

Practical Solutions for Engaging Consumers in the Design and Use of PHRs: Beyond User Centered Design

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Presenters:

**Patricia Flatley Brennan, RN, PhD
University of Wisconsin-Madison**

**Kathy Hajopoulos, MPH
University of California, San Francisco Medical Center**

Moderator:

**Teresa Zayas Cabán, PhD
Agency for Healthcare Research and Quality**



PHR

User Centered Design

Translating

observations into design requirements

Patricia Flatley Brennan, RN, PhD

Project HealthDesign:
Rethinking the Power and Potential
of Personal Health Records



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PHRs – The Current Landscape

- PHRs have emerged as tools for individuals to become more active in their own care or personal health management
- Personal health management tasks occur in the context of the individual's environment and specific needs
- Strategies are needed to gather key elements of users, personal health information tasks, and context
- Models can help translate this into design requirements

PHRs in context

Who are the Intended Users



What will the users do with PHRs



Where will they use PHRs



User-centered Design

User Centered Design (UCD)

A philosophy of ENGAGEMENT of the intended user or representative in the design life cycle

- Systematic design and evaluation methods that ensure:
 - User involvement in all stages of development, from requirements gathering, to early prototyping, to the final evaluation
 - User input is incorporated into design
 - More than just the interface– UCD results in end products users are more likely to accept
- Strategies are purposefully chosen to enhance naturalistic engagement
 - Users as member of design teams
 - Focus groups, target audiences
 - Ethnography, participant-observation, interviews

User Centered Design and PHRs

PHRs require USER CENTERED DESIGN

*Nowhere else in health IT design but in PHRs
is a user-centered approach, such as User-centered Design (UCD),
so important and challenging to execute*

- Various types of PHRs are available for consumers, but most are created around the vision that health professionals have of patient needs
- PHRs' usefulness to consumers will depend on:
 - Quality of information provided
 - Relevance and value of information and functionality to person
 - Feasibility of integrating PHR-based information into daily life

UCD and PHRs – Can it be done?

- UCD is not widely employed in PHR development
 - User satisfaction surveys are occasionally conducted after the implementation of finished systems
- Widespread use of PHRs will depend in part on better engagement of their primary users, consumers
- UCD helps PHR designers given:
 - Emphasis on the use of patients' needs and values as a basis for customization
 - UCD is a natural fit for the kind of patient-centered healthcare that PHRs represent

Focus on the Primary User

- PHR design to date has focused almost exclusively on the perspectives of *providers* of health data, i.e., health care providers and payers
- UCD in contrast focuses on a product's primary user
- By considering the skills, needs, preferences, limitations and context of primary users, UCD can inform PHRs
 - Content selection, including data sources
 - Functionality
 - Utilities

The UCD Process

- UCD techniques should be employed throughout the entire design and evaluation process, from requirements gathering, to early prototyping, to the final evaluation
 - Helps generate solutions informed by user input and the evaluations of designs
 - Incorporates user characteristics and input gathered through interactions with users
- Techniques are employed several times with progressive refinements
 - Ensures that users' needs and wants are met
 - Increases the likelihood users will accept the final product

Example of UCD techniques aiding in the development of PHRs

- Mock-ups and prototypes
 - Interactive tools to demonstrate what is being developed and solicit direct feedback from the intended user

Example:

- Allowing a diabetic patient to use a prototype of a food calculator to determine meal choices
 - Ensures feedback is based on real experiences

UCD applied to other real life situations

In Mobile Phones

- Nub on top of key on cellular phone instead of bar above it
- **Benefit:** Aided users in anchoring where they were in order to dial without looking.



In Aviation

- Improved navigation displays in airplane cockpits
- **Benefit:** Decreased errors at time of landing under low visibility conditions.



In Health Care

- Smoking cessation program tailored for inner-city women
- **Benefit:** Tailored program better suits inner-city women causing improved results.



UCD can provide similar insights into PHR design

- E.g., elements as simple as text colors and typefaces that individuals find easy to read.

