

Information sharing & collaborative technologies:

The power of peer support in online health communities



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University of Washington

MEBI 590 Jan 3, 2012

Outline

- Background
- Patient expertise sharing (PhD Thesis)
- Peer mentoring in online communities (NSF)
- Quality of life dashboards (NCI)
- Contributions

Everyday management of personal information

Information seeking

- Visualizing information quality
- Characterizing peer expertise



Information organization & use

- Organizing by folders, tags, project plans
- Managing personal health information



Information sharing

- Sharing & privacy in personal networks
- Sharing expertise in peer networks

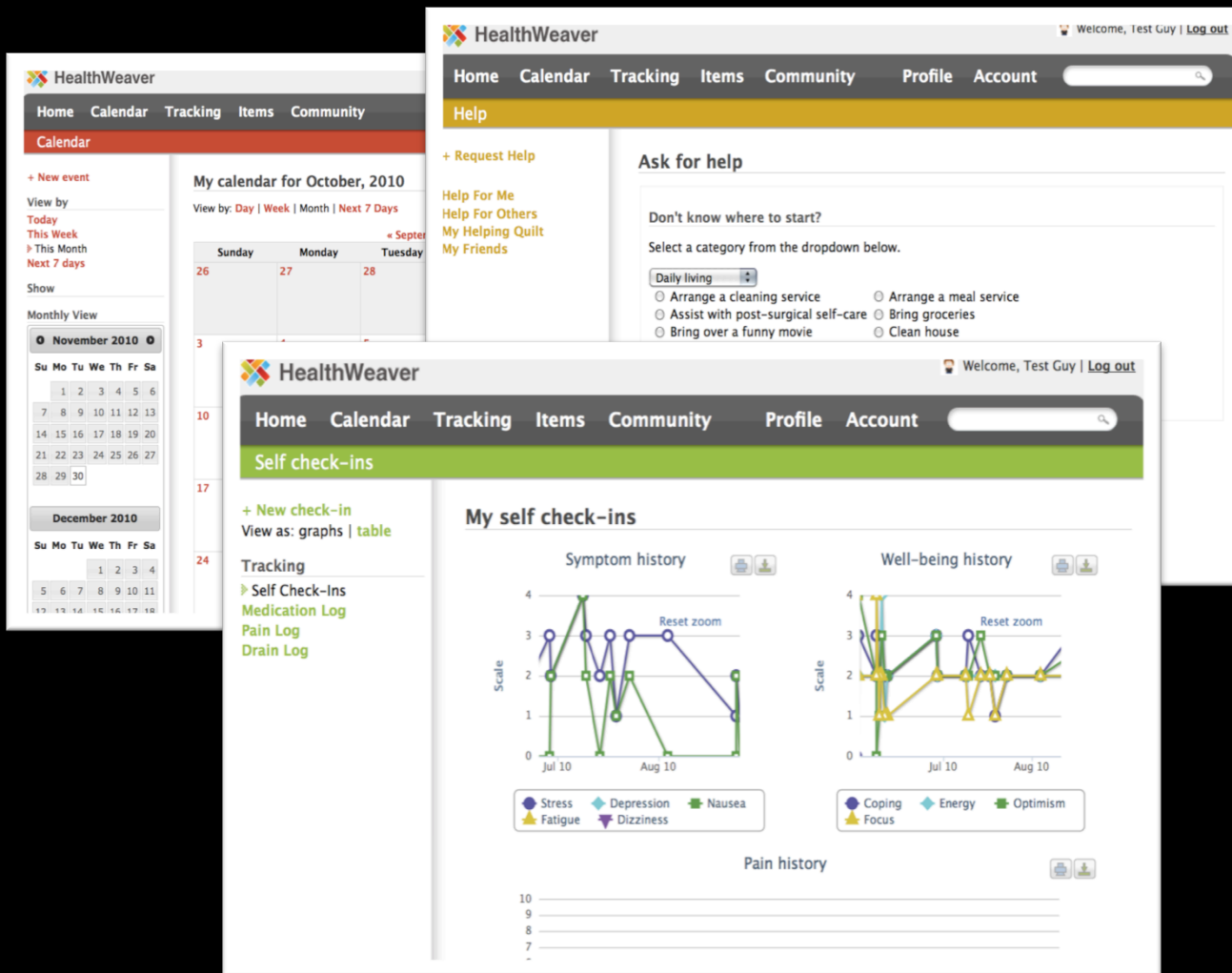


Planz personal project planner



- Jones, Klasnja, Civan et al. The Personal project planner: Planning to organize personal information. CHI '08 p.681-684
- Civan, Jones, et al. Better to organize personal information by folders or by tags?: The devil is in the details. ASIS&T 2008.

HeathWeaver information management tool



- Pratt, Unruh, Civan, et al. Personal Health Information Management. CACM 2006 49(1), 51-5.
- Civan, et al. Personal health information management: Consumers' perspectives. AMIA 2006 p.156-60.
- Klasnja, Hartzler et al. HealthWeaver mobile: Designing a mobile tool for managing personal health information during cancer care. AMIA 2010 p.392-96.
- Klasnja, Civan et al. Blowing in the wind: Unanchored Patient information work during cancer care. CHI'10 p. 193-02.
- Unruh, Skeels, Civan et al. Transforming clinic environments into information workspaces for patients CHI'10 p.183-92.
- Hartzler et al. Sharing is caring, but not error free: Transparency of granular controls for sharing personal health information in social networks. AMIA 2011 p.559-68.
- Klasnja, Hartzler et al. Supporting cancer patients' unanchored health information management with mobile technology. AMIA 2011 p.732-41.

