

Toward Personal Health Record Usability

National Library of Medicine

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Outline

- Emerging PHR
- The science of usability
- Usability issues and design space for PHRs
- New user interface styles and implications for PHRs
- Toward PHR usability guidelines



MHR→PHR

- MHRs: health costs, errors, IT culture, high profile
- PHRs:
 - Increase patient empowerment and improve decision making
 - Demographics (baby boomers)
 - IT and installed base of expertise and expectations
 - Health care costs and policies
 - Genetics, data mining, and personal histories
 - Self-serve society
- Growing literature on PHR advocacy but little on usability



Emerging Design Space

- PH record vs. PH system
- Print vs. **electronic** vs. hybrid
- Online vs. standalone vs. hybrid
- Generic vs. specialized (e.g. disease, function)
- Online or hybrid layering
 - To devices (personal monitors)
 - To MHRs and health care institutions
- Adjunct services
 - Help
 - Coaches



The Science (and Art) of Usability

- What we investigate
 - User interface techniques (treatment interventions)
 - Human capabilities and behaviors (ergonomics, work practices with emphasis on cognitive, affective, and physiological responses)
 - Socio and economic contexts (e.g., ROI)
- How we investigate
 - Prototypes and models
 - Laboratory experiments and field studies
 - Usability labs with logging (video, keystroke), eye tracking, biometrics (GSR, pulse, respiration, MRI)
 - Field studies with surveys, focus groups, observations, transaction logs
 - Effectiveness, efficiency, satisfaction
 - Time to learn, time to complete, accuracy, error types and rates, general satisfaction, adoption, engagement



Toward Usability Guidelines

- Interdisciplinary team at UNC-CH (Public Health, Medicine, Information & Library Science, Journalism & Mass Communication) integrates different knowledge bases and leverages existing usability labs
- Cross the PHR usability challenges with PHR functions and PHR data types to create a PHR usability matrix



Multiple Facets

- Literature synthesis
- PHR system landscape
- Four usability studies
- Design Mockups
- Synthesize framework



Extant PHRs

- Markle Foundation's Personal Health Technology list of 175 PHR products
- Characteristics
 - Connect to MHR? 36 (21%) yes, 139 (79%) no
 - Internet based? 151 yes (86%), 10 (6%) standalone, 15 (9%) device specific
 - Cost? Range from free to \$199 with some subscription models



New Interaction Styles

DL testphr1

Model	Health Data	Administrative Data	Other capabilities
0 Connected to an EHR system	18 Medication/prescription tra	17 Emergency contact	31 Physician messaging
116 Internet	18 Family history	24 Treatment history	10 Discussion/chat boards
0 Home-software	17 Medical history	27 Prescription refill	23 Online resources
0 Portable device	35 Immunizations	26 Appointment scheduling	7 Medication x-checking
	37 Allergies	20 Pay bills/expense tracking	22 Monitor
	29 Lab tests or results	17 Insurance	14 Information tailoring to pati
	4 Imaging documents	24 Reminders (appointments,	4 Consolidation service
	12 Diet and nutrition		
	13 Exercise		
	7 Physician documents		
	9 View critical data for emer		

0 result Search Fewer Categories << More Categories >>

PHR system name:	URL:	Cost:
PHR system name	URL	Cost

Java Applet Window



Usability for Installed Base and New Interaction Styles

IDL testphr1

Model: Health Data: Adminstrative Data: Other capabilities:

- 0 Connected to an EHR sys
- 12 **Internet**
- 0 Home-software
- 0 Portable device

Health Data:

- 2 Medication/prescription tra
- 5 Family history
- 3 Medical history
- 7 Immunizations
- 5 Allergies
- 4 Lab tests or results
- 0 Imaging documents
- 12 Diet and nutrition
- 11 Exercise
- 3 Physician documents
- 1 View critical data for emer

Adminstrative Data:

- 3 Emergency contact
- 5 Treatment history
- 0 Prescription refill
- 0 Appointment scheduling
- 0 Pay bills/expense tracking
- 0 Insurance
- 4 Reminders (appointments,

Other capabilities:

- 2 Physician messaging
- 4 Discussion/chat boards
- 4 Online resources
- 0 Medication x-checking
- 4 Monitor
- 2 Information tailoring to pati
- 1 Consolidation service

