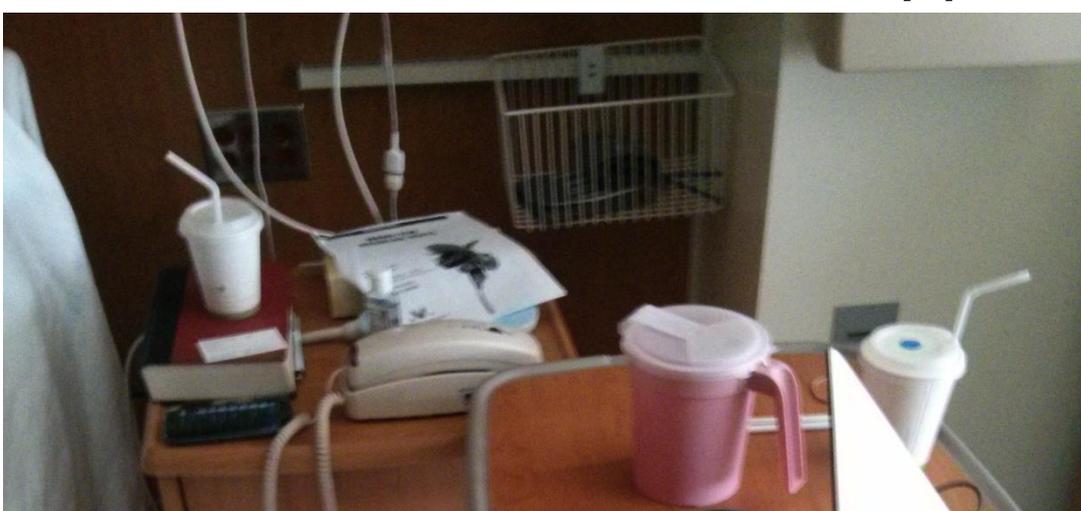
## Situation Awareness

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- Patient (n=22) and Caregiver (n=17)
  - ▶ Interviews
  - ▶ Observations
- Survey (n=157 previous inpatients or caregivers)
- Clinician Observations (*over 118 hours*)
  - ▶ Various providers (nurses, physicians, therapists, technicians, etc.)
  - ▶ Various settings (rounds, discharge, care conferences, therapy sessions, ad-hoc, etc.)

# Observation Findings: Poor Inpatient Workspaces

- Smartphones and computers not handy
- Nearby surfaces covered in food, trash, etc.
- Papers from clinicians often stacked by window
- Whiteboard located opposite the bed





# Information Challenges

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*“Most of it I scrawled it on the back of some pamphlets that came out of a box of dressings because I didn't have any paper. They did have a whiteboard in my room so I could keep track of some of it there, but some of it was embarrassing and I didn't want it available to be read by anyone who walked in the room”*

*“EMR eliminates ready review of what has been administered and when, etc.”*



# Provider-Centric Information Environment

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- Little patient access to information
- Primarily verbal dialogue
- Many information needs unmet
  - ▶ Expected workflow
  - ▶ Expected care activity and schedule
- Unsupported Patient and Caregiver Information Work!



# Barriers to Information Exchange With Patients

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- Receiving
  - ▶ Information dispersal among departments
  - ▶ Frequently changing care plans
  - ▶ Getting conflicting information
- Supplying
  - ▶ Lost requests
  - ▶ Social pressures
  - ▶ Poorly timed questions