]

My46 personal genome portal



Learn about the National Children's Study 



Welcome to My46

My46 is a website where research participants who are having whole genome sequencing (WGS) can learn more about genetics and how genes affect people's health.

My46 lets people indicate their preference for what types of genetic information they want to learn.

Later, they can view their selected genetic research results via My46.

Check out an introductory video to My46, a website where research participants who are having whole genome sequencing can learn more about genetics and how genes affect people's health.

Help Us Learn

My46 is a University of Washington research project. The study aims to learn about people's preferences for receiving genetic results in research studies.

Whole Genome Sequencing

A technology called whole genome sequencing makes it possible for scientists to examine a person's entire genetic sequence to learn more about health and disease.

Sharing Results

My46 is the first tool designed to return whole genome sequencing results via the Web to research participants based on their preferences.

- Tabor, Civan et al. My46: An innovative web-based tool for management of results return from exome & whole genome sequencing studies. 2011 Int Congress of Human Genetics, Am Soc Human Genetics.
- Anderson, Hartzler et al. Personalizing the return of genome sequencing results: Consumer health informatics meets bioinformatics. 2012 AMIA Joint summit trans sci.

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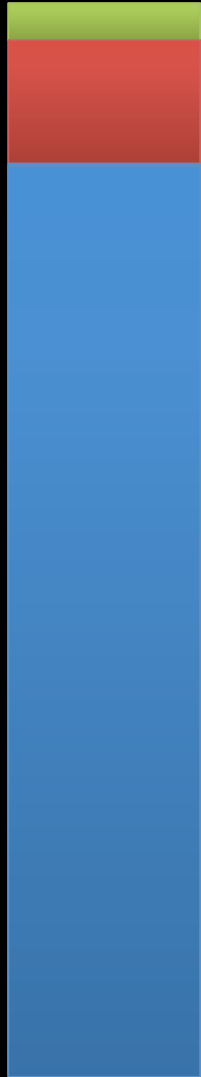


Information sharing in peer networks

- Who?
 - Peer – *an equal*
- What?
 - Personal, informal, experiential info exchange
- Why?
 - Obtain support - emotional, instrumental, informational
 - Learn from others and give back
- What settings?
 - Professional – apprenticeship, ‘water cooler’, teacher induction
 - Domestic - Big brothers/sisters, La leche league, AA groups

How?

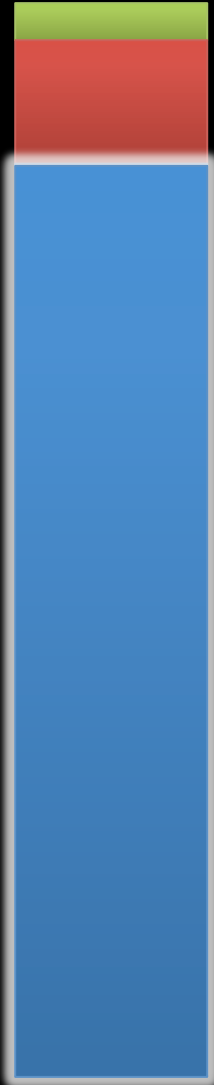
Today



BC

How?

Today



BC

- Traditional face to face

How?

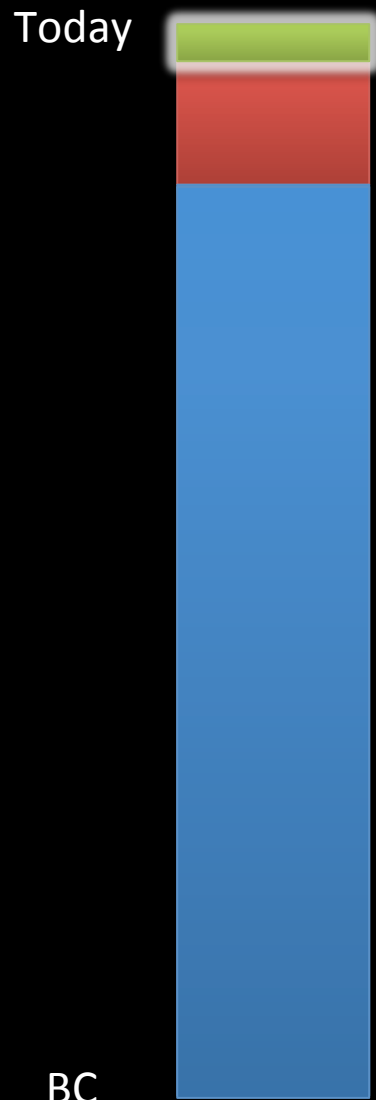
Today



- Mail, Phone
- Traditional face to face

BC

How?



- Email, usenet
- Mail, Phone
- Traditional face to face

How?