Benefits of UCD for PHR environment

UCD contributes to ensuring that the output or product is one that is likely to be easy to use and accepted by users

Acceptance of final product

- Keeping technology flexible
 - UCD helps PHR designers include what users want and *leave out what is not needed*
- UCD prompts an iterative design process
 - Results in making changes early in the design resulting in less expensive changes to the final product
- Meeting and managing users' expectations
 - By including the user in the design, users needs, wants and preferences will be appropriately addressed

Challenges of UCD in PHR environment

- UCD is often burdensome
 - Implementation is associated with considerable investments in:
 - Time
 - Resources
- Other easier to implement and less costly techniques are often attractive but do not yield the same results
 - E.g., expert review
- **UCD is especially difficult in the PHR environment** given PHRs have a diverse user base, hence it is difficult to obtain meaningful feedback from all potential users

Challenges of UCD in PHR environment: Who really is the *User*?

- Users
 - PHRs have diverse users
 - Can have conflicting preferences which complicate inputs to the design and evaluation process.
 - Designers must characterize the **needs of diverse groups of individuals** over a broad geographic area, in unusual environments, in different clinical care situations, with different tasks
 - PHR users are a scarce resource
 - Need to consider the personal and operational costs of gathering information from **ill individuals**

Communication & Care Plan for Breast Cancer Treatment: Creating a Tool for Patient-Centered Care

Kathy Hajopoulos, MPH



UCSF Breast Care Center

- Multidisciplinary clinic
 - Diagnostics, consultations, examinations, treatments, and appointments are co-located
- Supportive services provided
 - Genetic counseling, psychological care, dietary counseling, educational assistance, and consultation planning
- Developing patient-centered care models and implementing systems and tools to improve care delivery
- Breast Oncology Program's advocates are women who have experienced breast cancer themselves
- 2007 grant from the CHCF and RWJF as part of *Project HealthDesign* – a national initiative to support innovative solutions in care delivery

