

Connecting Americans to Their Health Care: *Empowered Consumers, Personal Health Records and Emerging Technologies*



**NATIONAL CONFERENCE
DECEMBER 7-8, 2006
WASHINGTON, D.C.**

Connecting Americans to Their Health Care:

*Empowered Consumers, Personal Health Records
and Emerging Technologies*

2006

User-Centered Design

Steve Downs - Robert Wood Johnson Foundation

Holly Massett - National Cancer Institute

Patti Brennan - University of Wisconsin-Madison

Stefanie Fenton - Intuit



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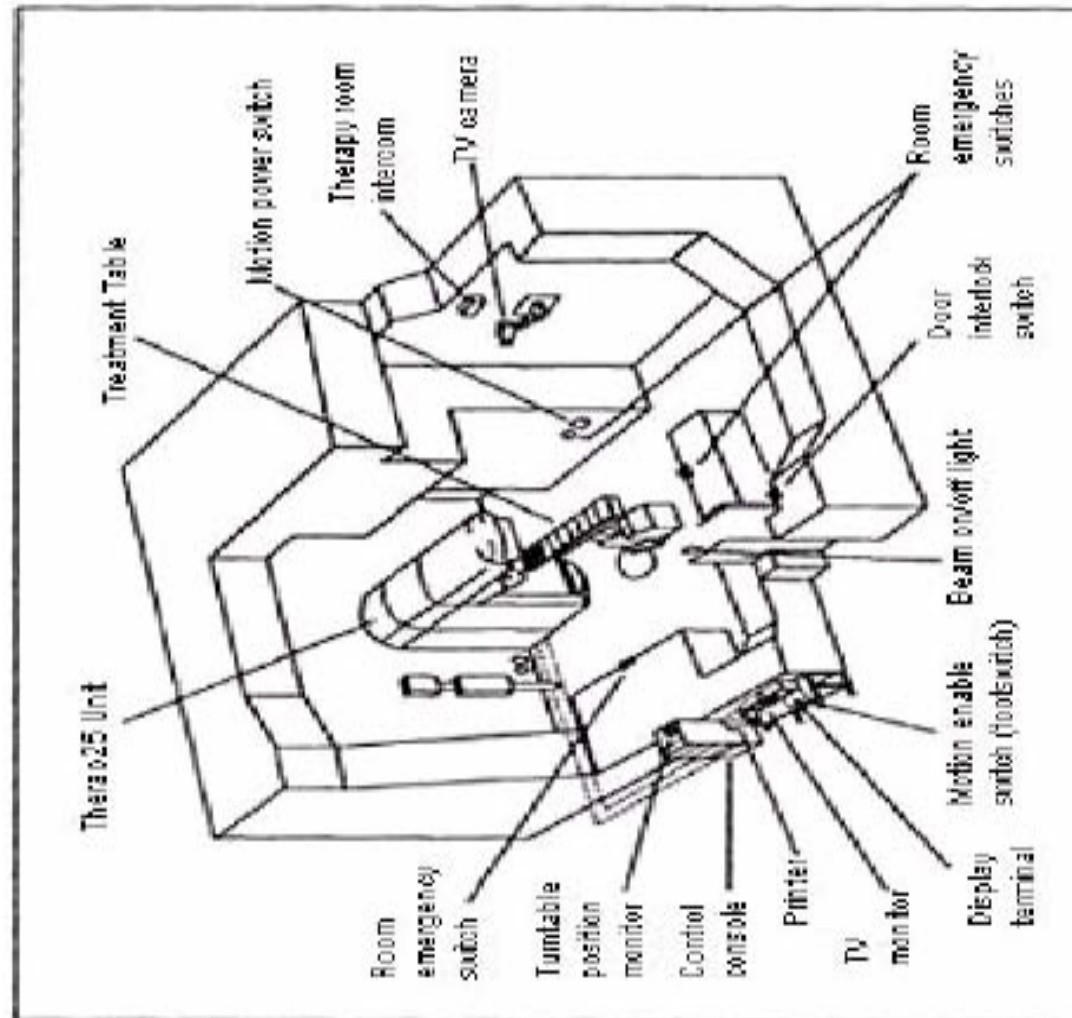
MARKLE FOUNDATION


Robert Wood Johnson Foundation

**It's all about the users:
Why and how we include them from
the beginning**

Holly A. Massett, PhD
National Cancer Institute

Therac-25 Case Study*



*Case study adapted from presentation given by Dan Russell, Google to the National Cancer Institute, March 2, 2006; <https://www.informaticsinaction.com/DanSlides.pdf>

Therac-25 Case Study (cont.)

PATIENT NAME	: TEST				
TREATMENT MODE	: FIX	BEAM TYPE	: X	ENERGY (KeV)	: 25
		ACTUAL		PRESCRIBED	
UNIT RATE/MINUTE		0		200	
MONITOR UNITS		50		200	
TIME (MIN)		0.27		1.00	
GANTRY ROTATION (DEG)		0.00		0	
VERIFIEDCOLLIMATOR ROTATION (DEG)		359.2	359	VERIFIED	
COLLIMATOR X (CM)		14.2	14.3	VERIFIED	
COLLIMATOR Y (CM)		27.2	27.3	VERIFIED	
WEDGE NUMBER		1	1	VERIFIED	
ACCESSORY NUMBER		0	0	VERIFIED	
DATE	: 84-OCT-26	SYSTEM	: BEAM READY	OP.MODE	: TREAT AUTO
TIME	: 12:55. 8	TREAT	: TREAT PAUSE	X-RAY	173777
OPR ID	: T25VO2-RO3	REASON	: OPERATOR	COMMAND	: _____

*Case study adapted from presentation given by Dan Russell, Google to the National Cancer Institute, March 2, 2006; <https://www.informaticsinaction.com/DanSlides.pdf>

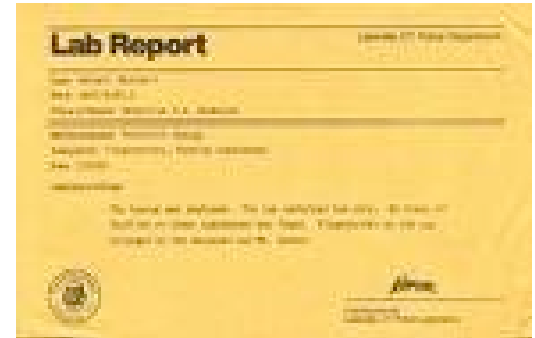
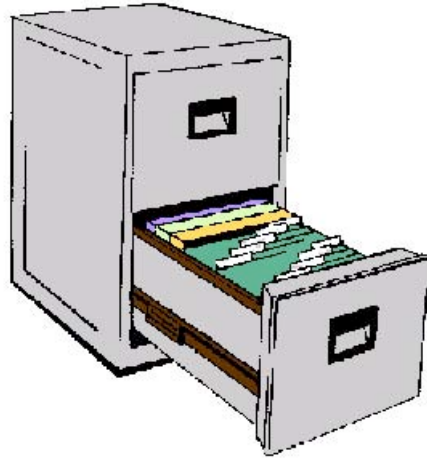
Inevitability of PHRs?

- PHR products now number 125...and growing^a
- 6 out of 10 Americans support the creation of a secure online PHR^a
- nearly 1 in 3 surveyed report they or a family member have created some form of medical record keeping^b

^aMarkle, 2005

^bKaiser /AHRQ/Harvard SPH, 2004

Current PHR systems



APRIL 2006

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	
	Business County Fair will	Live Oak at the Swanton	County Fairgrounds March 31-April 9	Concord the Town			
1	2. Essex Co. Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	4. Columbia County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	3. Rutland County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	5. South Co. Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	6. Grand Isle Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming		
8. Alameda County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	13. City of Champlain Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	14. Putnam County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	15. Addison County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	16. Franklin County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	17. Orleans County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	18. Washington County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	
19. Addison County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	20. Franklin County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	21. Orleans County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	22. Washington County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	23. Essex County Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	24. Grand Isle Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	25. South Co. Pioneer Day May 1833 Band at Middlebury College. Many local activities at Middlebury College. Pioneer Day Parade, Homecoming, Homecoming	
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**Doctor's appt
10:15**



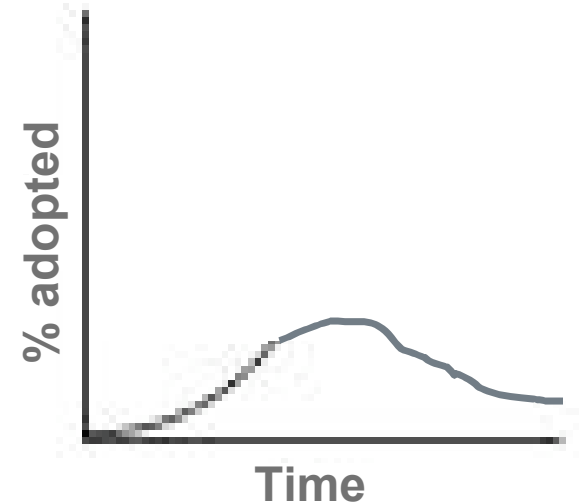
**The value of an idea lies in
the using of it.**