# Survey Results: Patient and Caregiver Attitudes

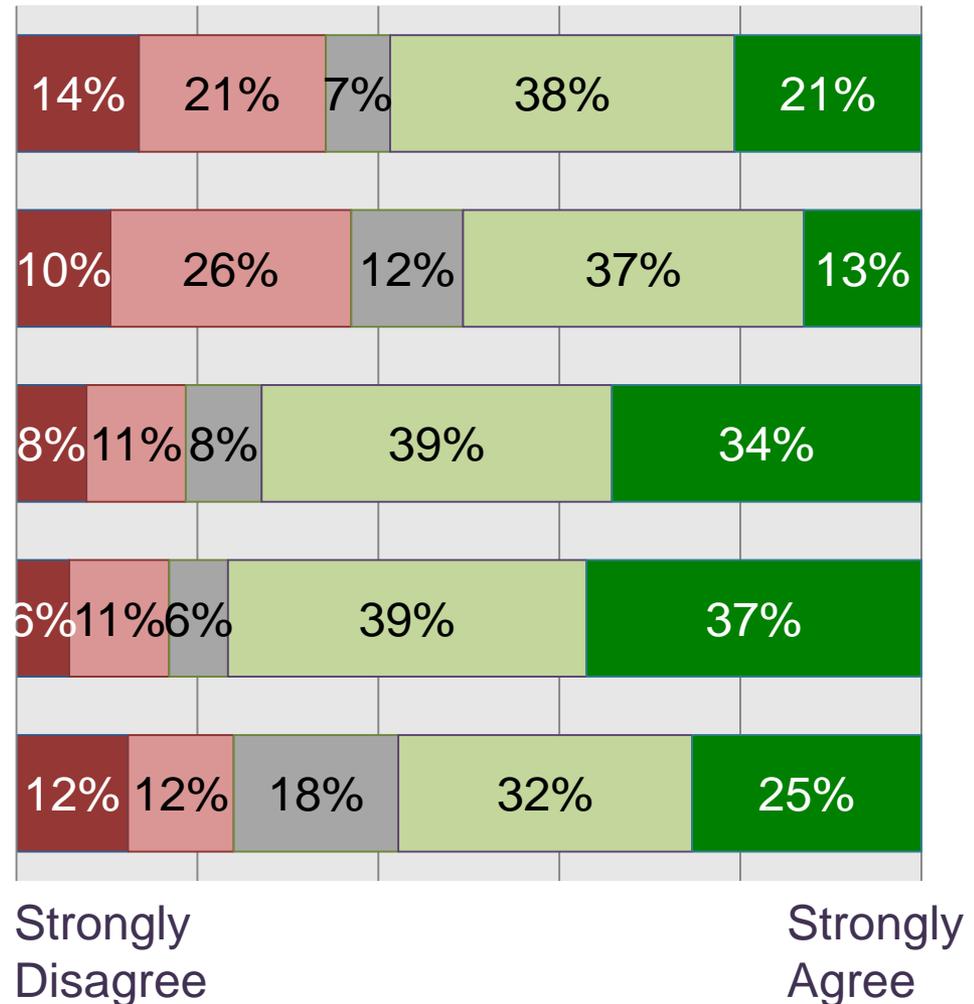
I was involved as much as I wanted to be in decisions made about the care and treatment provided. (N=151)

I was able to stay informed about all of the activities that occurred relating to the care provided. (N=154)

I felt comfortable asking the doctor(s) questions about the care that was provided. (N=154)

I felt comfortable asking the nurses questions about the care that was provided. (N=155)