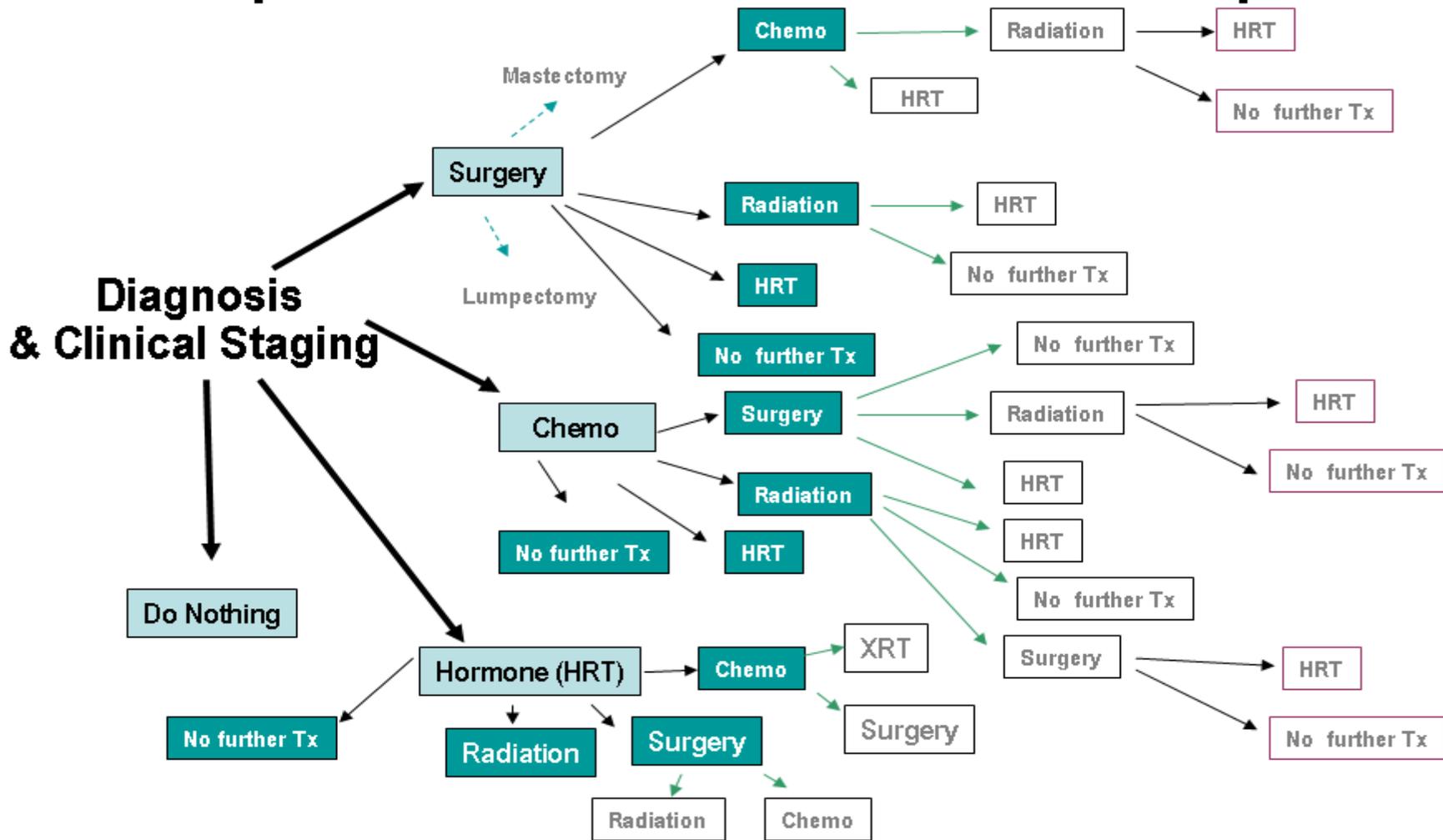
Current Care Paradigm

- Current system of care structured around institutions, providers and reimbursement
- Providers “produce” (diagnose, decide, treat)
- Patients “consume” (accept treatment)
- Care is reactive
- Minimal integration of patient feedback and values
- Institution/provider owns and controls patient data
- Silos of non-standardized data
- Communication about care plan is minimal

Creating a New Patient-Centered Paradigm

- Harness the power of 21st century information technology tools in order to profoundly impact every stage of breast cancer care
 - Give patients a voice and a window into their own care
 - Give providers more convenient, efficient access to synthesized information
 - Dramatically enhance the integration of clinical care and research and shorten the cycle of change
 - Spend resources on patients who need them and reassure patients who don't
- Design system of care to address the specific needs, experiences, and values of the patient

Example of Breast Cancer Treatment Options



Where We Started/ What We've Learned

- The Communication and Care Plan (CCP) tool will be used for entering, organizing, and integrating information about care and streamlining the delivery of services.
- CCP will support the decision making process & create an electronic timeline.
- Patient, provider, and staff focus groups were held to solicit input on information needs and to provide feedback on care planning tool developed.
- Currently developing a prototype model to reflect breast care patient requirements regarding calendaring and timeline functionality.

Communication & Care Plan and User Centered Design

- UCD Process – held focus groups to gain a better understanding of what key stakeholders wanted in a tool:
 - Breast cancer survivors were recruited via a support group list serv, Craig’s List and UCSF advocate group
 - UCSF IRB process completed
 - Providers and staff included surgeons, oncologists, nurses and clinic staff from UCSF.
- Once prototype developed, will invite previous focus group participants to review and provide additional feedback

Patient Focus Groups (2007)

- 20 breast cancer patients
 - Had completed their treatment
 - Participated in 3 focus groups
- Written survey data obtained from 90% of the participants
- Most indicated that they used the internet or e-mail to research issues related to their condition
- Only 20% used a PDA to manage their calendars, etc.
- Majority of the participants said would use a web-based care plan, most also wanted a printed copy

Patient Focus Group Feedback

- Security and confidentiality important
- Include pathology and MRI images
- Incorporate treatment details and test results, etc., into calendar
- Offer CD-Rom or DVD with visit information
- Usefulness increases if practitioners use it as well
- Other findings:
 - Detail in tool may be too overwhelming at diagnosis; better at second appointment
 - Need for information access may vary – women should be able to tailor the views to meet their needs
 - Recurrence/mortality information is too emotional and should not be “forced” on patients
 - Solutions needed for women without internet access or with language barriers

Patient-Requested Functionality

- Document original diagnosis, progression, post-treatment care, and second opinions
- Include test and lab schedules, chemo flow sheet, other drug information, radiation and other treatments
- Show continuum of care so patient can see where they are in treatment, normal findings, reactions to treatment, symptom management, etc.
- Provide summary page of all pertinent information
- Offer research protocols for clinical trials, glossary, address book, contact information, links to recommended web sites and resources
- Incorporate reminder system to push out messages or alerts that patients can create

Provider Focus Groups (2007)