~Thomas A. Edison

Diffusion of Innovations

Perceived Attributes:

- Relative advantage
- Compatibility
- Simplicity
- Observability
- Trialability



Failed adoption curve

Power of medicine

Medical errors the 8th leading cause of death in US^b

-most are system-related

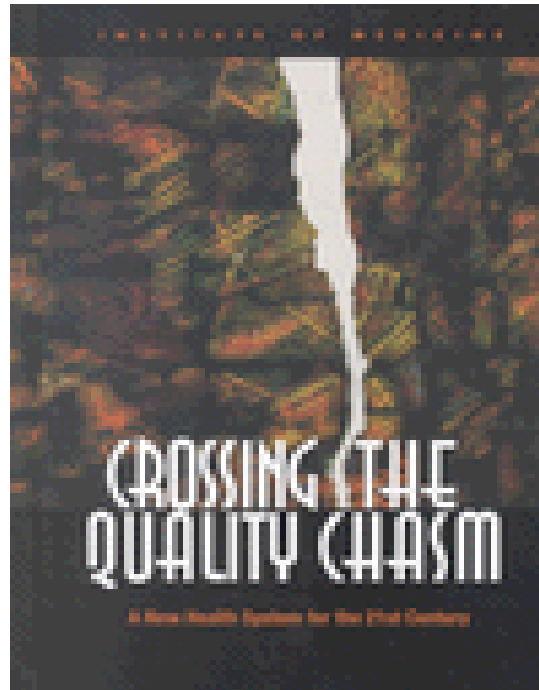
Garden City woman underwent surgery, radiation, only to be told of lab error - she never had the disease

(*Newsday*, New York, 09/27/2006)

^aChantler, Cyril. "The role and education of doctors in the delivery of health care." *Lancet* 1999; 353:1178-81.

^bInstitute of Medicine (IOM; November, 1999), *To Err is Human: Building a Safer Health System*

Need for New Health Care



Six Aims for Improvement

- 1) Safe
- 2) Effective
- 3) Patient-centered**
- 4) Timely
- 5) Efficient
- 6) Equitable



PHRs must function in context



Scientific approach to developing patient-centered PHRs

- Consider social, organizational & cultural context
- Specify users and tasks
- Predict and measure
- Improve satisfaction
- Accommodate individual differences

User-centered design (UCD) research

Understand the needs of your users and how your product will behave and be used in their real world.*

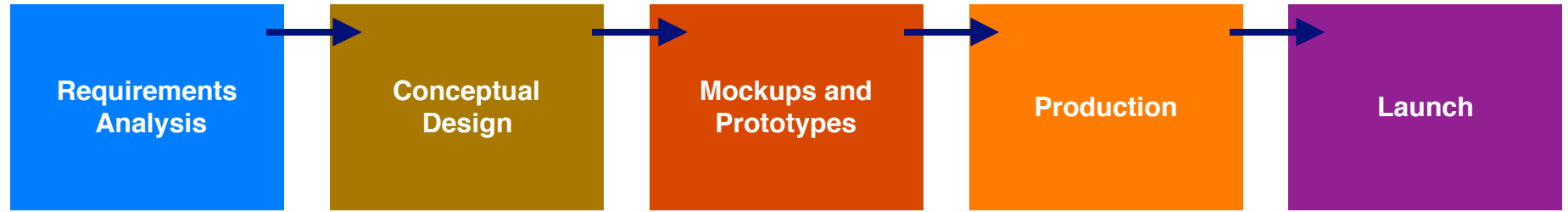
Our goal: Design PHRs that help users meet their needs

*Adapted from: Garrett, J. J. (2003). The elements of user experience: User-centered design for the web.

What to learn

- What people think
- What people do
- People's mental model
- Opinions, preferences, and emotional reactions to a concept or user interface
- How well users respond to your interface design

Many UCD options



- Market scan
- Goal setting
- Audience analysis
- Interviews
- User panels
- User survey
- Contextual inquiry
- Usage log analysis
- Search log analysis
- Usability tests
- Expert review

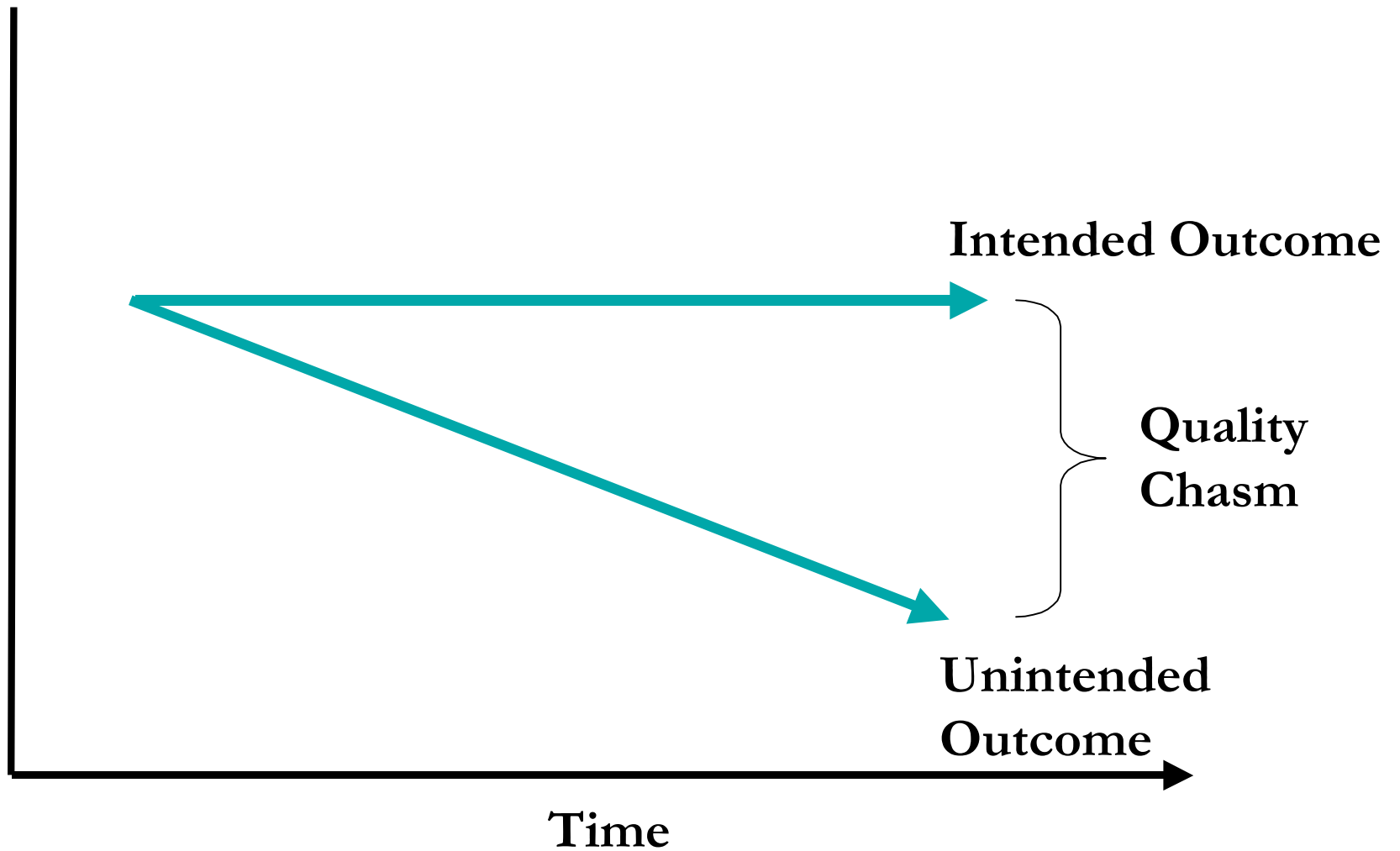
- Site Mapping
- Brainstorming
- Card sorting
- Task analysis
- Storyboarding
- Info. architecture
- Function specs
- Integrate with marketing plans
- Design guidelines
- Expert review