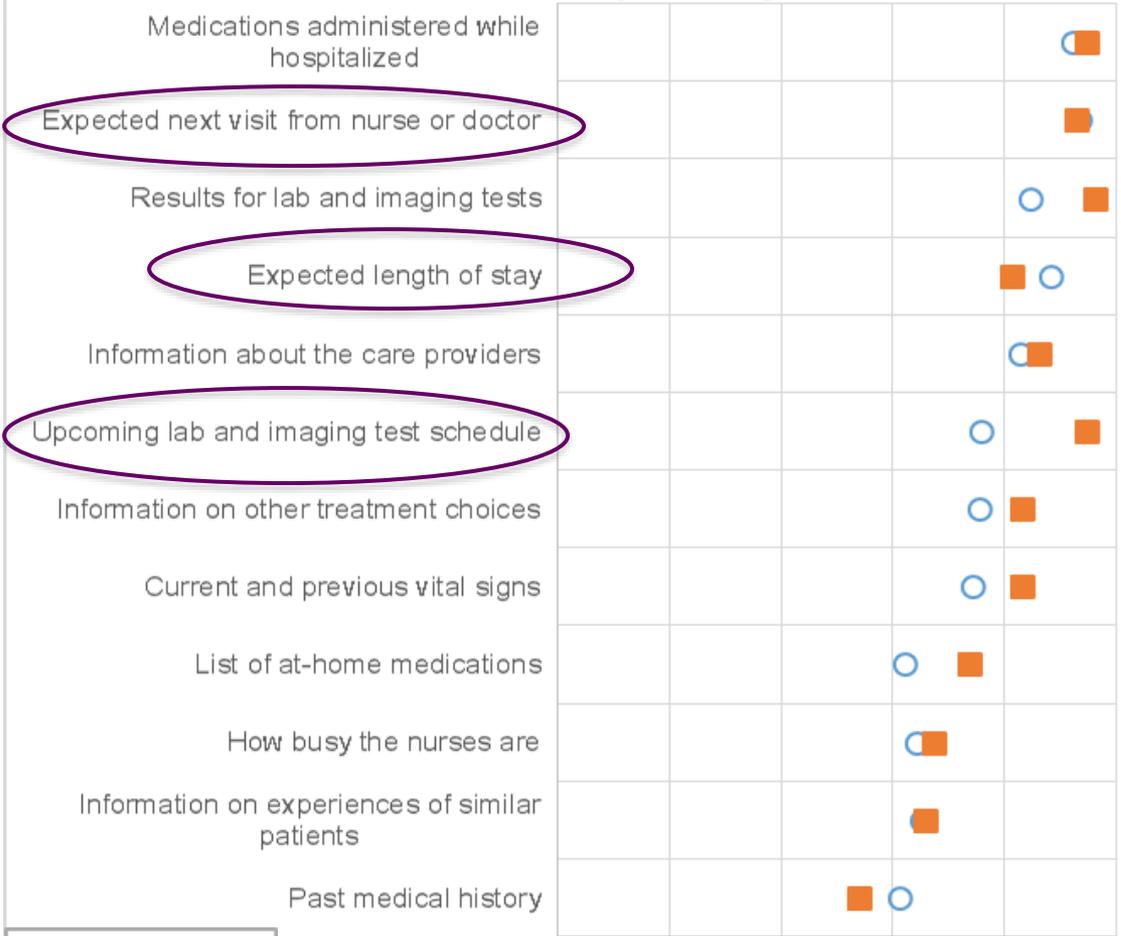
When I had important questions to ask the doctor or nurse, I was able to get answers that I could understand....