Today



BC

- Collaborative technologies
- Email, usenet
- Mail, Phone
- Traditional face to face



Some specific interests in health

Challenges

- Nature of knowledge
- Personalization
- Social recommendation
- Information quality vs. misinformation
- Privacy/anonymity vs. transparency
- Various collaboration styles

Approaches

- Content analysis
- Ethnographic field study
- Surveys
- Focus groups
- Participatory design
- Automated processing & profiling
- Iterative prototyping (low/high fidelity)
- Heuristic testing
- Usability testing
- Field testing
- Pilot testing
- Field experiment
- Clinical trial

Core concepts

- Patient expertise

*Personal health knowledge gained through the experience of coping with illness**

- Patient expertise sharing

*Processes through which individuals exchange personal health knowledge with one another**

- Social matching

*Systems that bring people together—either physically or in online worlds—for social interaction and collaboration around shared interests or goals***

*Civan. Understanding and facilitating patient expertise sharing. Dissertation thesis 2009 University of Washington.

**Terveen & McDonald. Social matching: A framework and research agenda. Transactions on CHI 2005 12(3),401-434.

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- Peer mentoring project
- Quality of life dashboard project
- Contributions

Project 1: Patient expertise sharing

- PhD thesis

“Understanding & facilitating patient expertise sharing”

- Motivation

- Learning to manage health is challenging
- Growing body of self-management knowledge
- Fears about patient sharing – ‘amateur doctor’

Learning to manage health

Health-care System

Biomedical expertise
from professionals

- Health-care team
- Researchers



**Personal Health
Knowledge & Skills**

Learning to manage health

Biomedical Expertise



Personal Health
Knowledge & Skills

Learning to manage health

Biomedical Expertise



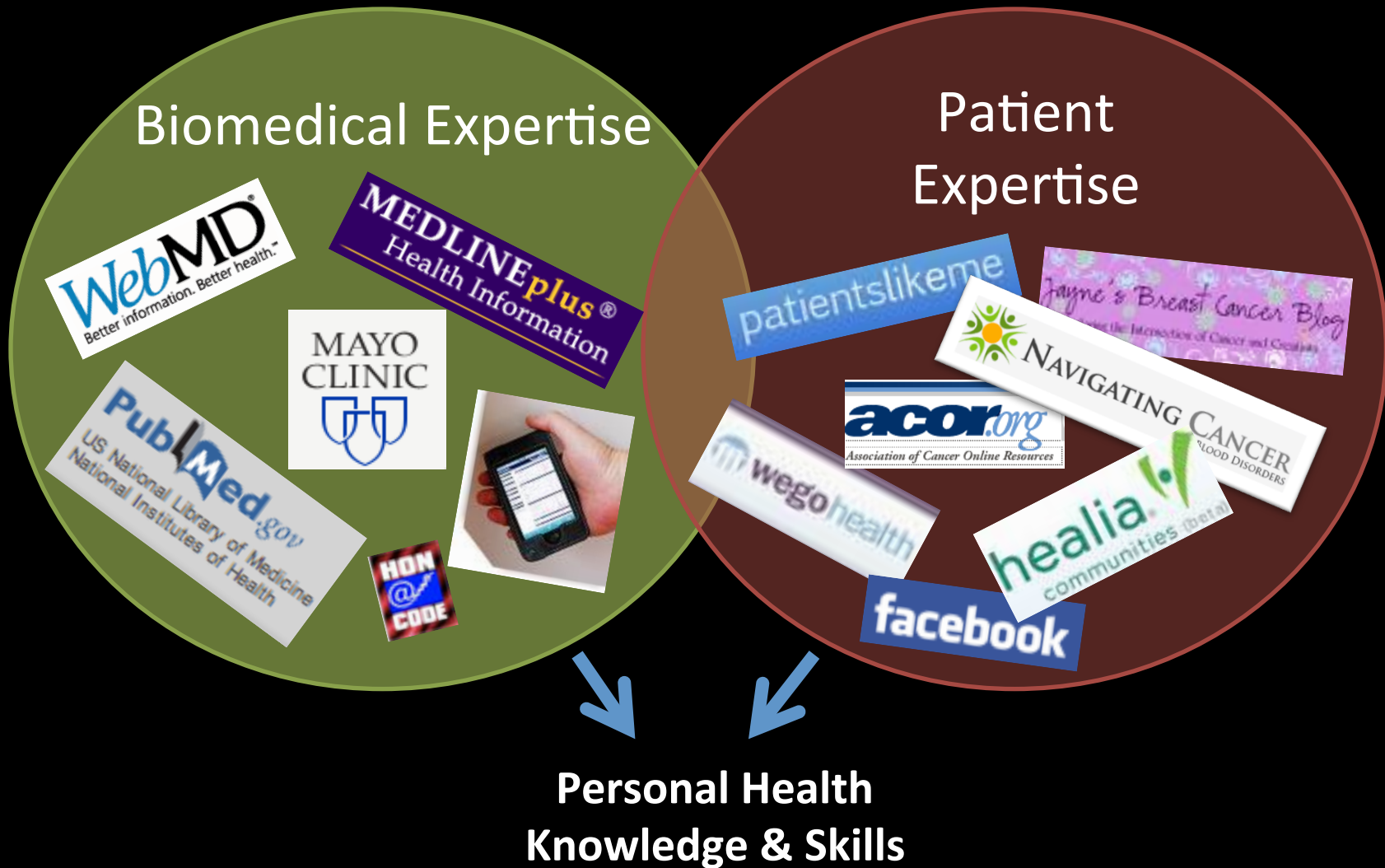
Everyday life outside the clinic

Patient expertise from 'peers'