- Focus groups
- Interviews
- Usability testing
- Behavioral coding

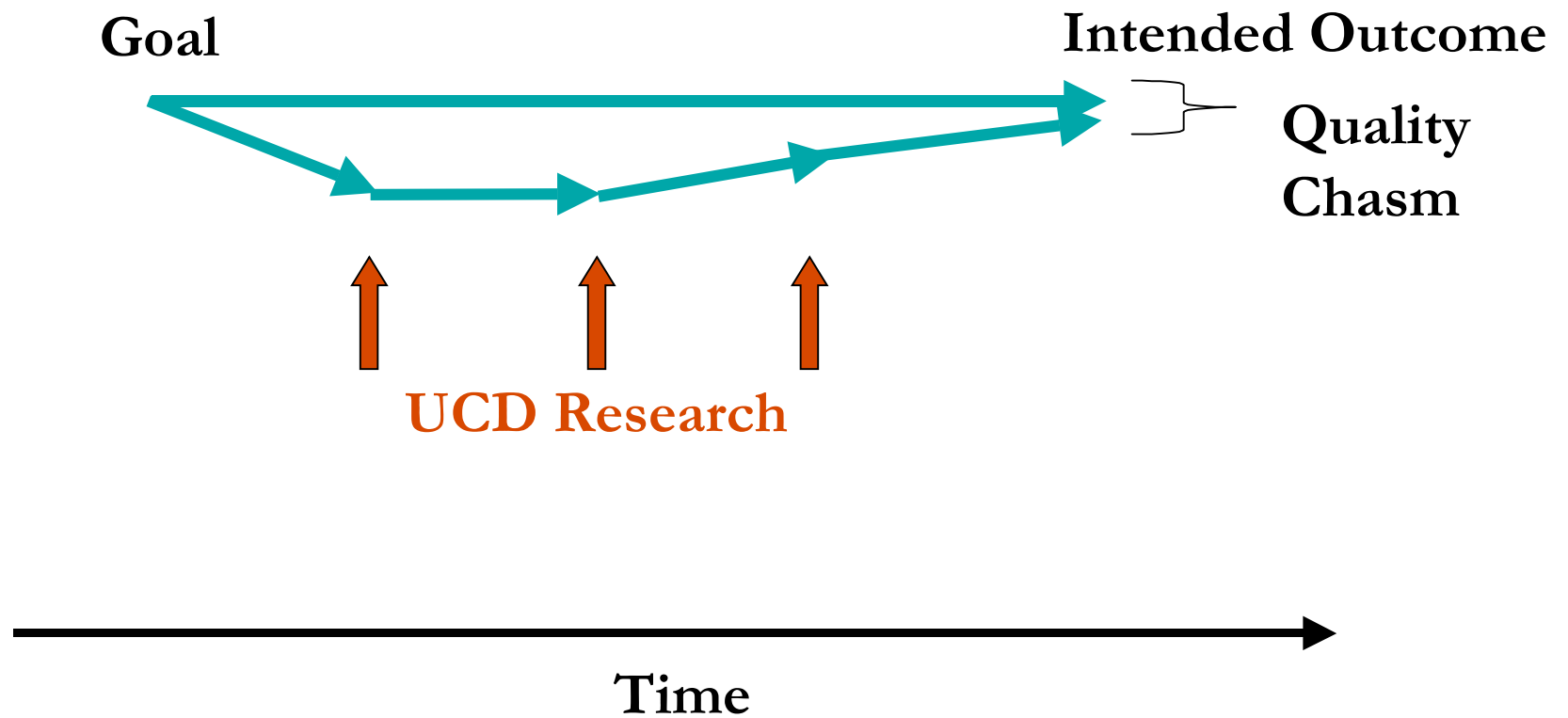
- Usability checklists
- Design guidelines
- Template use
- Usability testing
- Behavioral coding

- Usage log analysis
- Bounce-back Surveys
- Remote usability Testing
- Expert review
- Behavioral coding

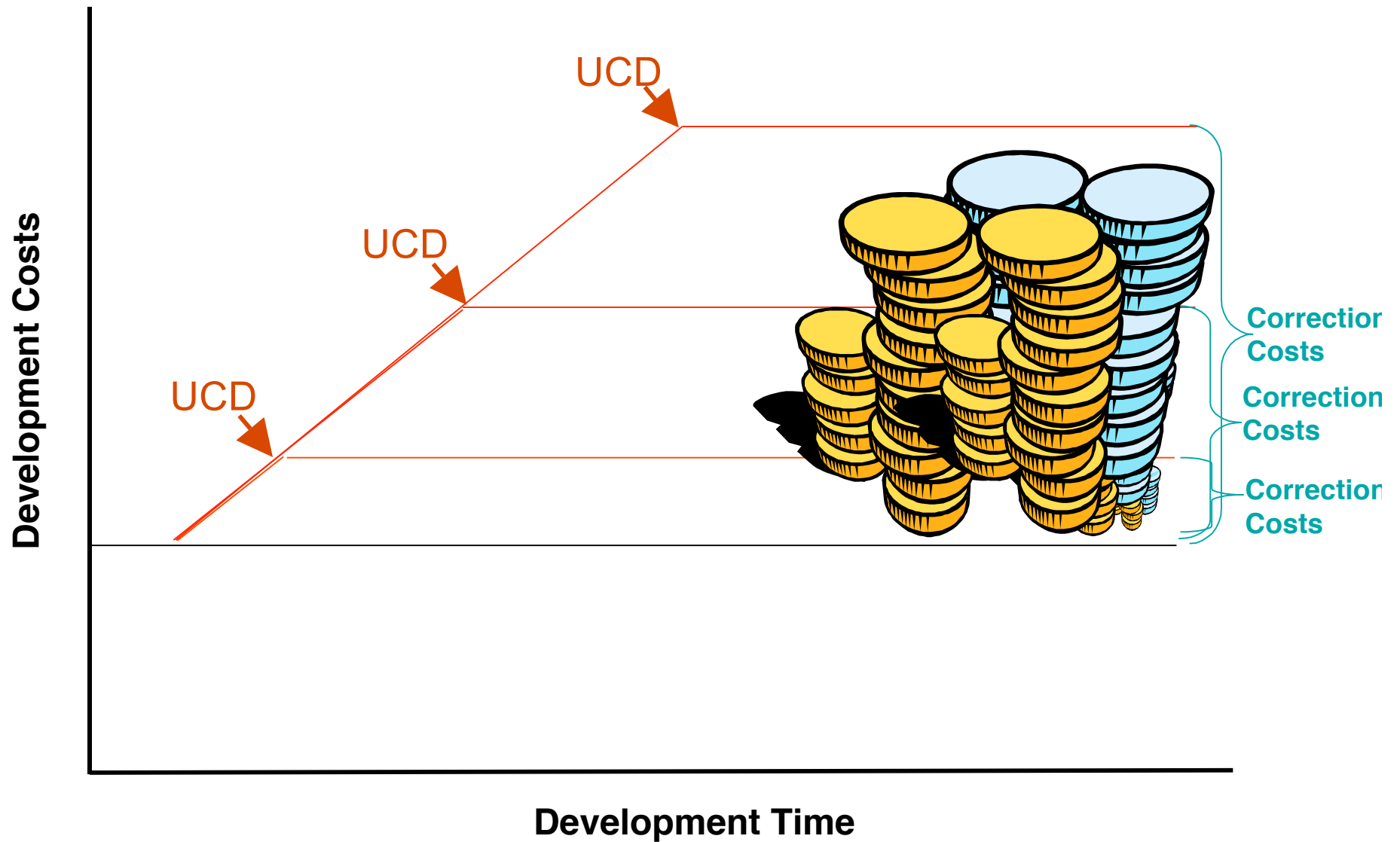
The Quality Chasm



Closing the Quality Chasm



UCD Should Occur Early in Cycle



Costs of NOT Conducting Research

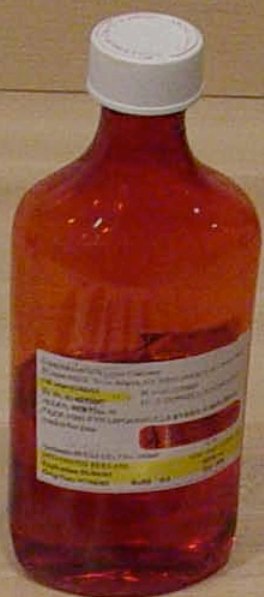
- “Inadequate [UCD] in software development projects ... cost the U.S. economy about \$30 billion per year.”^a
- “Once a system is in development, correcting a problem costs 10 times as much as fixing [it] in design.”^b
...[Once released] it costs 100 times as much.”