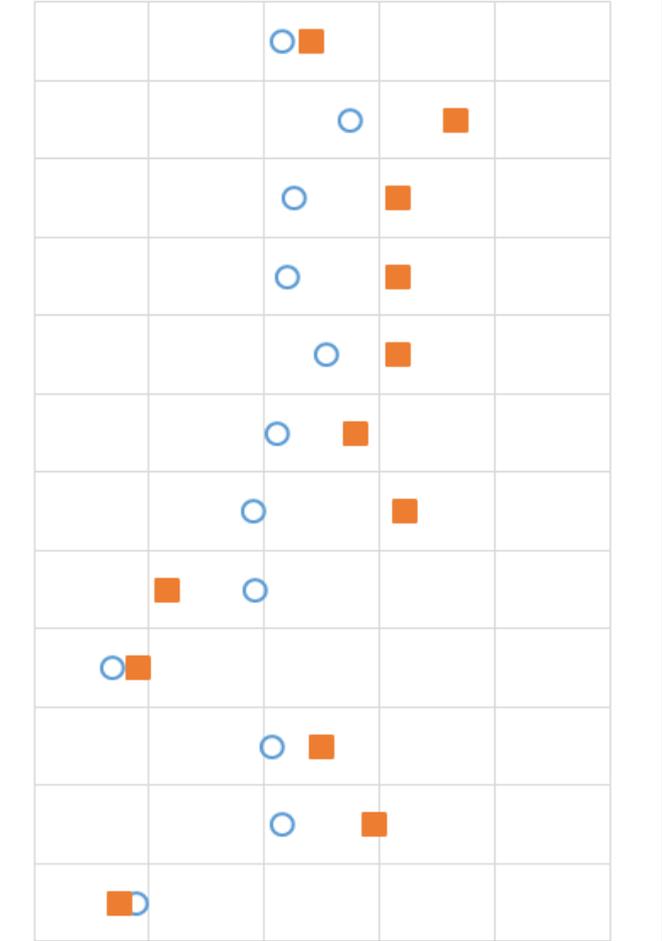


# Survey Results: Importance and Difficulty of Getting Information

**(a) Important to get information about....**



**(b) Difficult to get information about..**



patient   
 caregiver 

0% 20% 40% 60% 80% 100% 0% 20% 40% 60% 80% 100%



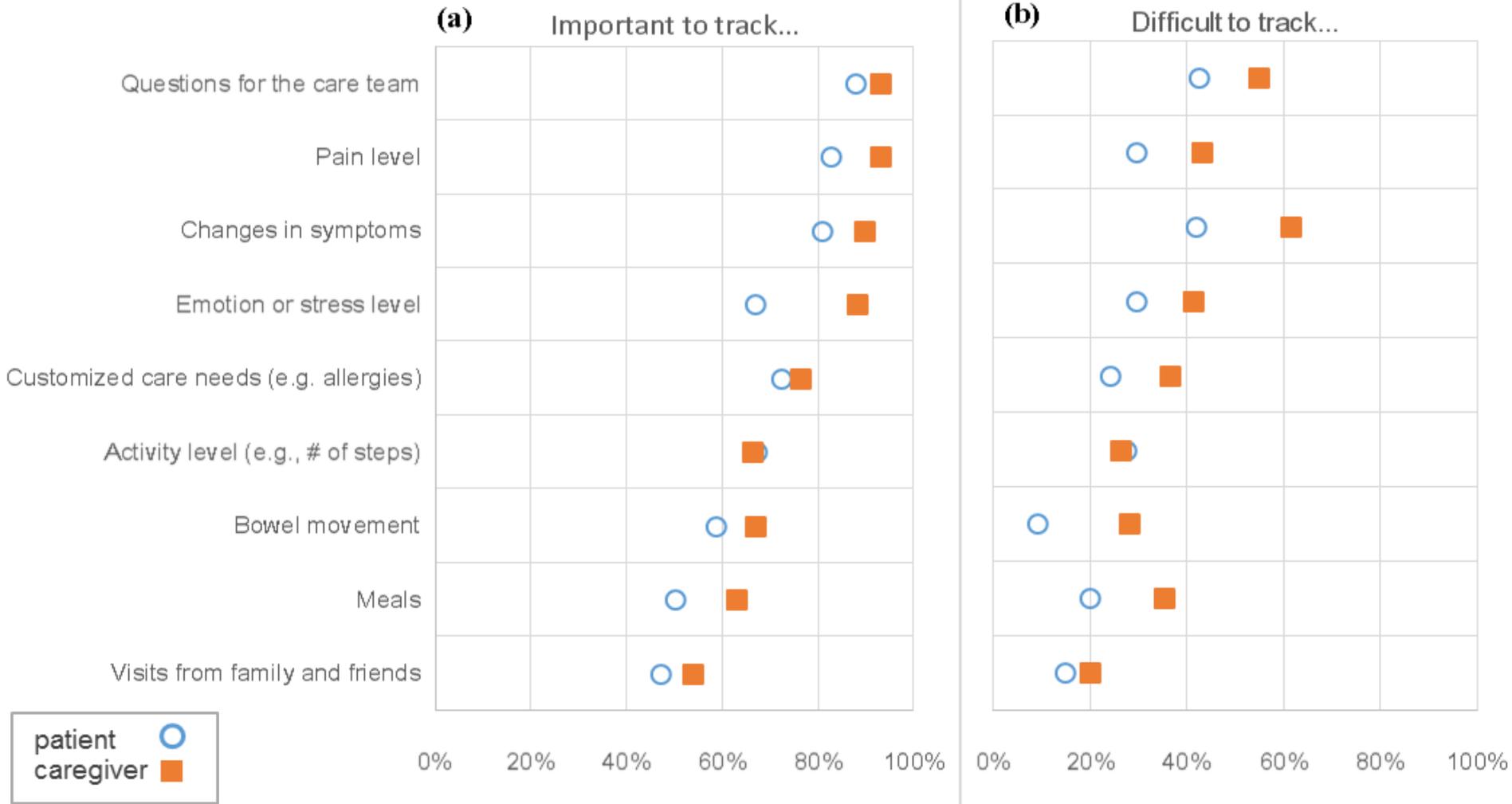
# Frustrations Expressed

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*“We spent a lot of time sitting around waiting for the doctors. Then we would go to the bathroom or to get food, and come back and they would have been there without speaking with any of us. We would have to wait another day to ask our questions or share information or observations”*



# Survey Results: Importance and Difficulty of Tracking Information





# Survey Results: Rationale for Tracking

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- Being active participant
- Being in the know
- Monitoring care quality/safety
- Improving communication with staff
- Coping with patient health challenges
- Dealing with too many different events occurring
- Being prepared for visits with staff
- Complying with clinician request
- Managing pain