12 result(s) Restart Fewer Categories << More Categories >>

PHR system name:	URL:	Cost:
PHR system name	URL	Cost
My Health Connection - Excellus	https://www.excellusbcbs.com/	
HotHealth	https://www.hothealth.com/	
HealthRecordsOnline	http://www.healthrecordsonline.com/	\$44.95 CAD/yr
Your Portable Health Record ?	https://w	
feelWell Online	http://www	
Medicompass	http://www	
Personal Health Diary on the Web	http://www	
LifemastersOnline	www.life	
The Personal Fitness Expert Body Analyzer and Calorie Tra...	http://we	
WellPatient	http://www	
Personal Health Manager (PHM)	https://he	
Health Activity Tracker	http://www	

(Model=Internet) AND (Health Data=Diet and nutrition)



User Needs Assessment

- 43 semi-structured interviews, each 30-45 minutes with participants in four groups
 - Parents of young children
 - Adults with chronic illnesses
 - Adults caring for elderly parents
 - Older adults
- Qualitative coding



Results

- Current status:
 - Health records of some kind (primarily financial) are kept
 - Little confidence in ability to find and use records
 - Sharing records across health providers resulted in repetition of tests and procedures
- Ideal PHR
 - Data: lab test results, medications, appointments and their outcomes, providers' notes, and personal notes
 - Uses: prior to a visit to the doctor, to monitor trends in their health indicators over time, and when needed for emergency care
- Access and use
 - Comfortable with their health care provider accessing/updating, but very wary of anyone having access who is not directly involved in their care
 - Not universally comfortable with any external entity holding their records
 - Uncomfortable with responsibility of holding records themselves



Test Result Format

- 106 participants in two laboratory studies of display effects for bar charts versus tables with variation by number of results, normality, and order
- Experiment 1 (between subjects)
 - Quicker when looking at bar charts
 - Recall more accurate (strict criterion) when looking at bar charts
- Experiment 2 (within subjects)
 - Bar charts perceived to be easier to use
 - Tables especially disliked when compared to bar charts



Design Mockups for a PHR for Pregnancy

- Designs by UNC students: Songphan Choemprayong, Sanghee Oh, and Laura Sheble
- Time as the organizing dimension
 - Calendar motif
 - Timeline motif
- Five key facets: events (appointments), money, health data, journal, and resources



Flat Calendar Design

File Edit View Report Go Print Help

New Entry Edit Delete Today Go to... Day Week Month 5 weeks Log

Welcome, **Magnolia Cox**.
You are expecting your baby in 29¹/₇ weeks!

November 2005

December 2005

View: App Fin Jrnl Hea

SUN	MON	TUE	WED	THU	FRI	SAT
28	29	30	31	App 1 Fin Jrnl Hea	App 2 Fin Jrnl Hea	App 3 Fin Jrnl Hea
App 4 Fin Jrnl Hea	App 5 Fin Jrnl Hea	App 6 Fin Jrnl Hea	App 7 Fin Jrnl Hea	App 8 Fin Jrnl Hea	App 9 Fin Jrnl Hea	App 10 Fin Jrnl Hea
App 11 Fin Jrnl Hea	App 12 Fin Jrnl Hea	App 13 Fin Jrnl Hea	App 14 Fin Jrnl Hea	App 15 Fin Jrnl Hea	App 16 Fin Jrnl Hea	App 17 Fin Jrnl Hea
App 18 Fin Jrnl Hea	App 19 Fin Jrnl Hea	App 20 Fin Jrnl Hea	App 21 Fin Jrnl Hea	App 22 Fin Jrnl Hea	App 23 Fin Jrnl Hea	App 24 Fin Jrnl Hea
App 25 Fin Jrnl Hea	App 26 Fin Jrnl Hea	App 27 Fin Jrnl Hea	App 28 Fin Jrnl Hea	App 29 Fin	App 30 Fin	App 31 Fin

Wed, Dec 7 2005

- Appointment
- Financial
- Journal
- Health data**

Data

Weight _____

Pulse _____

Blood Pressure _____

Antibody _____

Hb g/L _____

RPR / TPHA _____

Hep B _____

Rubella Titre _____

Urine / MSU _____

Glucose _____

Other... _____

View (main window)

Chart my progress: weight

Compare: Pr

Log: Health d

Notes

Resources



Vertical Flat Timeline

File Edit View Report Go Print Help

New Entry Edit Delete Today Go to... Day Week Month 5 weeks Log

Welcome, **Magenta.Fox**.
You are expecting your baby in 29¹/₇ weeks!