^aLandauer, 1995

^bGilb, 1998

PHR user challenges

- **Interaction design**
 - Complexity
 - Vocabulary mappings
 - Older users
 - Health literacy
- **Access and control**
 - Data entry and data collection
 - Error checking
 - Online/Offline
 - Privacy/security
 - Preservation and life long use



The doctor
said "1
teaspoon 4
times a
day..."



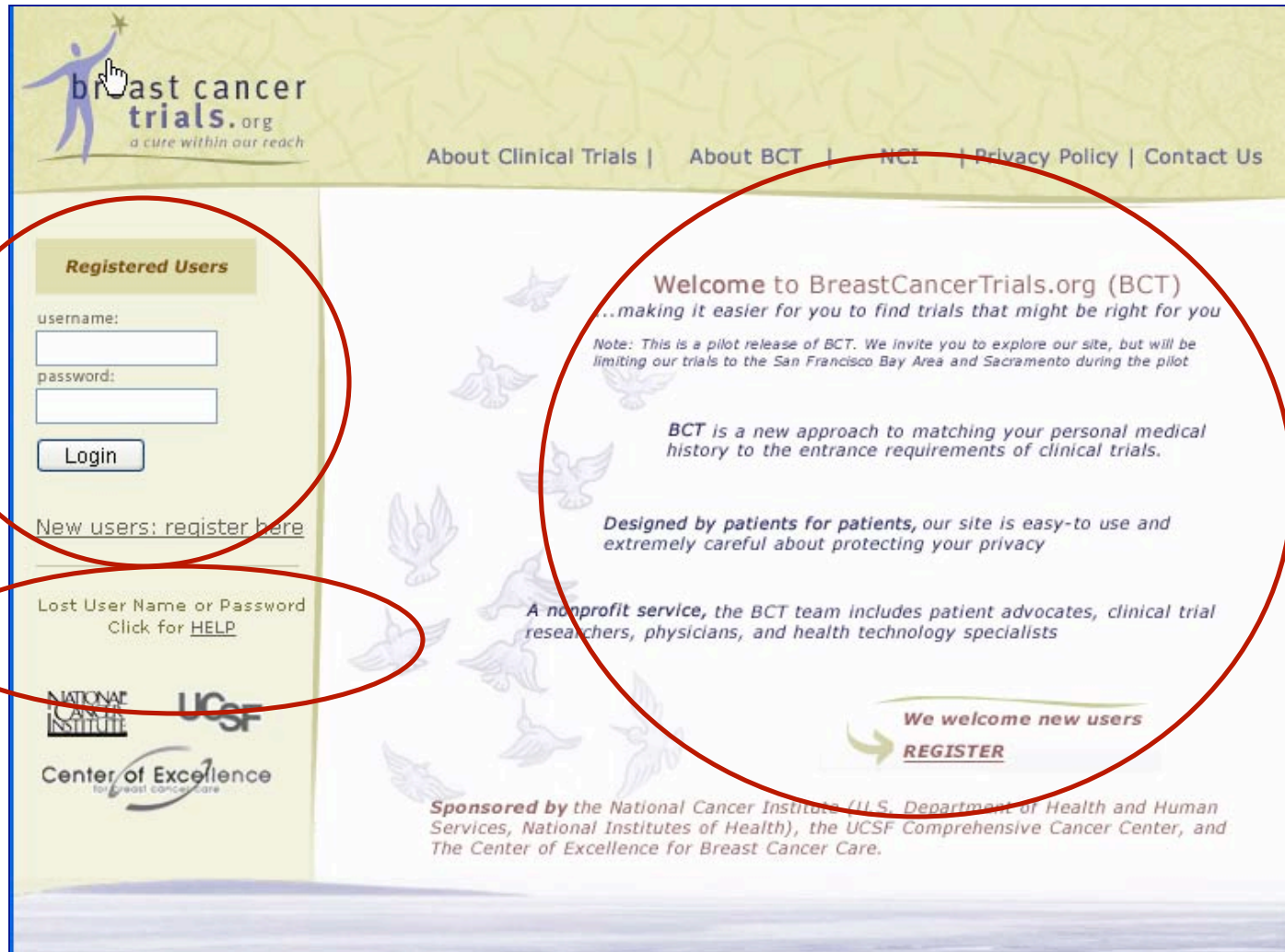
Health literacy: Losing weight safely

“The Dietary Guidelines for Americans recommends a half hour or more of moderate physical activity on most days, preferably every day. The activity can include brisk walking, calisthenics, home care, gardening, moderate sports exercise, and dancing.”




“Do at least 30 minutes of exercise, like brisk walking, most days of the week.”

caMatch (breastcancertrials.org): Before






caMatch: After




breast cancer
trials.org
a cure within our reach

Sponsored by:

[Home](#)
[About Clinical Trials](#)
[About This Site](#)
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[Contact Us](#)

WELCOME TO BREASTCANCERTRIALS.ORG 

helping you find the right breast cancer clinical trials

BreastCancerTrials.org (BCT) is a new approach that matches your personal medical history to research studies seeking patients like you. This is a free service sponsored by the National Cancer Institute, the University of California, San Francisco Comprehensive Cancer Center and The Center of Excellence for Breast Cancer Care.

What are breast cancer clinical trials?
 Breast cancer clinical trials are research studies to find better ways to treat breast cancer. They often compare the most accepted treatment (standard treatment) with a new treatment that doctors hope will be even better. It is important that people of all ages and backgrounds take part in these studies so that what is learned will help breast cancer patients now and in the future. [LEARN MORE](#)

What makes us better?
 First, create your private, online Personal Health Record (PHR). You will be asked to provide information about your current health, your cancer diagnosis, and your treatment. Then, using this information, you will be matched with any clinical trials that might be right for you. As time goes on, you will be alerted, via email, to additional matches that may arise. [LEARN MORE](#)

When there is a match, you will get a summary of the trial and contact information for the research team. It is entirely up to you whether or not to make contact.

Why should I register to use the site?
 When you register you ensure that your personal health information is saved and protected with a password. You will be able to come back to the site without having to re-enter information, and will enable BCT to notify you via email as new trials become available that match your health history.

Is the site safe?
 All of the information you enter on this site is protected with your password and stored securely at the National Cancer Institute. Your information will never be released without your permission and members of the research team cannot view your PHR without your consent. [LEARN MORE](#)

Can I get help using the site?

NEW to this site?

- [View examples of trials in your area.](#)
- [Take a tour of the service.](#)
- [Find trials specific to your diagnosis.](#)

Returning Users Login

Username:

Password:

[Forgot Username/Password?](#)

New users: [Find trials specific to your diagnosis.](#)

Final thoughts on UCD

- Conduct UCD early and often: be Informed and Iterative
- Real world: *Some* information is better than none
- You are not your users—even if you are. . . 😊
- Garbage In, Garbage Out – demand professional, unbiased research
- Essential to act on the findings and re-evaluate your new design

“People just need to understand the vision.”



“There’s a problem? We’ll fix it in the next software release.”

“Users just need more training.”

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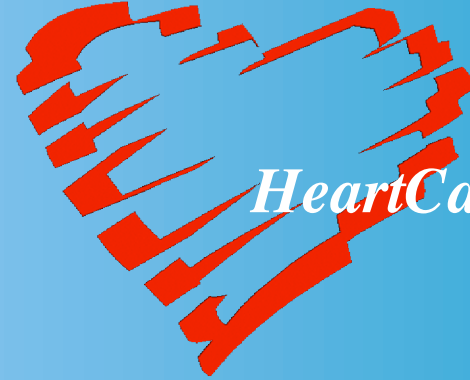
2006

User-Centered Design

Patricia Flatley Brennan

University of Wisconsin-Madison





HeartCare II

Personal Health Records: Design for activation

Patricia Flatley Brennan, RN, PhD, FAAN

Overview

- ▶ Personal Health Records: Actionable Information
- ▶ The challenge of design
- ▶ Environments as a way of organizing design recommendations
- ▶ Conclusion