# Survey Results: Methods for Tracking

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Written 49%



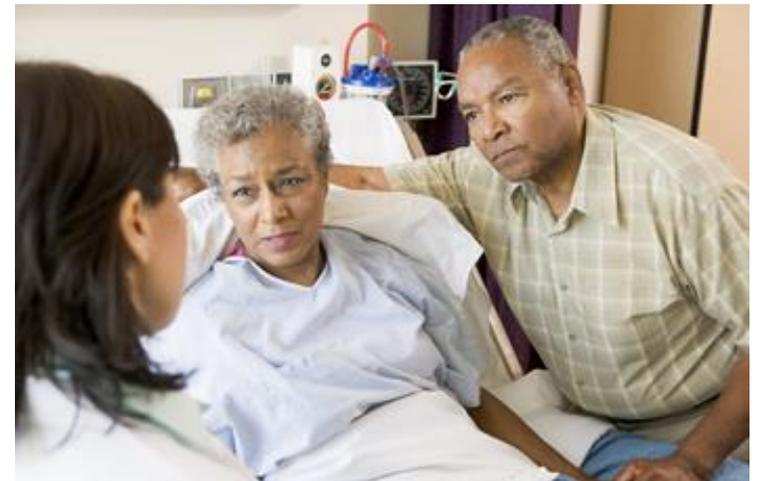
Memory 19%



Verbal 19%



Electronic 14%



Caregiver 5%

# Real-life Example

**Atrial Fibrillation, HR = 42**  
**2<sup>nd</sup> degree AV block**



Metoprolol is contraindicated

- heart rate < 45 beats/min
- 2<sup>nd</sup> and 3<sup>rd</sup> degree heart block



# Early Lessons

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1. Provide information to increase situational awareness.
  - ▶ Beyond patient portals
    - Schedule of activities
    - Plan of care
2. Capture information to inform.
3. Support active dialogue among patients, caregivers, and providers.

# Conclusion

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- Subjective methods critical
  - ▶ Uncovers latent variables
  - ▶ Identifies patients' needs, perspectives, and priorities
- Patients' information work in a hospital
  - ▶ Important and desired
  - ▶ Challenging
  - ▶ Poorly supported by environment and technologies
- Patient information work must be supported to provide an additional safeguard to prevent medical errors.