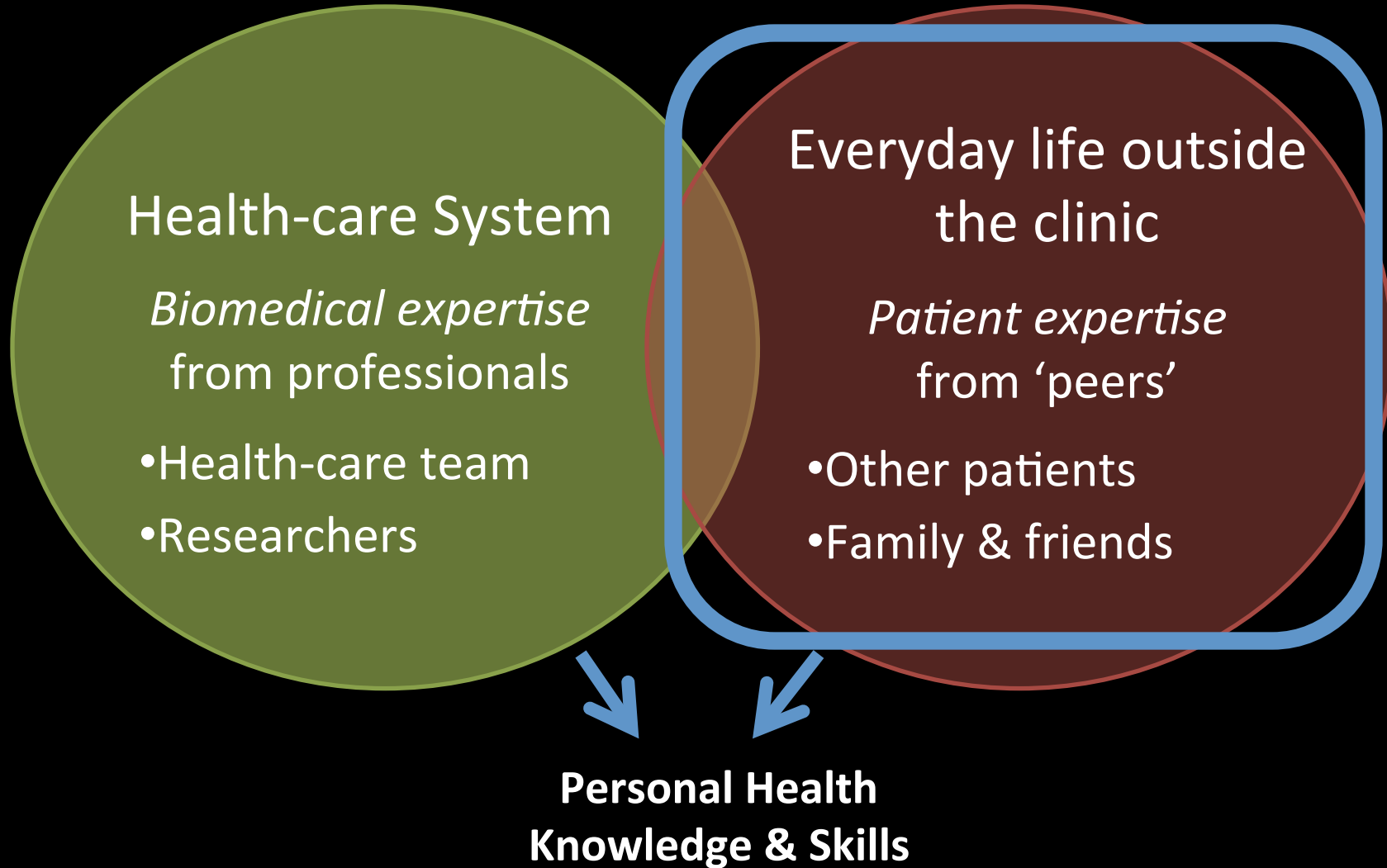
- Other patients
- Family & friends

Personal Health Knowledge & Skills

Learning to manage health



A focus on the Informal



Research aims

- What is the nature of patient expertise?

Aim 1. To describe the characteristics of patient expertise

- How do patients share their expertise?

Aim 2. To describe the practice of patient expertise sharing

- How can we facilitate patient expertise sharing?