- 10 breast care providers in 2 focus groups
- Almost all providers would prefer electronic care plan connected to the UCSF EMR
- Additional hard copy version of the care plan
- Physicians not amenable to entering patient data or accessing an on-line tool not already integrated into the existing practice management systems

Provider Focus Group Feedback

- Not having organized, readable information frustrating
- Initial patient information gathering most time consuming
- Helpful to know what information patients already have
- Need critical data to be able to match what you know and what patients need
- Data currently not easily accessible or in one format/place
- Care coordination between providers critical
- Should be able to access certain data points that are standard in advance of a patient visit
- Define “customers” for each component of the CCP tool

Provider-Requested Functionality

- Information on pathology, tumor size and characteristics, receptor status, etc.
- Clear timeline
- UCSF and non-UCSF data for current and prior episodes, relevant medical history
- Way to know if patient is following “Plan A” vs. “Plan B” after initial consult
- Repository of general information about decisions made
- Template to manage order of treatment
- Standard set of orders linked to electronic timeline
- Set of rules for all system users for entry of information in CCP
- Electronic flow sheet populated with labs, connected to EMR
- Connection to relevant patient educational materials

COMMUNICATION & CARE PLAN PROTOTYPE

SAMPLE SCREEN SHOTS



+ New ▾ Find

+ New ▾ Find

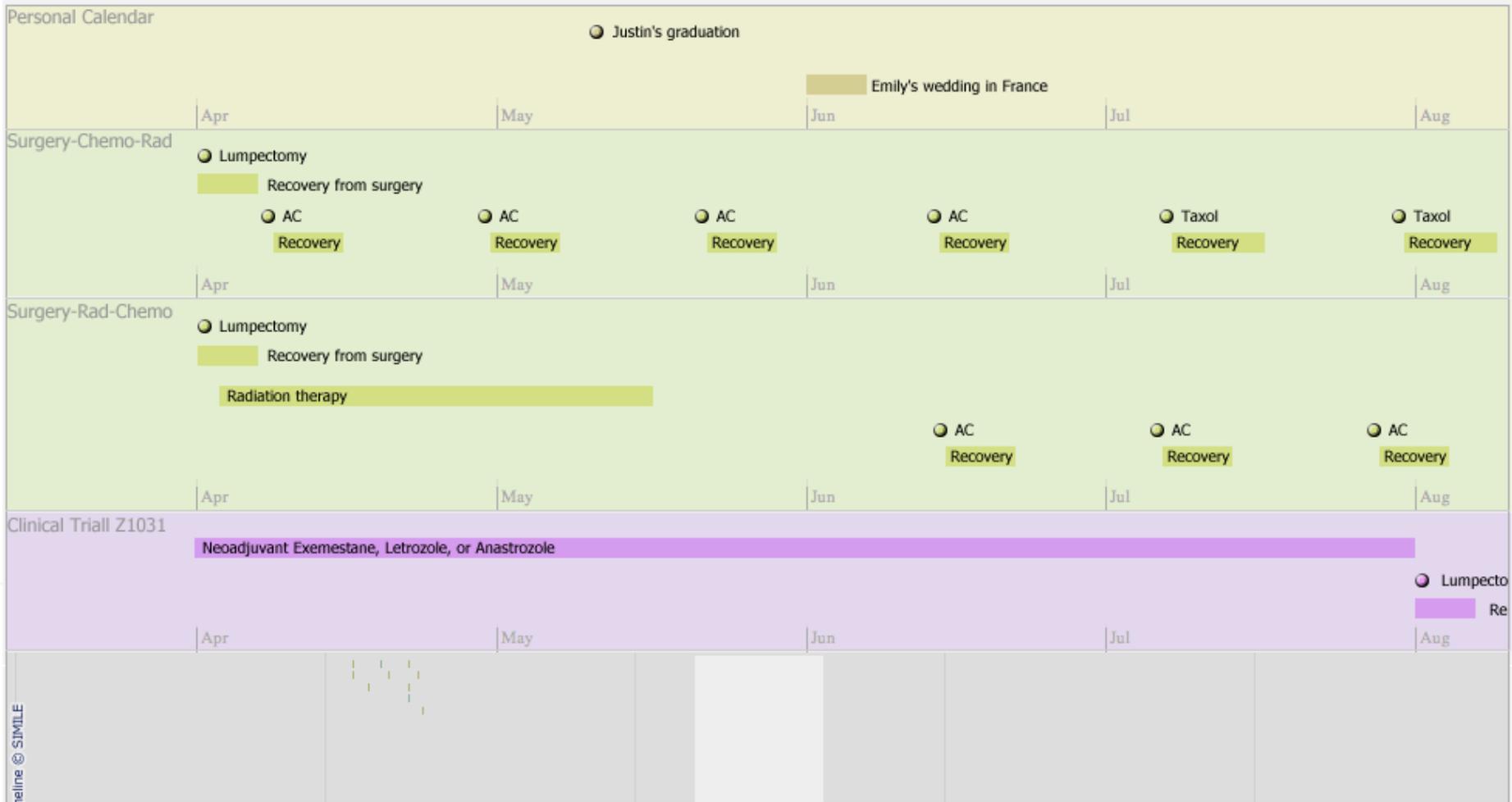
- Appointment
- Office Visit Note
- Chemotherapy regimen
- Radiation therapy
- Lab value
- Radiology exam
- Surgery