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# Designing Reminders and Notifications for Patients

James Ralston, M.D., M.P.H.  
Group Health Research Institute  
AHRQ grant R01HS021590



# Why Reminders and Notifications

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- Reminders work
- More tasks to remember
- More ways to connect with patients and families
- Growing need for personalization
- Meaningful use requirement



# Limitations of Current Reminders

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- Effectiveness established for single prevention needs and limited sets of chronic care services.
- Reminders for multiple screenings may be less effective than single reminders.
- Unclear how to time reminders for different health care activities.



# Definitions

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- Patient reminders alert people to schedule medical visits, medical tests, and screenings or other chronic or preventive care activities.
- Notifications inform patients of results from screening tests and other chronic care or preventive services.



# Goal and Initial Approach

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Goal: Understand the needs and preferences of individuals for health care reminders and notifications.

Initial approach: Study the work individuals and families do at home to remember what to do each day.



# Population and Setting

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- Men and women with type 2 diabetes who have other chronic health conditions, including at least hypertension (n = 20)
- Women age 18–40 with one or more children under 12 years old with active asthma (n =20)
- Oversampled individuals from racial and ethnic minority groups and with lower education level
- Group Health Cooperative, an integrated delivery system in Washington State

# Understanding Reminders

- Traditional



- Opportunistic



# Traditional Reminder Tools



# Method 1: Home Visit

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- Question
  - ▶ How do you remember what to do each day?
- Methods
  - ▶ Home tour
  - ▶ Semi-structured interview
  - ▶ Content analysis

■ = 1 tool observed

Participant ID	Private Tools								Shared/Public Tools								Total tools used
	<-analog-->				digital-->				<-analog-->				digital-->				
	wall calendar (paper)	paper reference	white board	desk calendar	planner	tablet	e-calendar	phone	wall calendar (paper)	paper reference	white board	desk calendar	planner	tablet	e-calendar	phone	
Asthma cohort	01						■	■ ■			■						4
	02								■	■							2
	03		■			■			■ ■								5
	04						■	■	■	■							4
	05								■ ■								4
	06						■	■ ■									3
	07								■ ■								4
	08										■						2
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	20							■	■			■					3
Diabetes Cohort	01				■		■	■									3
	02	■	■		■					■							4
	03										■	■					2
	04						■										1
	05		■		■		■										3
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	20							■	■	■							2



# Challenges from Outside the Home

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*“If I go in for an appointment and the doctor says, ‘okay, we need to see [the children] back in six months,’ I’ll usually get home, I’ll call the next day, even though it’s six months out – sometimes their calendars don’t even, they’re not even that far out. But I call the next day because I might forget so well, I’ll just call and say, ‘okay, are you scheduling this far out?’ “*

-Mother of children with asthma



# Memory Failures

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*“If I don’t have anything immediately reminding me of it, it’s out of my head because I have so much going on. We have kids to pick up, drop off. We have cleaning house, I’ve got selling things, I’ve got to meet people.”*

-Mother of child with asthma



# Reminder Tool Failures

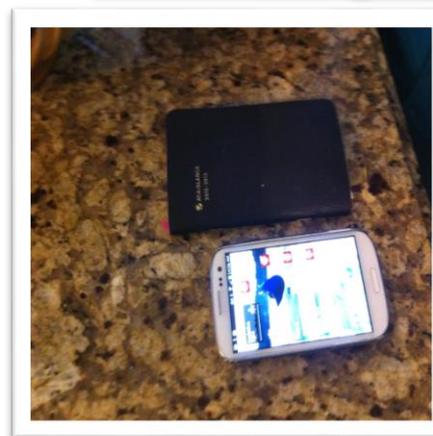
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*“I was freaking out, because I had actually taken the time to write everything down—they had a trove of information on it. I couldn’t find it and then I was like, ‘How the heck am I going to do this if I don’t have a backup?’”*

-Mother of child with asthma

# Mitigating Failure

- Redundancy
- Diversity
- Monitoring





# Design Implications

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- Minimize the current extensive work at home needed to incorporate health care reminders into daily life.
- Consider variations in user needs for reminders.
- Enable detection and response to reminder failures.