Aim 3. To design a patient expertise locator

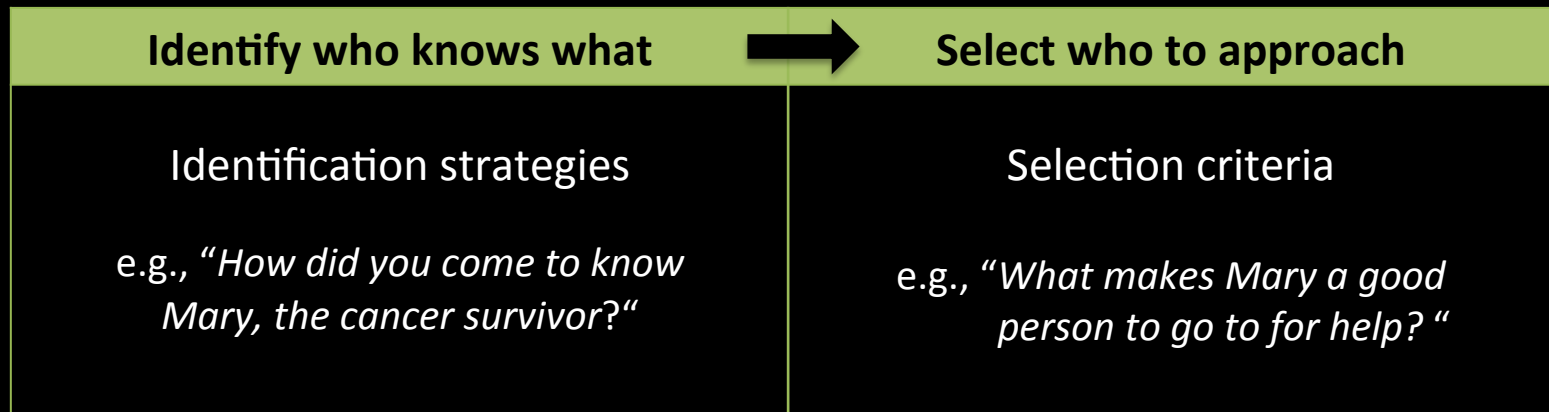
1. What is the nature of patient expertise?

- Comparative content analysis for breast cancer
- Characterized patient vs. biomedical expertise
 - Code topic, form, style
 - Compare distributions

Type of source	Peer	Ask the expert	Difference (X^2)
Topic	Personal <ul style="list-style-type: none">• Personal care & life• Home life• Work life• Social network	Medical <ul style="list-style-type: none">• Health care delivery system• Biomedical research• Health professionals' work	$p < 0.001$
Form	Action-oriented advice	Facts and opinions	$p < 0.001$
Style	Narrative	Prescriptive	$p < 0.001$

2. How do patients share their expertise?

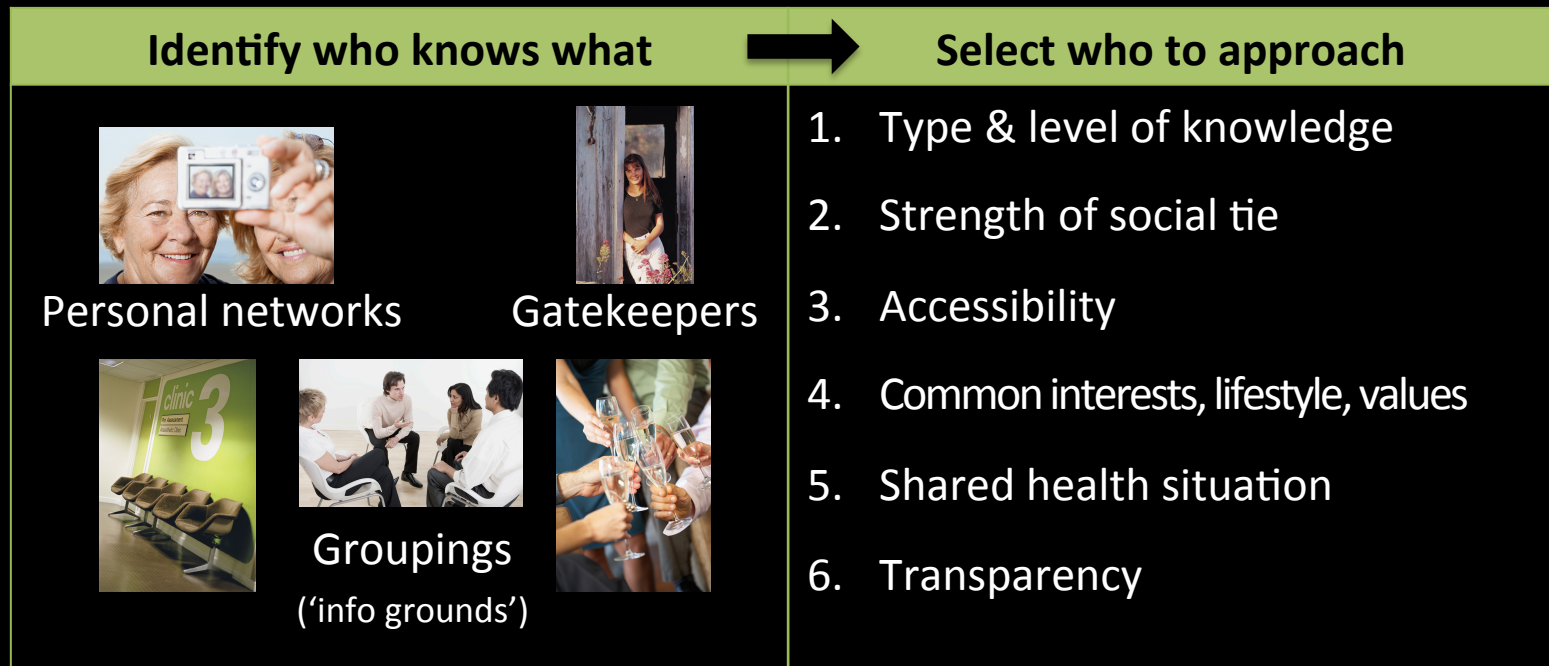
- 6-week field study with 15 cancer patients
- 2-phase expertise locating framework*



*McDonald & Ackerman. Just Talk to Me: A Field Study of Expertise Location. CSCW'98.