Project

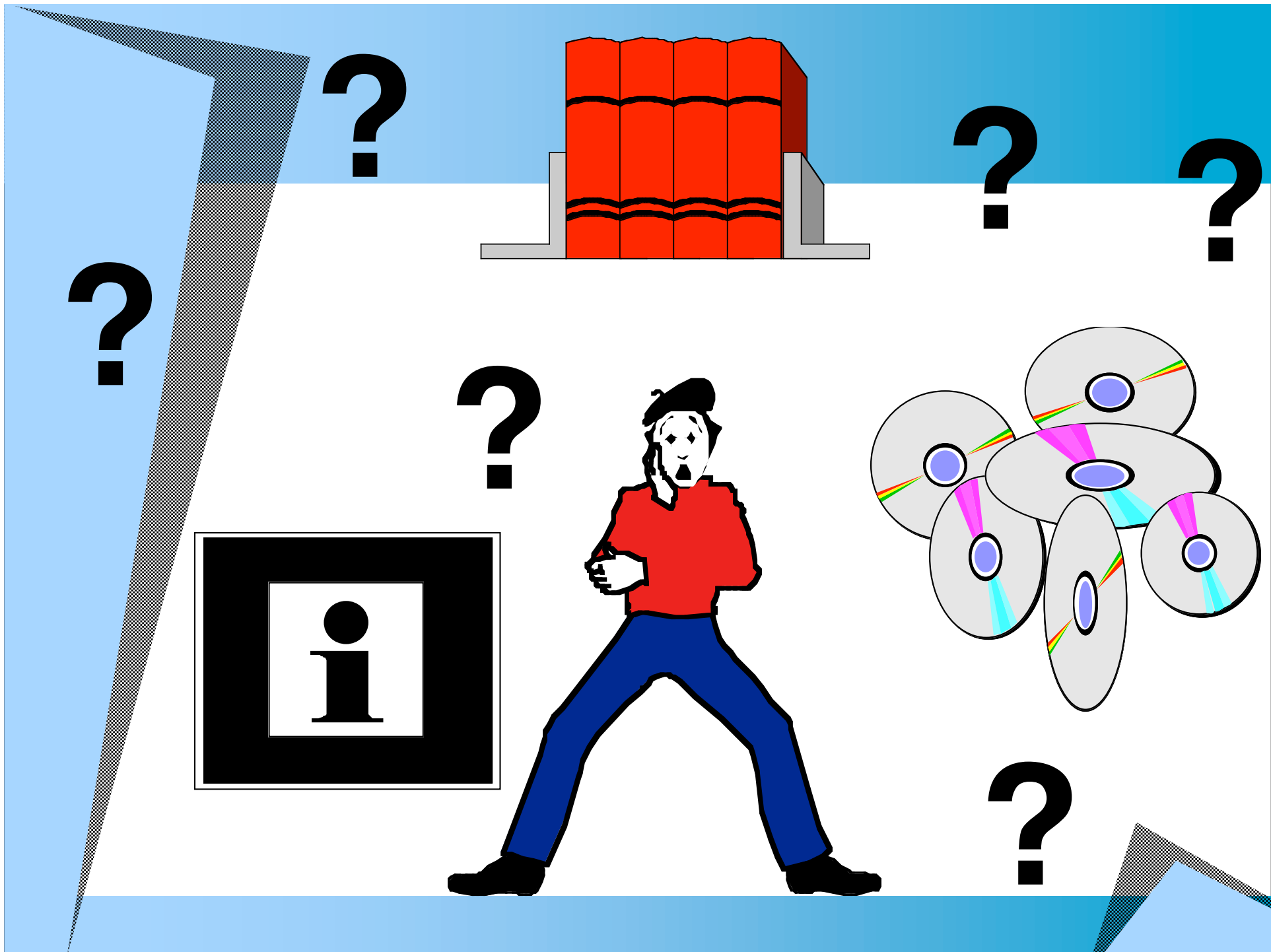
Paper mock-ups

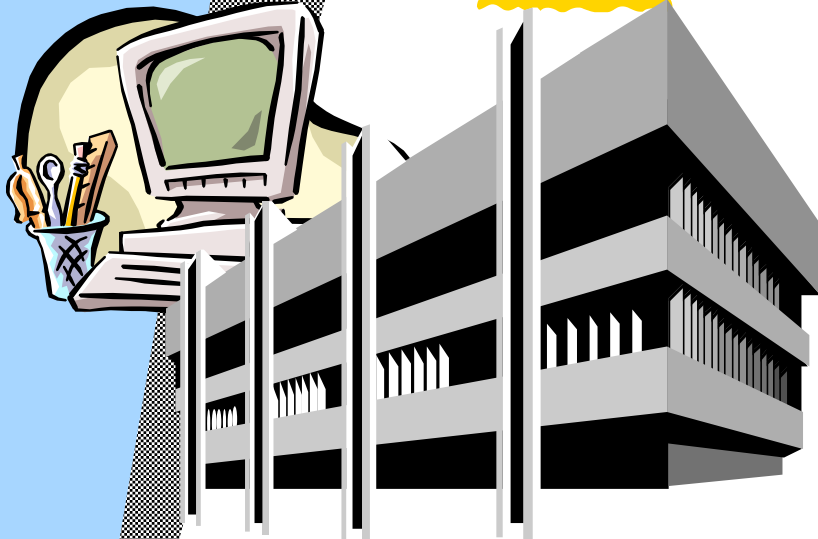
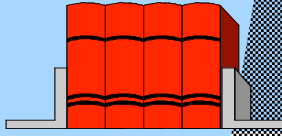
Electronic prototype

Conclusion

What are we expecting patients to do?

-
- ▶ Motivate
 - ▶ Monitor
 - ▶ Mentor
 - ▶ Mend
 - ▶ Manage!