◀ November 2005 ▶

S	M	T	W	T	F	S
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

Pregnancy Log

View

App Fin Jnl Hea

Time	Date	Event	Title / First line
10:00 a	1 Dec 05	App	Eleanor - Discuss complementary therapies
--:--	1 Dec 05	Fin	Supplements: Folic acid tablets
9:24 p	1 Dec 05	Jnl	When I went to the market today, the smell of oranges overcame me
8:55 a	1 Dec 05	Hea	Weight: 129
8:53 p	2 Dec 05	Jnl	I'm so tired of being inside, but it is freezing out. Maybe we should
9:00 a	2 Dec 05	Hea	Weight: 129
9:37 p	3 Dec 05	Jnl	Just got off the phone with Penelope! I guess I'll give her a call back.
9:02 a	3 Dec 05	Hea	Weight: 130
8:57 p	6 Dec 05	Jnl	At last, an evening to myself. Between this and not having to change
10:20 a	6 Dec 05	Hea	Weight: 130
6:45 p	7 Dec 05	Jnl	What a day, what a day! If there is one thing that is for certain, it's this:
9:05 a	7 Dec 05	Hea	Weight: 130
10:00 a	29 Dec 05	App	Eleanor - Routine visit 138 Kalamazoo Ave Dahlonega, GA 67692 (404) 555 - 1212 Apt. Recommendation: Open in side window. Notes: None Open in side window to edit
--:--	30 Dec 05	Fin	Deposit - Lamaze class due

▶ Wed, Dec 7 2005

▶ Appointment

▶ Financial

▶ Journal

Arial b i T MS

6:45p: What a day, what a day!
If there is one thing that is for certain, it's this: becoming pregnant has made me no more on time than I ever was. I didn't get out of the house until 9:45 - definitely not enough time to get to Eleanor's office. Good thing I was instructed not to eat anything before going in. There is no way I'd've been able to eat at any rate.

At least everything went well once I got in to see Elanor. Just a bit of poking and proding. But this is pretty exciting all at once. I keep saying to myself: "Take it easy, take it easy. Don't rush things." One more day until the end of the first trimester! I'm still active - light jog or fast walk in the afternoon a couple of times a week, but I can

▶ Health

▶ Resources



Layered Timeline

File Edit Report View Go Help Pregnancy Records [X]

Login as: Magenta Fox | Update Profile

Today

December 7, 2005

Overview	Daily	Weekly	Trimester
Nov. 24, 2005	Week 11	Nov. 30, 2005	Dec. 1, 2005
Week 11	Week 11	Week 12	Week 13
Dec. 1, 2005	Dec. 7, 2005	Dec. 8, 2005	Dec. 14, 2005
<p>Today</p> <p>- Glucose test with Dr. Lyda (8:30am-10am)</p> <p>December 4, 2005 (2 appointments) December 1, 2005 (1 appointment)</p> <p style="text-align: right;">Appointment</p>		<p>December 10, 2005 (1 appointment) December 11, 2005 (1 appointment) December 13, 2005 (1 appointment) December 14, 2005 (1 appointment)</p> <p style="text-align: right;">Appointment</p>	
<p>What a beautiful day (12/7/05) Home sweet home (12/5/05) Nothing to worry about, I said (12/4/05) Mom is coming to town (12/3/05) Oh la la la (12/3/05)</p> <p style="text-align: right;">Diary</p>		<p>What a beautiful day (12/7/05) Home sweet home (12/5/05) Nothing to worry about, I said (12/4/05) Mom is coming to town (12/3/05) Oh la la la (12/3/05)</p> <p style="text-align: right;">Diary</p>	
<p>Total for this week: \$0.00 Reimbursement: \$0.00 Actual Paid: \$0.00 Accumulative: \$786.52 Total Reimbursement: \$493.02 Total Actual Paid: \$293.52</p> <p style="text-align: right;">Finance</p>		<p>Total for this week: \$129.00 Reimbursement: \$59.00 Actual Paid: \$70.00 Accumulative: \$851.52 Total Reimbursement: \$551.52 Total Actual Paid: \$300.00</p> <p style="text-align: right;">Finance</p>	
<p>Wikipedia: Pregnancy Overview Information</p> <p>Dietary Advice - Dr. Peter Steptoe</p> <p style="text-align: right;">Resources</p>		<p>Wikipedia: Pregnancy Overview Information</p> <p>BBC Pregnancy Timeline - Screening for down's syndrome should be about now.</p> <p style="text-align: right;">Resources</p>	
<p>Weight 175 lbs Normal Blood Pressure N/A Urinalysis Normal Normal Gestation 28 inches Normal Presentation Head left Normal</p> <p style="text-align: right;">Health</p>		<p>Weight 160 lbs Normal Blood Pressure 110-80 Normal Urinalysis Normal Normal Gestation 30 inches Normal Presentation Head down Prompt</p> <p style="text-align: right;">Health</p>	
Nov. 24, 2005	Week 11	Nov. 30, 2005	Dec. 1, 2005
Week 11	Week 11	Week 12	Week 13
Dec. 1, 2005	Dec. 7, 2005	Dec. 8, 2005	Dec. 14, 2005