2. How do patients share their expertise?

- 6-week field study with 15 cancer patients
- 2-phase expertise locating framework



Initiating locating

- P1: *“One of the things that I chose to do is be very transparent with people ... as a result things came to me without asking.”*
- P13: *“I let people come to me ... I've gotten all these comments [on my blog]”*

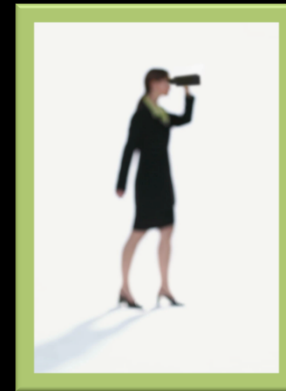


3. *How to facilitate patient expertise sharing?*

- Limitations of online communities
 - Broadcast identification
 - Fragmented expertise
 - Barren representations



- Participatory design of 'patient expertise locator'
 - Identify candidates through topic search
 - Select through detailed expertise profiles



Lily

Should I work through treatment or go on disability?



- Side effects?
- Income?
- Insurance?



Lily is preparing for surgery

Post a question

Find people who know about

Connections (3)



FatimaD



Aditya P



LisaG

Forum

People

What should I know about recovering from lumpectomy?

I will be having surgery in a few weeks and not sure how best to prepare myself, home, or family. Any tips?

Posted by [Lily](#) 2/1/09 7:12pm -2 answers



My aunt set up after school play dates for her kids and had a house cleaning service come a few times until she felt back up to speed. Also, friends brought by meals since she wasn't up to cooking. Wishing you a speedy recovery!

Answered by [Fatima D](#) 2/1/09 11:01pm-



I pulled out all my button down shirts –a must! I also purchased a special pillow for sleeping which helped tremendously – I got it on sale online from Bed & Bath.

Answered by [Aditya P](#) 2/2/09 9:31am

[How to help a cancer patient with the fiber consumption?](#)

Posted by [Jodie H](#) 2/1/09 7:45pm -3 answers

[How long after they're diagnosed do they start treatment?](#)

Posted by [Elna W](#) 2/1/09 9:02pm -24 answers



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Post a question

Enter question

Post

Find people who know about

chemo, work, disability

Find

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Last login 2/25/09

Post a question

Enter question

Post

Find people who know about

chemo, work, disability

Find

Connections (3)



Fatima D



Aditya P



Lisa G

Forum

People

work, chemo, disability [See all 12](#)



Available after 3/1/09:
Sorry - busy with my sister's surgery

[Alysa W](#) is the sister of cancer patient

cancer certification children confident
difficult employees feel
health life history hospice insurance
life-insurance-coverage limit
medicare options part-time personal-
experience plans post-surgery private-policy
qualify questions services standard
uninsured worry



Open to requests
[Contact Chelsey L20](#)

[Chelsey L](#) is a cancer survivor

african-american apply
assistance avon programs



Open to requests
[Contact Chris P2](#)

[Chris P](#) is awaiting bone marrow transplant

b-cell-leucaemia book cancer
carer chemo-side-effects
elderly
mental personal rewarding
story success talking
trauma



Open to requests
[Contact Fatima D5](#)
Fatima D5 is one of your connections

[Fatima D](#) is the niece of a cancer survivor

god peace positive
talk trust



Open to requests
[Contact Jodie H17](#)

[Jodie H](#) is the friend of a breast cancer survivor

blog breast cancer cards
discount earn ebay ebay from-home
greenicks guidebaba home help
hubpages income insurance jobs
legitimate money plans
rider scam websites work
work-from-home



Contact information

Available after 3/1/09

Sorry-Busy with sister's surgery

Alysa W is the sister of a cancer patient

Last login 2/20/09

Sister's Health situation

Diagnosis: Stage II Breast cancer (12/08)

Treatment(s): Lumpectomy (2/09)

Side effect(s): Lymphedema (4/09)

Personal Information

Birthday November 11, 1971

Gender Female

Livelihood School teacher

Hometown New Monty, PA

Marital status Married

Prefers Allopathic, CAM

Interests Yoga

Connections (13)



Jodie H



Marietta B



Kathryn G



Robert R

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cancer certification children company confident
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health hire history hospice **insurance**
 life-insurance-coverage limit
 medicare options part-time personal-
 experience **plans** post-surgery private-policy
 qualify **questions** services **standard**
uninsured worry

Alysa W's Answers (141)

[Any tips on working from home during treatment?](#)



I'm a single mom with breast cancer . I need to keep working and want to exploring options from home...