**But *health*, and
much of
health care,
happens here**

We

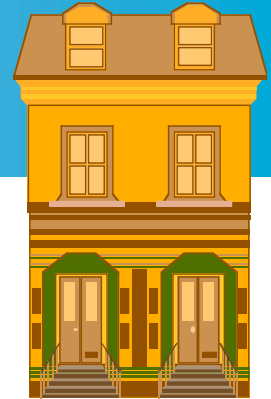
think

health

care

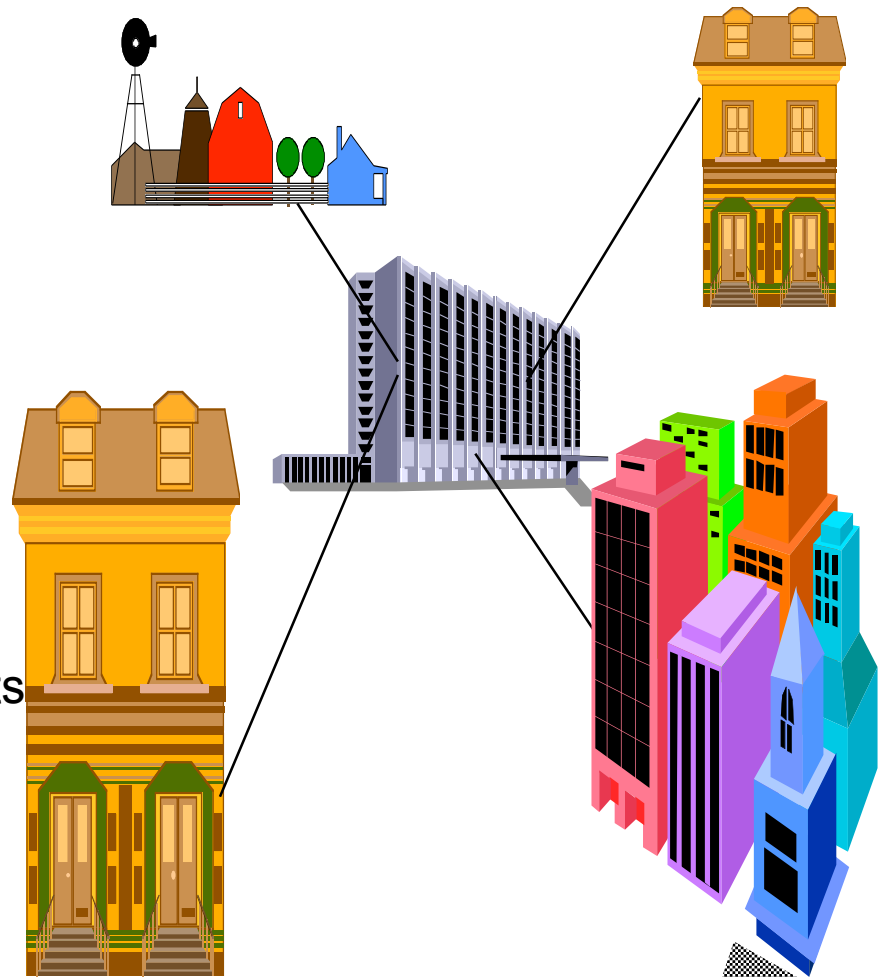
occurs

here



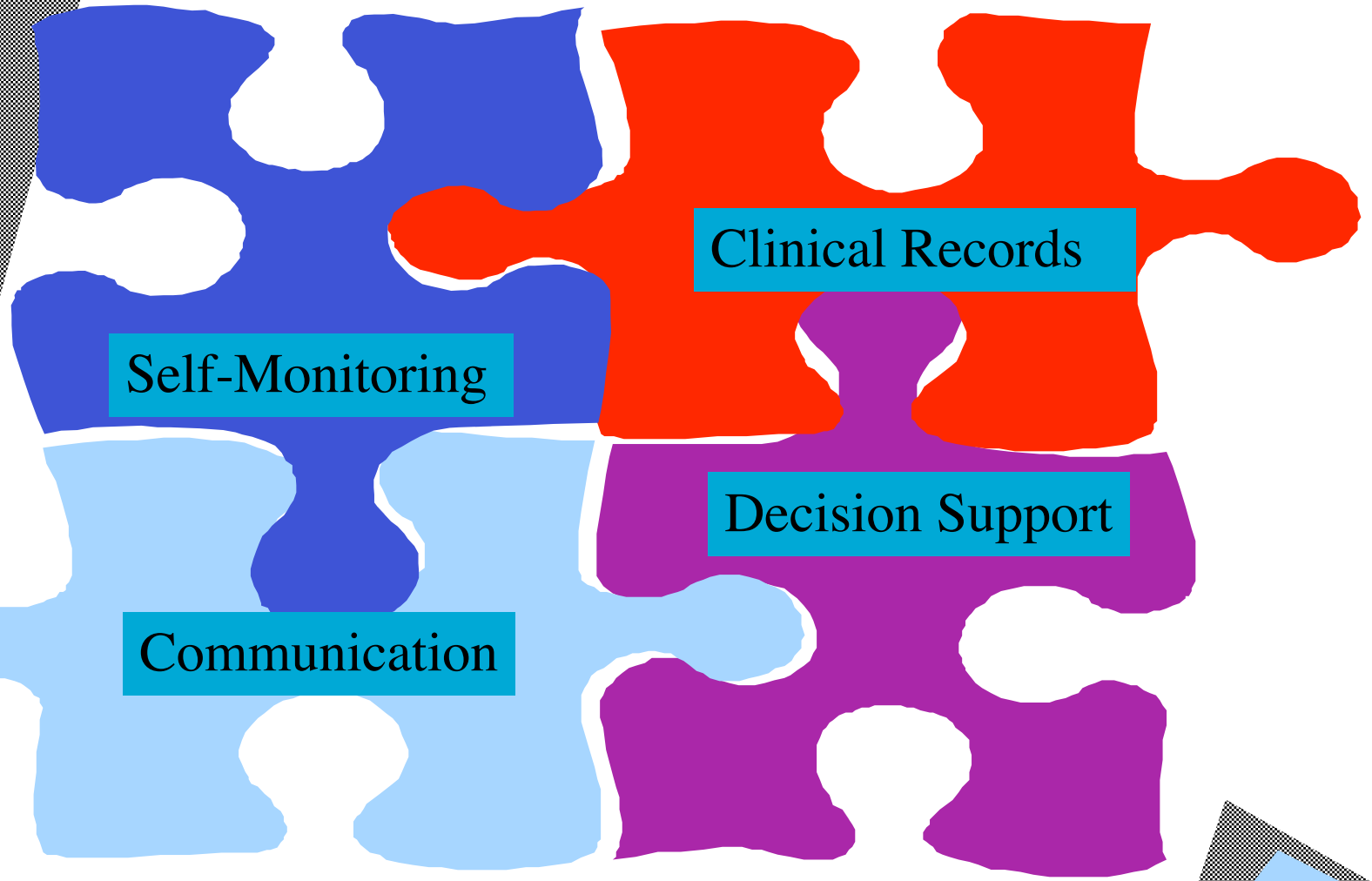
The Contexts of Care

- ▶ Living Environment
- ▶ Social Environments
- ▶ Psychological Environments
- ▶ Technological Environments
- ▶ Health Services Environments





Components of a personal health information system



Project HealthDesign

- ▶ Compilation of personal observations
- ▶ Extracted elements from clinical records
- ▶ Links to consumer information



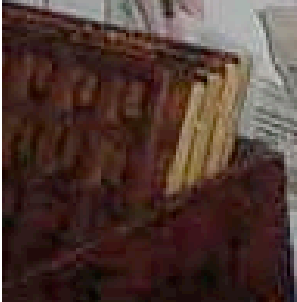
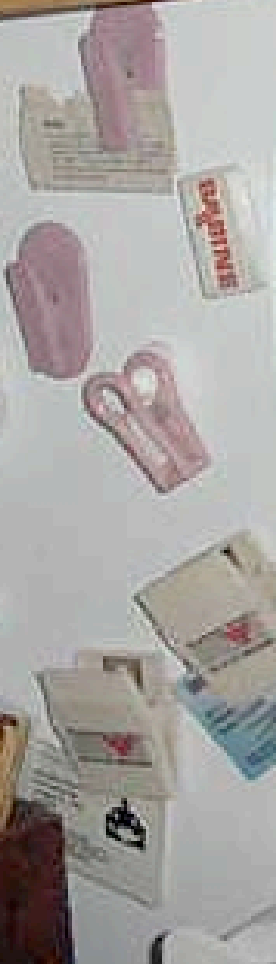


JANUARY 2002

Sunday Monday Tuesday Wednesday Thursday Friday Saturday

		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			

SAVE \$3.00







Project HealthDesign

- ▶ Re-think the power and potential of personal health records
- ▶ Stimulation innovation in the development of applications
- ▶ Specify properties of a robust technical platform

Project HealthDesign

- ▶ 3-year, \$3.5 million national program
- ▶ Administered by the University of Wisconsin-Madison



THE UNIVERSITY
of
WISCONSIN
MADISON

Our vision of Personal Health Record Systems

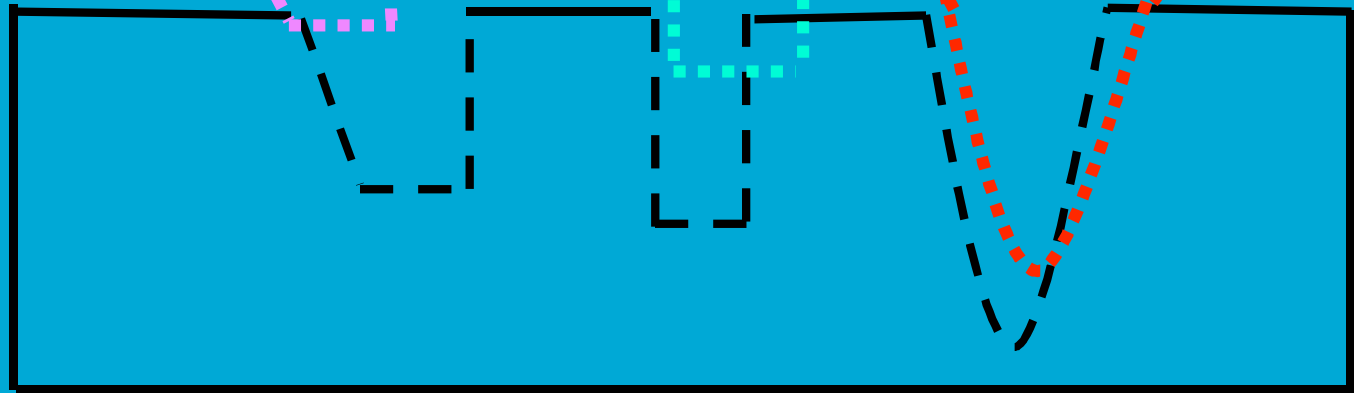
**Personal
Health
Applications**

Obtain
Med list,
Search Internet
suppliers
to find the
least-expensive
sources for
prescriptions

Monitor
air
quality
and,
from Med List
set next
dose of
rescue
inhaler

Record time,
and intensity of
exercise,
plot it against
personal
performance
goals & establish
settings for weight
machines

**Common
Platform**



www.projecthealthdesign.org



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User-Centered Design

Stefanie Fenton

Intuit



MARKLE FOUNDATION


Robert Wood Johnson Foundation



Applying Consumer Driven Invention to Healthcare

Stefanie Fenton
Director, Healthcare Division

December 7, 2006



Agenda

- **Intuit's Approach to User Centered Design: Consumer Driven Invention (CDI)**
- **Applying CDI to Healthcare**
- **What We Have Learned from Consumers**
- **Overview of Quicken for Healthcare**

Who is Intuit?