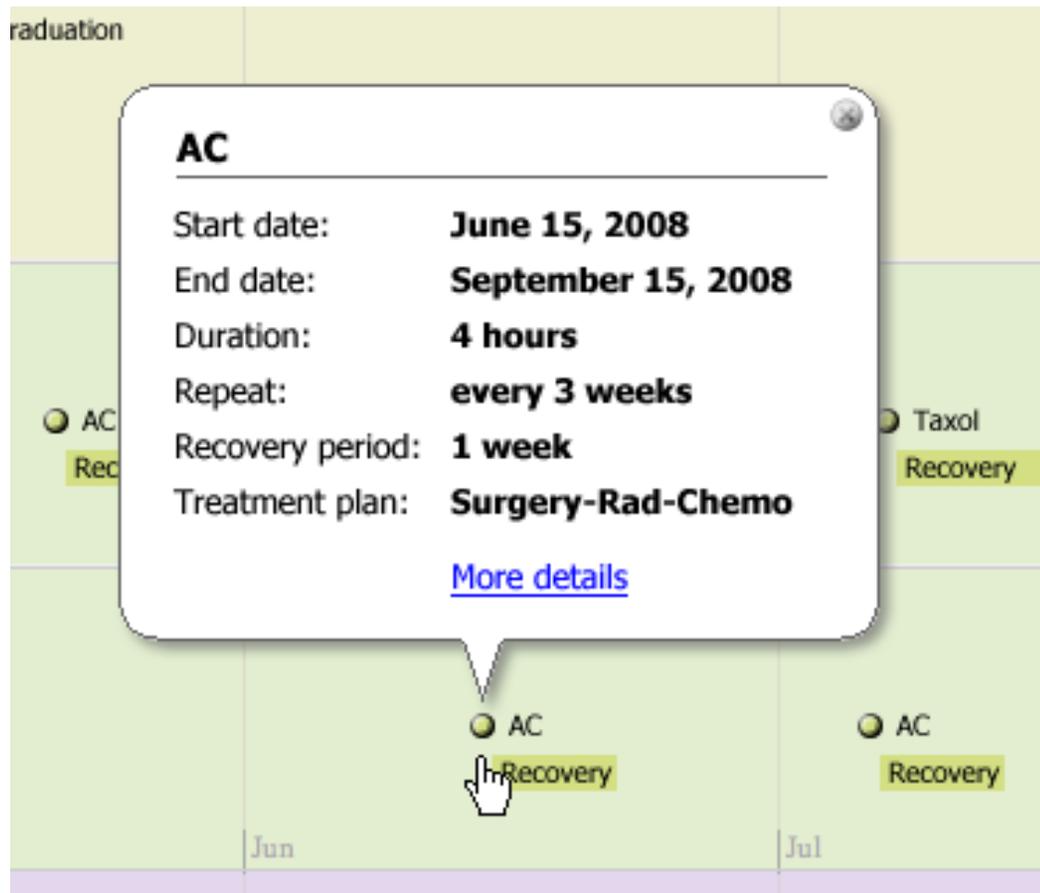
[Allergies: Click Here for Details](#)

Overview Problems Medications Allergies Results Appointments Encounters Diagnoses Observations Procedures