# Opportunistic Reminders

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# Method 2: Cultural Probe

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- Cultural-probe inspired activity
- Participants photographed and described good reminders
- Thematic analysis



# Using Artifacts

*“So I took a picture of... my cane to remind me of my condition before I started taking my blood sugars really serious, (and) the condition I was in, to remind me ‘You don't want to go back there.’”*

-Patient with diabetes



# Using Routines

*“I need to walk to add to my regular exercise classes. It gives me extra exercise by walking my dog. She reminds me to please go on a walk. I would probably not think of walking without her as a reminder. She is my shadow.”*

-Patient with diabetes



# Using Relationships

*“I got a picture of my husband and my daughter that lives next door, and they're the ones that got me through my stroke years ago by encouraging me and helping me.”*

-Patient with diabetes





# Design Implications

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- Keep reminders meaningful.
- Support reflection in reminders.
- Connect reminders inside and outside the home.



# Key Points

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Reminders for health care tasks should seek to:

- ▶ Incorporate the depth of meaning in patients' own opportunistic reminders.
- ▶ Minimize the extensive work of incorporation into the home environment.
- ▶ Account for the large variation in user needs preferences and capabilities.



# References

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From this study

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Other references for designing reminders

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- Reason J. Combating omission errors through task analysis and good reminders. Qual Saf Health Care 2002.



# Acknowledgments

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- Logan Kendall
- Katie O’Leary
- Wanda Pratt, Ph.D.





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# **vizHOME: A Context-Based Health Information Needs Assessment Strategy**

**Patricia Flatley Brennan, R.N., Ph.D.  
University of Wisconsin-Madison**

**Supported by grants from the Graduate School,  
UW-Madison and AHRQ R01HS22548**





# Basic Premises

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- Clinicians are experts in professional practice, and patients are experts in everyday living.
- Health care happens in clinics and hospitals, but health happens every day in people's living rooms and bedrooms.
- **Where** one does "health" influences how well it is done.
- Homes are private, personal, intimate, and messy spaces.
- We can capitalize on emerging technologies to better study the home environment.