Multilayered Timeline

File Edit View Report Go Help

Welcome **Magenta** Today is **December 7, Wednesday**. You have **203** days to meet your baby

Daily

Weekly

Trimester

Week 9	Week 10	Week 11	Week 12	Week 13	Week 14	Week 15
11/28 - 11/24	11/21 - 11/17	11/14 - 11/10	11/07 - 11/13	10/31 - 12/06	10/24 - 10/30	10/17 - 10/23

Week 12' Highlight 2005. 12. 07 (Wed) - 2005. 12. 13 (Tue)

Search

- Appointment
- Diary
- Test Records
- Finance
- Resources

Appointment

[7 \(Wed\)](#) 1:30 pm Regular check-up

3:00 pm Meet Greg Mom

[9 \(Fri\)](#) 11:00 am Childbirth class

[more](#) ↘

Diary

[7 \(Wed\)](#) What a beautiful day-!

[more](#) ↘

Health

Lab result				
7 (Wed)	A	150	0.4	1.1
8 (Thu)	N/A	N/A	N/A	N/A
9 (Fri)	N/A	N/A	N/A	N/A

[more](#) ↘

Finance

[7 \(Wed\)](#) Medicine: Vitamin (\$30)

[13 \(Tue\)](#) Health insurance: monthly payment (\$60)

[more](#) ↘

Resources

Publications

- Health & Child
- How pregnancy can be safely maintained
- AOL video [more](#)

Support groups

- Durham mom club
- UNC Education center

[more](#)

Directory

- Urgent Care
- Dr. Smith
- Midwife: Elanor [more](#)

Internet Resources

- [UNC Hospital](#)
- [Online Childbirth Class](#)

[more](#)

PubMed

Google



PHR Usability Challenges

- Challenges related to interaction design
 - Complexity
 - Vocabulary mappings
 - Older users
 - Health literacy
- Challenges related to access and control
 - Data entry and data collection
 - Error checking
 - Online/Offline
 - Privacy/security
 - Preservation and life long use



PHR Functionality Space

- Find and view data
- Enter and collect data (direct or download)
- Exchange data (send and receive, including local and intermediate devices)
- Make decisions (information, tools)
- Alerts and Reminders
- Manage finances
- Manage PHR (e.g., security, preferences)



