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

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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

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# Usability for Installed Base and New Interaction Styles

<table>
<thead>
<tr>
<th>Model</th>
<th>Health Data</th>
<th>Administrative Data</th>
<th>Other capabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connected to an EHR sys</td>
<td>Medication/prescription</td>
<td>Emergency contact</td>
<td>Physician messaging</td>
</tr>
<tr>
<td>Internet</td>
<td>History</td>
<td>Treatment history</td>
<td>Discussion/chat boards</td>
</tr>
<tr>
<td>Home-software</td>
<td>Medical history</td>
<td>Prescription refill</td>
<td>Online resources</td>
</tr>
<tr>
<td>Portable device</td>
<td>Immunizations</td>
<td>Appointment scheduling</td>
<td>Medication x-checking</td>
</tr>
<tr>
<td></td>
<td>Allergies</td>
<td>Pay bills/expense tracking</td>
<td>Monitor</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>Lab tests or results</td>
<td>Insurance</td>
<td>Information tailoring to pati</td>
</tr>
<tr>
<td>Exercise</td>
<td>Physician documents</td>
<td>Reminders (appointments, medication)</td>
<td>Consolidation service</td>
</tr>
<tr>
<td>View critical data for emergence</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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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

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Vertical Flat Timeline

Pregnancy Log

- 12 Dec 05 10:00 a App: Eleanor - Discuss complementary therapies
- 1 Dec 05 12:00 p Fin: Folic acid tablets
- 1 Dec 05 9:24 p Jnl: When I went to the market today, the smell of oranges overcame me
- 1 Dec 05 8:55 a Hea: I'm so tired of being inside. But it is freezing out. Maybe we should
- 1 Dec 05 9:00 a Hea: Just got off the phone with Penelope! I guess I'll give her a call back.
- 3 Dec 05 9:37 p Jnl: At last, an evening to myself. Between this and not having to change
- 3 Dec 05 9:02 a Hea: Just got off the phone with Penelope! I guess I'll give her a call back.
- 6 Dec 05 8:57 p Jnl: What a day, what a day! If there is one thing that is for certain, it's this:
- 6 Dec 05 10:20 a Hea: What a day, what a day! If there is one thing that is for certain, it's this:
- 7 Dec 05 6:45 p Jnl: What a day, what a day! If there is one thing that is for certain, it's this:
- 7 Dec 05 9:05 a Hea: What a day, what a day! If there is one thing that is for certain, it's this:
- 29 Dec 05 10:00 a App: Eleanor - Routine visit
- 30 Dec 05 12:00 p Fin: Payment - Lamaze class due

Welcome, MagentaFox.
You are expecting your baby in 29+ weeks!
Layered Timeline

<table>
<thead>
<tr>
<th>Overview</th>
<th>Daily</th>
<th>Weekly</th>
<th>Trimester</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nov. 24, 2005</td>
<td>Week 11</td>
<td>Nov. 30, 2005</td>
<td></td>
</tr>
<tr>
<td>Dec. 7, 2005</td>
<td>Week 12</td>
<td>Dec. 1, 2005</td>
<td>Week 13</td>
</tr>
<tr>
<td>Dec. 8, 2005</td>
<td>Week 13</td>
<td>Dec. 14, 2005</td>
<td></td>
</tr>
</tbody>
</table>

Today
- Glucose test with Dr. Lila (8:30am-10am)
- December 4, 2005 (2 appointments)
- December 1, 2005 (1 appointment)

Appointment

Diary
- 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 (12/3/05)

Finance
- Total for this week: $120.00
- Actual Paid: $70.00
- Accumulative: $851.22
- Total: $851.22
- Total Actual Paid: $20.00

Resources
- Weight: 175 lbs Normal
- Blood Pressure: N/A Normal
- Urinalysis: Normal Normal
- Gestation: 28 inches Normal
- Presentation: Head left Normal

Wireless: Pregnancy
- Overview Information
- Dietary Advice: Dr. Peter

Resources
- Weight: 180 lbs Normal
- Blood Pressure: 110-80 Normal
- Urinalysis: Normal Normal
- Gestation: 30 inches Normal
- Presentation: Head down Prompt

Wireless: Pregnancy
- Overview Information
- Dietary Advice: Dr. Peter

Resources
- Weight: 180 lbs Normal
- Blood Pressure: 110-80 Normal
- Urinalysis: Normal Normal
- Gestation: 30 inches Normal
- Presentation: Head down Prompt
Multilayered Timeline

Welcome Magenta

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

Week 12

Week 9  Week 10  Week 11  Week 12  Week 13  Week 14  Week 15

0 Daily

0 Weekly

0 Trimester

Week 12' Highlight


Appointment

7 (Wed)  1:30 pm  Regular check-up
3:00 pm  Meet Greg Mom
9 (Fri)  11:00 am  Childbirth class

Diary

7 (Wed)  What a beautiful day~!

Health

Finance

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

7 (Wed)  Medicine: Vitamin ($30)
13 (Tue)  Health insurance: monthly payment ($60)
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)
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