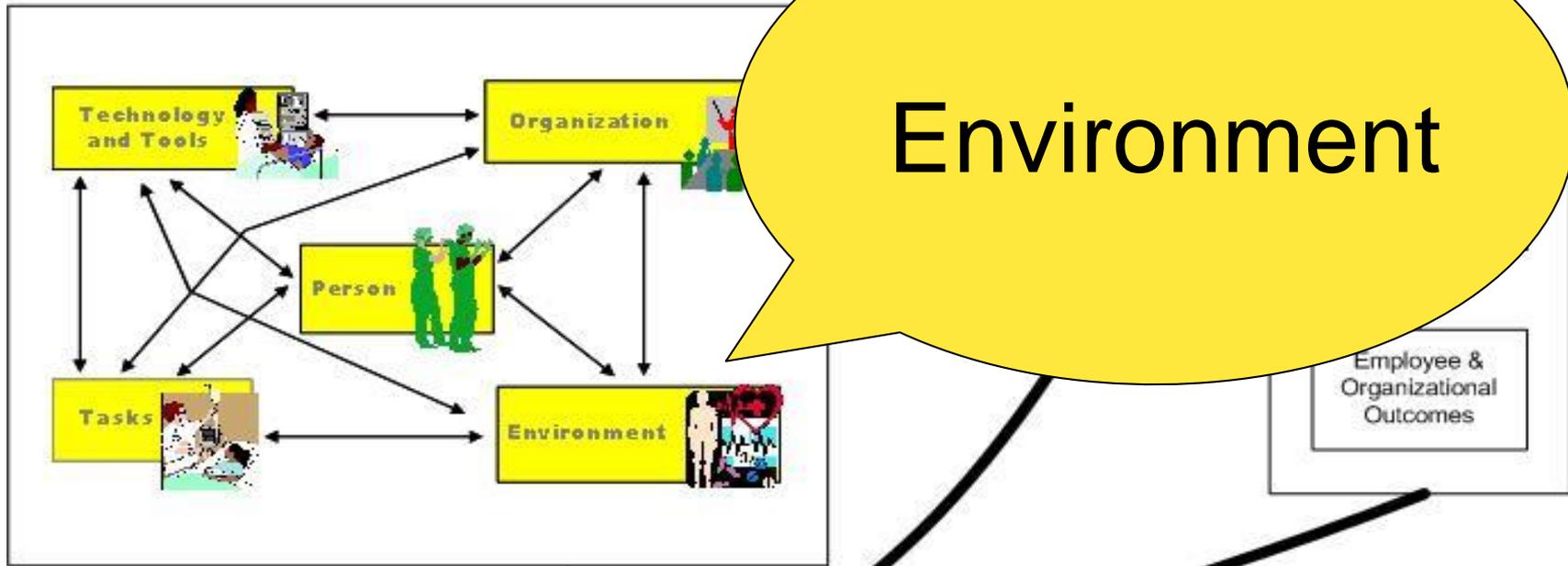
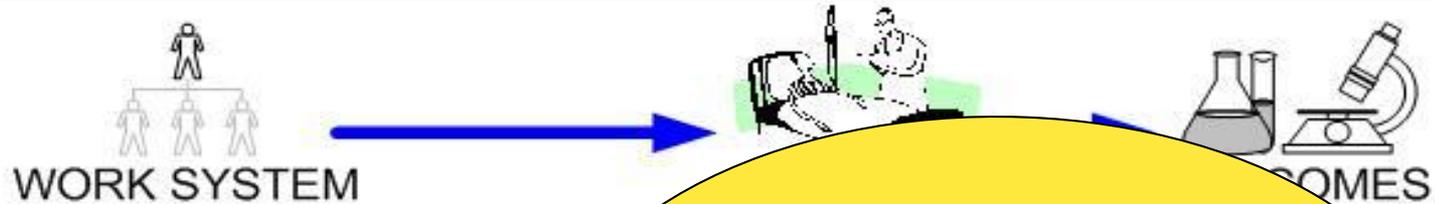


# How Do We Bring a Sense of Place Into the Design Process?

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- Create a place where nurses, engineers, computer scientists, and others can envision every environment on earth.
- Use that environment to *immerse* designers into the real world of health in everyday living.

# SEIPS Model of Work System and Patient Safety



<http://www2.fpm.wisc.edu/seips>



# vizHOME:

## A Context-Based Health Information Needs Assessment Strategy

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## vizHOME:

# A Context-Based Health Information Needs Assessment Strategy

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- Determine how personal spaces and the orientation of objects within those spaces affect personal health information management (PHIM).
- Overview:
  - ▶ Capture the interior of 20 households using LiDAR.
  - ▶ Render those homes in an immersive virtual reality CAVE (cave automatic virtual environment).
  - ▶ Identify features likely to influence PHIM using a BeamCounter.
  - ▶ Verify the features and their influence.
  - ▶ Create the Assessment of Home Environment (ACHE Scale).

# Home Scanning

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Kevin Ponto

Ross Tredinnick

Naveen Subramaniam

Andrew Morland

- 6 hours for a 1,700 ft<sup>2</sup> home
- Generates 950 million data points (point cloud)



# vizHOME: Context-Aware Design

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# Walking Through a House ... *Virtually*

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# Early Findings

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- Personal health information management:
  - ▶ Suite of behavioral activities and cognitive strategies used by an individual to record, organize, act on, store, retrieve, or coordinate information
- Health happens all over the house.
- Sensory cues, not just printed information, aid in health information management.



# Next Steps and Collateral Activities



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