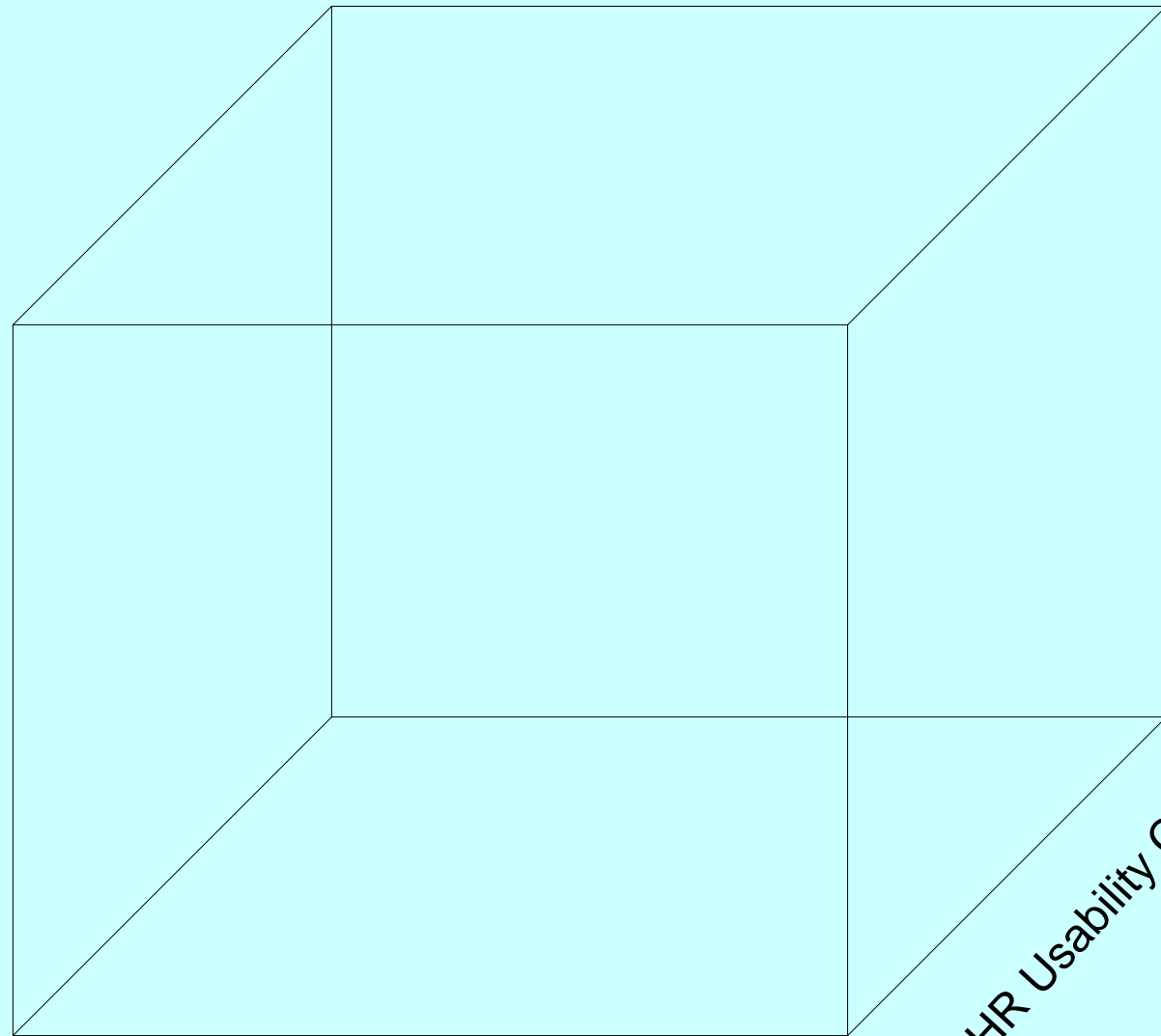
PHR Data Space

- Personal Information (individual, family, health care providers and contact info, insurers, history, pets)
- Complaints (problem list)
- Diagnoses
- Procedures
- Lab results
- Immunizations
- Allergies
- Medications
- Advance Directives
- Nutrition and diet
- Exercise
- Personal commentaries
- Information Resources (literature, glossaries, encyclopedias, webpages, listservs)



PHR Usability Guideline Framework

PHR Data Types



PHR Functions

PHR Usability Challenges



Develop the PHR Usability Guideline Framework

- Link the cells to evidence
 - Related specifically to PHRs
 - Related to MHRs or other similar systems
 - General studies of usability on systems that could generalize to PHRs
- Evaluate specific vectors within a health behavior framework (e.g., cancer treatment plans)
- Influence new PHR system design to promote adoption and leverage new capabilities



The Vision:

Usable PHRs will be adopted.

this implies:

Patient involvement will increase

People will lead healthier lives

Health resources will be maximized