- #1 web delivered application and #1 best-selling software
- 79% retail market share
- Prepared 21 million 2005 tax returns
- 25% of all U.S. tax returns prepared with Intuit products



- #2 best selling software in the U.S. behind TurboTax
- Over 15 million users
- 72% U.S. retail segment share
- 80% brand awareness (in households with PCs)



- 88% U.S. retail segment share
- 3.5 million U.S. small businesses use QuickBooks
- #1 payroll service

Our Mission

Revolutionize Peoples' Lives



Create changes so profound that people can't imagine going back to the old way of doing things

What Intuit Does

Simplify and Streamline the Complicated

**Build integrated solutions and tools
that clarify the complex for consumers**

**Educate, empower, and help them
organize information for action**

Gives Users a Simple Way to Organize Things

TurboTax ✓

Personal Info | **Federal Taxes** | Federal Review | State Taxes | Print & File | Planning

Income | **Deductions** | Taxes & Credits | Miscellaneous

Federal Refund
\$206

Where Do I Enter?
Search for a Topic

Get Answers
Find Tax Help ▶
Using TurboTax ▶
View Tax Summary
Service and Support
Live Tax Advice
Send Us Feedback

Your Deductions

Ready to Get Started?
Enter your deductions by selecting the buttons below, and we'll determine the best possible deduction for you, **standard or itemized**.

OR

Not Sure What to Enter?
We'll lead you through all the deduction-related topics step by step.
[Walk Me Through All ▶](#)

Deduction	2005 Amount
1. Mortgage Interest Form 1098 More Info	Edit
2. Income Taxes Paid Federal, state, local tax paid More Info	Edit
3. Taxes Real Estate, vehicle More Info	\$5,270 Edit
4. Charitable Contributions Cash, noncash More Info	\$3,167 Edit
5. Child-Care Expenses Day care, dependent care More Info	Edit

Puts All The Information In One Place

The screenshot displays the Quicken 2007 Premier software interface. At the top, there is a menu bar with options like File, Edit, Tools, Online, Cash Flow, Investing, Property & Debt, Planning, Tax, Reports, and Help. Below the menu is a toolbar with icons for Back, Forward, Update, Reports, Calc, Port, Budget, Print, and Quotes. A search bar is located on the right side of the toolbar.

The main content area is divided into several sections:

- Projected Cash Flow:** This section is divided into three columns: IN (Income), OUT (Expenses), and WHAT'S LEFT (Balance).

IN NOV 1 - NOV 30		OUT NOV 1 - NOV 30		WHAT'S LEFT NOVEMBER	
Expected Income	8,762.59	Bills	4,423.95	Current Balance on Nov 6	↓ \$14,624.65
Other Deposits	0.00	Other Expenses	0.00	Checking Balance as of Nov 1	\$14,695.93
		Transfers to Savings	250.00	Cash Flow difference for Nov	\$1,902.70
		Loan payments	2,185.94	Total Available through Nov 30	\$16,598.63
Total	\$8,762.59	Total	\$6,859.89		
- Scheduled Bills & Deposits:** A table showing upcoming bills and deposits.

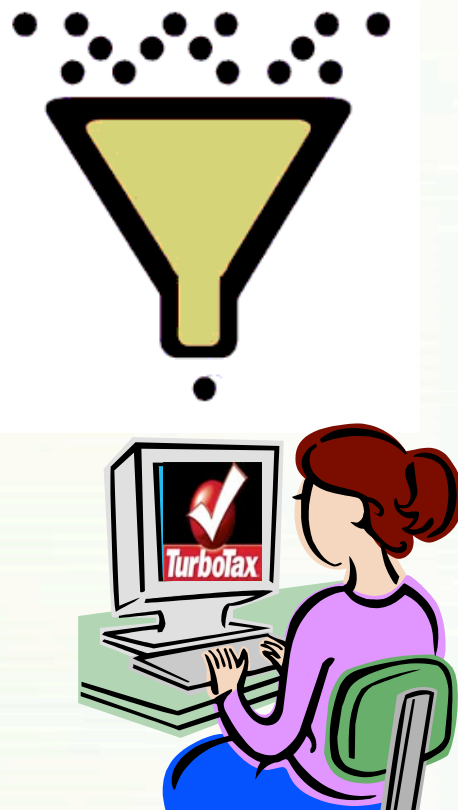
Status	Due Date	Payee	Amount	Web	Action
Overdue!	11/5/2006	Spouse Payc...	1,632.32		Enter Edit Skip
Due Today	11/6/2006	Anytown Aut...	-192.61		Enter Edit Skip
✓ Paid	11/6/2006	Transfer	-250.00		
	11/7/2006	Telephone C...	-55.54	Go	(Auto) Edit Skip
	11/8/2006	Cable Company	-37.08	(Auto)	Edit Skip
- Financial Overview:** A sidebar on the left showing various financial metrics:
 - Online Savings: 10,087.03
 - Credit Card: 2,999.16
 - Total:** \$41,545.17
 - Investing Center:
 - Stocks & Bonds: 92,940.11
 - Lisa's IRA: 23,187.71
 - John's 401k: 53,247.16
 - Total:** \$169,374.98
 - Property & Debt:
 - Home: 280,000.00
 - Customer V...: 1,951.73
 - Net Worth:** \$234,741.00

Two yellow callout boxes with red arrows point to specific areas:

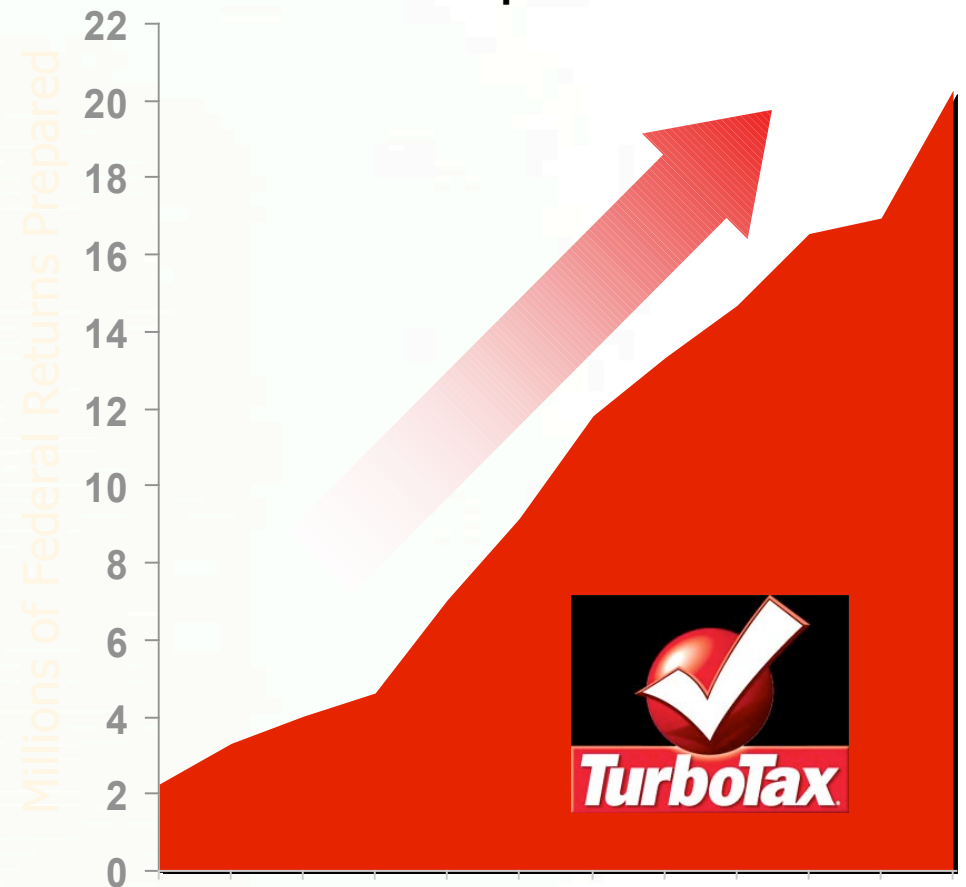
- The top box, labeled "Forest-level" see where you stand, points to the overall financial overview sidebar.
- The bottom box, labeled "Tree-level" register of transactions, points to the Scheduled Bills & Deposits table.