Asked by [Chelsey L](#) -8/2/08 2:17 am -10 answers


Alysa W : My sister runs a home daycare -both before her diagnosis and has continued up until.....[Read more](#)

Alysa W Recommends

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Note: Useful list of 'work from home' Jobs

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Design refinements

- Multiple identification routes
 - Gatekeepers with the most network connections
 - Suggest profiles based on recent searches ('information gifts')
- Profile changes
 - Remove star award
 - Add cancer connection, geographic network, family status, connection strength
- Designated collaboration levels
 - Opt-in to be recommended
 - Control privacy and effort

Profile – Refined design

Forum People My Profile My Suggestions

April is looking for reconstruction photos for a friend

Connection to cancer has gone through it

Health situation
Diagnosis: Stage II breast cancer
Treatment: Surgery (9/2006), chemo (2007), Rads (2007)

Personal information
Birthday: 12/7/1943
Gender: Female
Livelihood: Research Tech
Marital status: Married
Family status: Grown children
Prefers: Allopathic
Interests: Yoga, gardening
Boston network

Connections (4)
 [Lindsey](#) (2)
 [Patty](#) (1)
 [Kerry](#) (1)
 [Janice](#) (1)

Member since 2006

Topics April has mentioned

based books breast cancer chest
effect frequently http
lesion manual means merck
metastases metastasis occur
pretty result risk scalp site skin
slightly spread states statistical surmise
survivor typical wall year

April's answers (5)

[Link between breast and ovarian cancers?](#)
April's answer: I can't pull up any scientific citations to support it, but "slightly increased" risk of ovarian cancer and colon cancer (as well as

[Any information on breast cancer skin metastasis?](#)
April's answer: According to the Merck manual: Most skin metastases surgery; scalp metastases also are common. (<http://www.merck.com/>

[Estrogen Positive Breast Cancer and Soy?](#)
April's answer: I don't have specific links, but I have read pretty reliable [site](#), and also [breastcancer.org](#). You can try searching those sites for

[What insurance is available to a breast cancer survivor who is n](#)
April's answer: Have you looked at AARP's insurance programs?... 5

[What is the likelihood of breast cancer reoccurring in the opposi](#)
April's answer: Actually statistically it's pretty low. No more likely the first time. Breast cancer spreads (recurs) more frequently in the liver,

April's websites (5)

[Merck http://www.merck.com/mmpe/sec18/ch253/ch...](#)
April mentioned this website in: [Any information on breast cancer skin](#)

[Cancer Chemotherapy and Pharmacology](#)
April mentioned this website in: [Any information on breast cancer skin](#)

Star awards are too general



P2: "Since every situation is different, 'Carol' could be great when it comes to mastectomy, but you could have 25 people that that is not their diagnosis.

So, it doesn't matter if it is a thumbs up or not, because they don't have to deal with that... it's 9 stars for those who are going through mastectomy, but its zero for [the others]."


Summary

- Patient expertise is personal, actionable, narrative
- Patients locate peers through identification, selection, 'information gifts'
- Expertise locating features can enhance social media
- Patient expertise is a valuable resource to share

Outline

- Background
- Patient expertise sharing project
- Peer mentoring project
- Quality of life dashboards project
- Contributions

Peer mentoring project

- 3-year National Science Foundation (NSF) grant
“Matchmaking for health: Facilitating peer mentoring in online health communities” (Pratt, McDonald, Hartzler)
- Partnership The logo for CancerConnect.com features the word "CANCER" in green and "CONNECT.COM" in blue. Below the main text, the words "community", "content", and "connection" are written in a smaller, light blue font, separated by small green floral icons.

CANCERCONNECT.COM[®]
community ✿ content ✿ connection
- Goals
 1. Profile community members
 2. Develop social recommendation tools
 3. Assess mentor recommendations

1. Profile community members

- Community data dump (~1400 members)
 - User profiles - demographics, log in, group memberships
 - Posts - status updates, forum, blog
 - Friend connections
 - Search text
- How can we detect member characteristics?
 - Health interests
 - Personal qualities
 - Mentoring needs/skills



Automated
text extraction

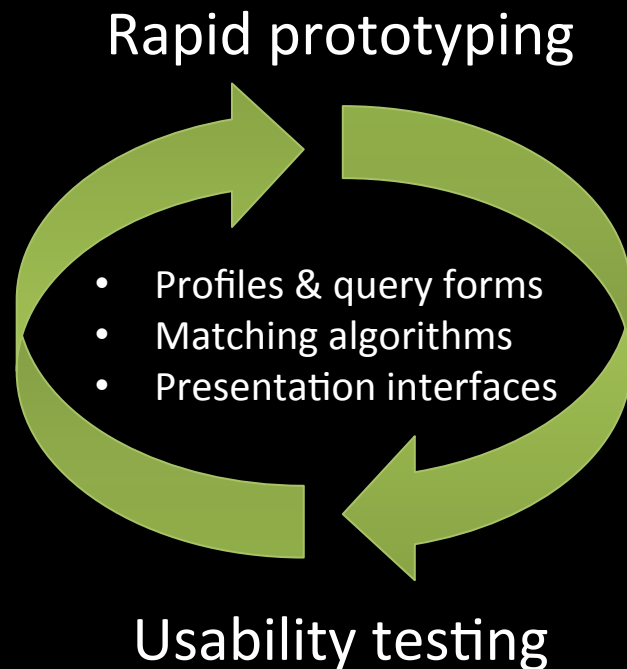
VS.