Summary Timeline Calendar

Show only







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Today **April 2008**
[Print](#)
[Day](#)
[Week](#)
[Month](#)
[Next 3 Days](#)
[Agenda](#)

« **April 2008** »

S	M	T	W	T	F	S
23	24	25	26	27	28	29
30	31	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	1	2	3
4	5	6	7	8	9	10

▼ ▼

My Calendars

- [Mary Bauske](#)
- [Surgery-Rad-Chemo](#)

Other Calendars

[Manage calendars](#)

Sun	Mon	Tue	Wed	Thu	Fri	Sat
30	31	1	2	3	4	5
			13:00 FW: review		11:15 Dr. Adams	
6	7	8	9	10	11	12
		Pre-Op Blood Draw		14:45 Dr Esserman	Send email to offic	
13	14	15	16	17	18	19
	08:00 Check in for S	Off work	Off work	11:00 Radiation Onc 15:00 Follow up visit		
20	21	22	23	24	25	26
11:00 Radiation						
27	28	29	30	1	2	3
11:00 Radiation						00:00 Jean's birthda

Where Do We Go From Here?

- CCP timeline/calendaring prototype completed by June 2008
- Additional focus groups and usability testing in Fall 2008
- Plan to incorporate *www.breastcancertrials.org* clinical trial matching service into CCP in Phase II
- Allow for structured pathology data to be uploaded into CCP tool
- Developing common data elements to incorporate structured patient intake survey data into CCP tool in Phase II
- Migrate video and booklet decision aids into on-line tools

Beyond User Centered Design

Wrap-Up

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Implementing UCD in the PHR environment

*UCD is more than just talking to a handful of
anticipated users*

- *Need to know:*
 - *Where to find users*
 - *How engage users*
 - *UCD techniques such as usability testing, prototyping, etc.*
 - *How many users you need*
 - *1 user to go all the way through the design and evaluation process*
 - *A set of users that you pull from at different stages*

Special Considerations

- Need to Consider:
 - Users are often ill, hence should be considered a **scarce resource**
 - Users participating in UCD have perverse motivation
 - Benefits of effort are not for the individual participating but for future users
 - PHRs also need to incorporate the perspectives of **secondary users**, e.g., clinicians or caregivers.
 - UCD can facilitate the tasks that multiple users want to accomplish, and when and where they will use the tool
 - ***E.g.***, data may be self-reported by the patient but must be recorded and presented in a manner accessible and useful to the physician

What can UCD Provide?

UCD is not only finding out what users want and need, but solutions that are congruent with their lives

- Need to Consider
 - UCD process:
 - Occurs throughout the product life cycle
 - Includes continuous improvement and evaluation
 - The full benefits of UCD are likely to occur when user input is incorporated early in the design and evaluation
 - Design requirements and scope will be better specified
 - Modifications introduced early are less costly than even minimal changes to the final product
 - Withholding these techniques until the evaluation phase is wasteful of both the respondents' time and the designers' efforts