Consolidates Data from Multiple Sources

Brokerages
Credit Unions
Payroll Providers
Banks
Mutual Funds

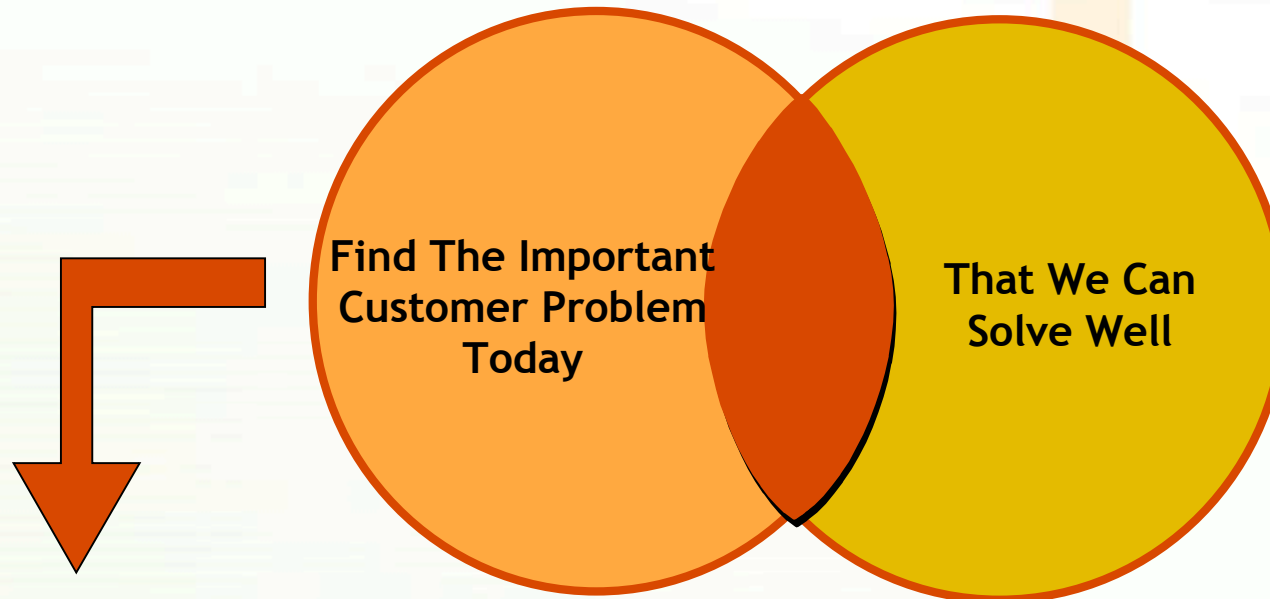


Total (in Millions) of Federal Returns Prepared Over 10 Years



How Intuit Learns

Consumer Driven Invention (CDI)



- Deeply understand people's current pain points
- Watch people and build tools that work they way they work
- Create solutions that help them make better decisions and feel more confident
- Focus on the prospect. Non-customer behavior can yield the greatest learnings

Follow-Me-Homes: Build From the Outside-in



Follow people home



Have them show you how they track information



Capture learnings, review and share

2001 Taxes

	PROF	INT	DIV	RET	AGG	AGG	AGG	AGG	AGG
CHEM. ENG.	30,000	400.00	400.00	---	2,500	350	1,450	1,450	Co-owned
CHRYSLER CR.	50,000	1,000.00	500.00	4,000.00	27,000	800	11,000.00		
LOAN INT.	2,000.00	1,000.00	3,000.00	7,000.00	20,000	1,000	15,000.00		
THOMAS CO.	100,000	1,000.00	2,000.00	7,000.00	20,000	1,000	15,000.00		
FOUR BAL.	100,000	1,000.00	2,000.00	7,000.00	20,000	1,000	15,000.00		

This is the form Chris gives to his accountant.

Observe their behaviors



Use Town Halls and user groups



Listen to their calls and questions

CDI Methods and Principles

Methods

- Follow-Me-Home observations
- 1:1 interviews
- Town Hall meetings
- Usability testing
- User groups
- User forums
- Surveys

Principles

- Observe customers in their own environments
- Trust Follow-Me-Homes more than usability
- Trust the customers' words more than our preconceived notions
- Trust verbatims more than survey research
- See the actions behind the words

How Intuit is Learning about Healthcare

Since 2004, Intuit has reached out to more than 1,450 consumers to learn about their key points of pain

300+ personal interactions

- More than 75 in-home visits to watch people interact with the healthcare system and identify problems we can help solve
- iLab observation
- Focus groups
- 1:1 interviews

We've scoured hundreds of survey results, but the in-person studies are so valuable we use survey data just to validate our overall direction.

Homegrown Manual Methods Aren't Working



During our observations, we saw piles of unopened envelopes and letters from collection agencies

Manual methods tend to be time-consuming, inefficient and lead to feeling out of control and overwhelmed



Findings from Consumer Research

- **41% want new tools to better manage their healthcare**
- **Consumers care significantly more when they have ‘skin in the game’**
 - Higher deductibles, FSAs, HSAs, chronic illnesses, recent illnesses or caregivers
- **There is a lot of healthcare information coming at consumers**
 - EOB’s from health plans
 - Bills from providers and facilities
 - Benefit information from employers and plans
 - Reminders and health tips
 - Web sites (plans, employers, PBMs, physicians, labs, public portals, etc.)
- **Information is fragmented, unfocused and promotes exasperation—not engagement**
 - Instead of acting upon information, people are stuck trying to make sense of it

Points of Pain Span Across Cost and Care Issues

Consumers want help...

- Making sense of bills and claims
- Avoiding unanticipated expenses
- Understanding how to impact costs and save money
- Interacting effectively with the healthcare system
- Finding accurate information about their medical conditions and treatment options on a self-service basis

Consumers' biggest points of pain focus on solving problems for which they do not have a reliable approach today

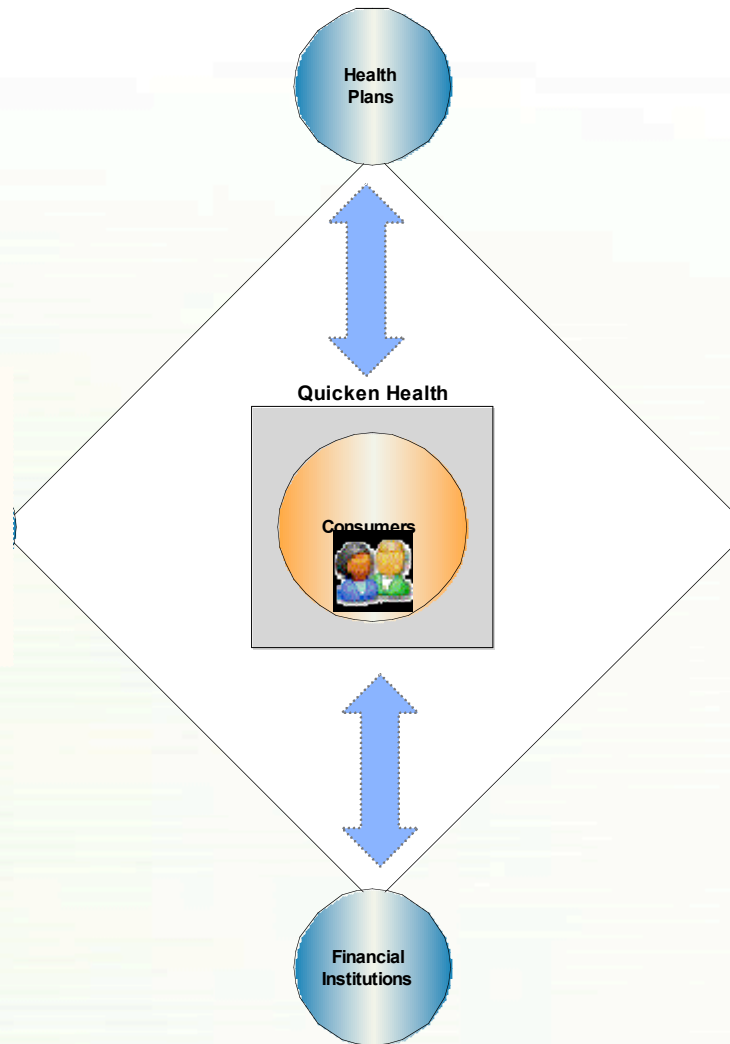
Solution Fundamentals - What Consumers Require

- **Data must be kept private and secure**
 - More sensitivity over healthcare data than financial data
- **Data must be delivered in an understandable way**
- **Data must be accessible all in one place**
- **Must be easy to use and take less time than paper methods**
 - No manual data entry

What Might A Solution Look Like?

- **Easy to get, use, understand**
- **A Web based service**
 - Access anytime, anywhere
 - Easy start-up, no installation hassles
- **Electronic access to relevant data**
 - No more paper
- **Secure data transfer**
 - Bi-directional certificate-based user authentication and fully encrypted data exchange
- **Clear answers to basic questions**
 - What is my deductible and how does it work?
 - What is my out of pocket maximum, and how does it work?
 - Who do I owe? How much do I owe? When is it due? Is this bill right?
- **Easy electronic bill payment**
 - Via my bank if I prefer, no new account needed
- **Help with decision making**
 - Spend less on Rx drugs
 - Find a high quality, low cost, provider
 - Manage chronic disease effectively using best standards of care

Quicken for Healthcare



Claims
EOB
Billing

FSA, HSA
Checking, Credit





Q & A

**Connecting Americans
to Their Health Care:**
*Empowered Consumers,
Personal Health Records
and Emerging Technologies*



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