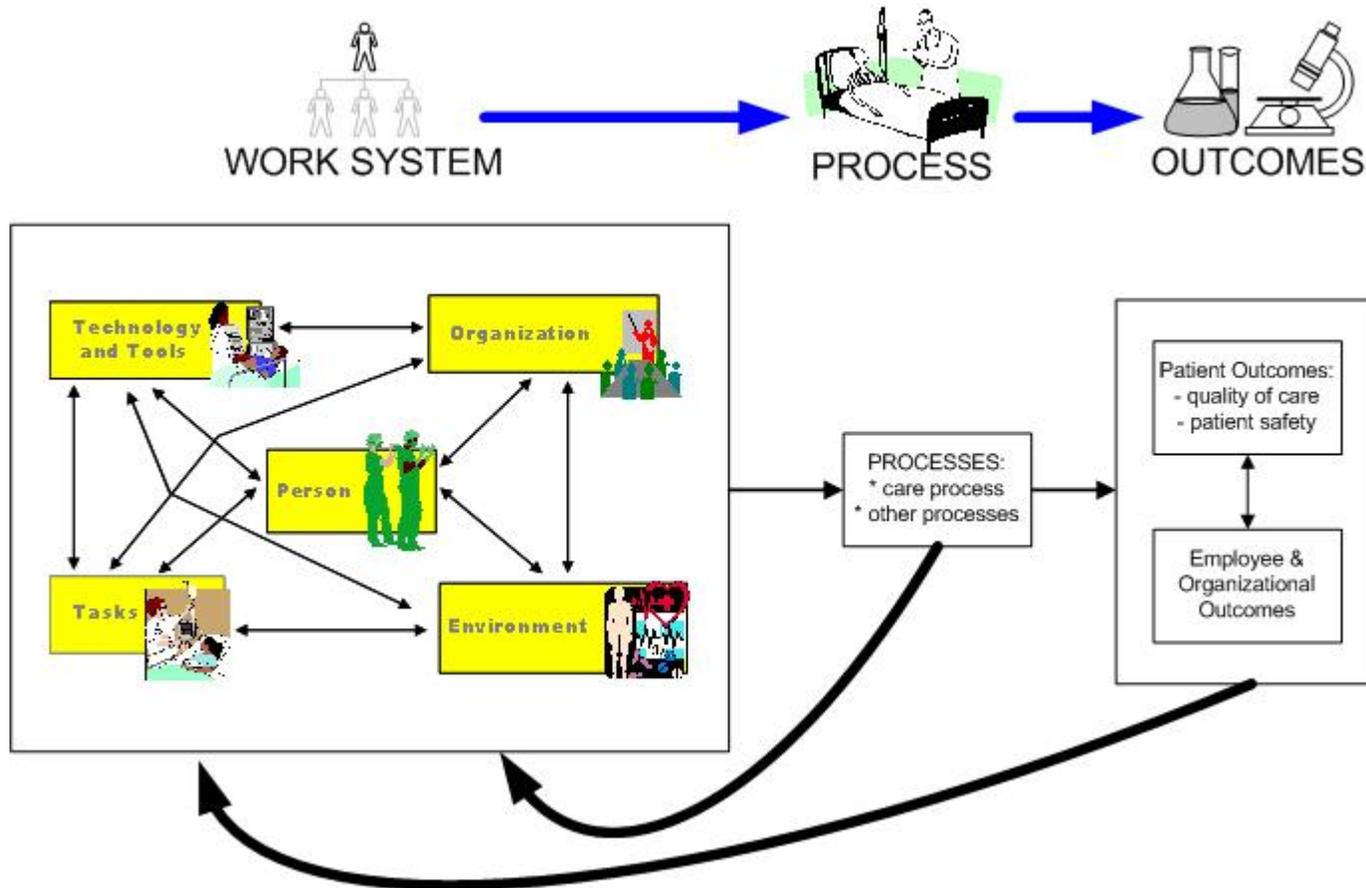
UCD helps keep the technology flexible

- Designers can:
 - Focus on the tools and functions desired by the intended users
 - Determine the tasks users want to perform and those they would prefer the technology do for them
 - Assessing appropriate levels of automation

Translating User Needs into Design Requirements

- A framework that organizes needs and aids requirements determination
- SEIPS – Systems Engineering Initiative for Patient Safety (<http://www2.fpm.wisc.edu/seips/>)

SEIPS Model of Work System & Patient Safety



Carayon, P., Hundt, A.S., Karsh, B.-T., Gurses, A.P., Alvarado, C.J., Smith, M. and Brennan, P.F. "Work System Design for Patient Safety: The SEIPS Model" to be published in *Quality & Safety in Health Care*, 2006.

SEIPS Model for PHRs

- Understand the
 - *Person*– lay people, caregivers, professionals
 - In a specific *environment*- home
 - Connected to selected *organizations* health care systems
 - Who must perform specific *tasks*- health information management, health behaviors
 - Using certain *tools and technologies* – computers, cell phones, monitors
- That are part of larger *Processes* – disease prevention or management
- Which lead to anticipated *Outcomes* – optimum well-being

Translating User Needs into Design Requirements

- A framework that organizes needs and aids requirements determination
- SEIPS – Systems Engineering Initiative for Patient Safety
- Design Requirements:
 - Technical – tools & technologies
 - Content – tasks, individuals who do them
 - Functions – tasks, environment, organization
 - Context – organization, environment

SEIPS-directed transformation of Needs → Design Requirements

- Technical – tools & technologies
- Content – tasks, individuals who do them
- Functions – tasks, environment, organization
- Context – organization, environment

Questions?

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Please visit us:

www.projecthealthdesign.org

healthsystems. engr.wisc.edu

pbrennan@ engr.wisc.edu

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