Direct
user survey

2. Develop social recommendation tools

Goal: Augment discovery of candidate mentors
with matched circumstances



- Social matching strategies
 - Similarity match – “Homophily”
 - Difference match – “Weak ties”
 - User-defined match
- Mentoring contexts
 - Buddy
 - One shot
 - Campaign

3. Assess mentor recommendations

- Live field experiment
 - Performance - mentor ratings
 - User-satisfaction survey

- Select follow up interviews
 - Potential & barriers for uptake
 - Potential for impact

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3 Matching strategies
X
3 Mentoring contexts



Summary

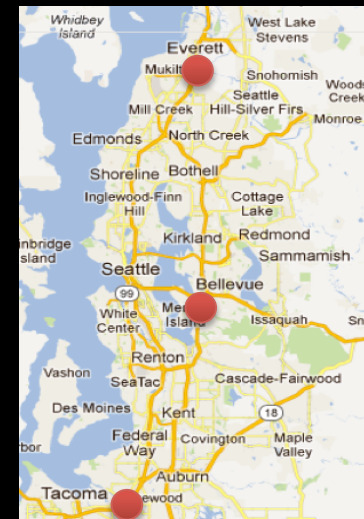
- Understand critical features of peer mentorship
- Demonstrate value of social matching in health
- Offer tested designs for online settings
- Status
 - Currently profiling health interests
 - Next step is profiling personal qualities (e.g., sentiment)

Outline

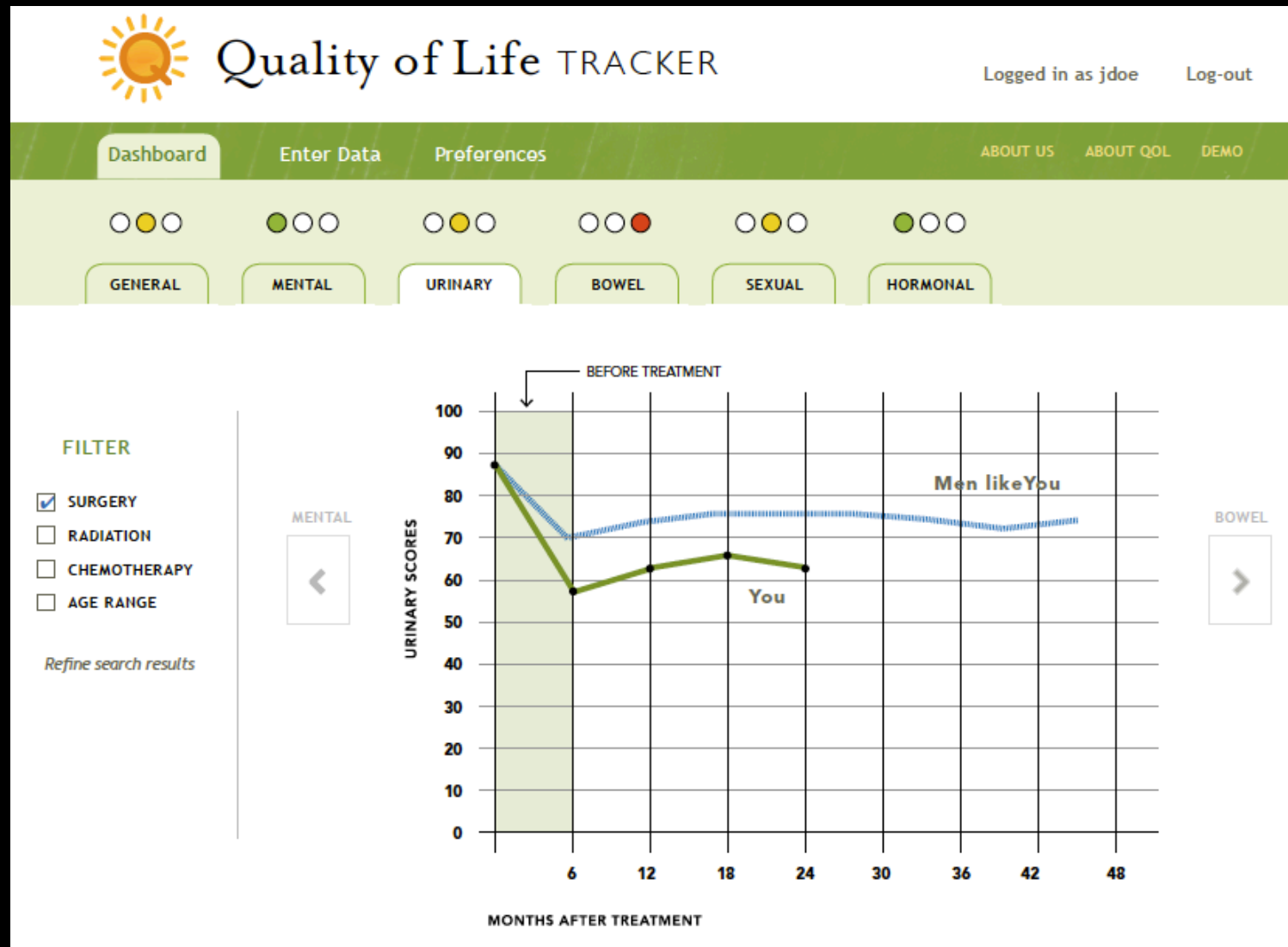
- Background
- Patient expertise sharing project
- Peer mentoring project
- Quality of life dashboard project
- Contributions

Quality of life (QOL) dashboard project

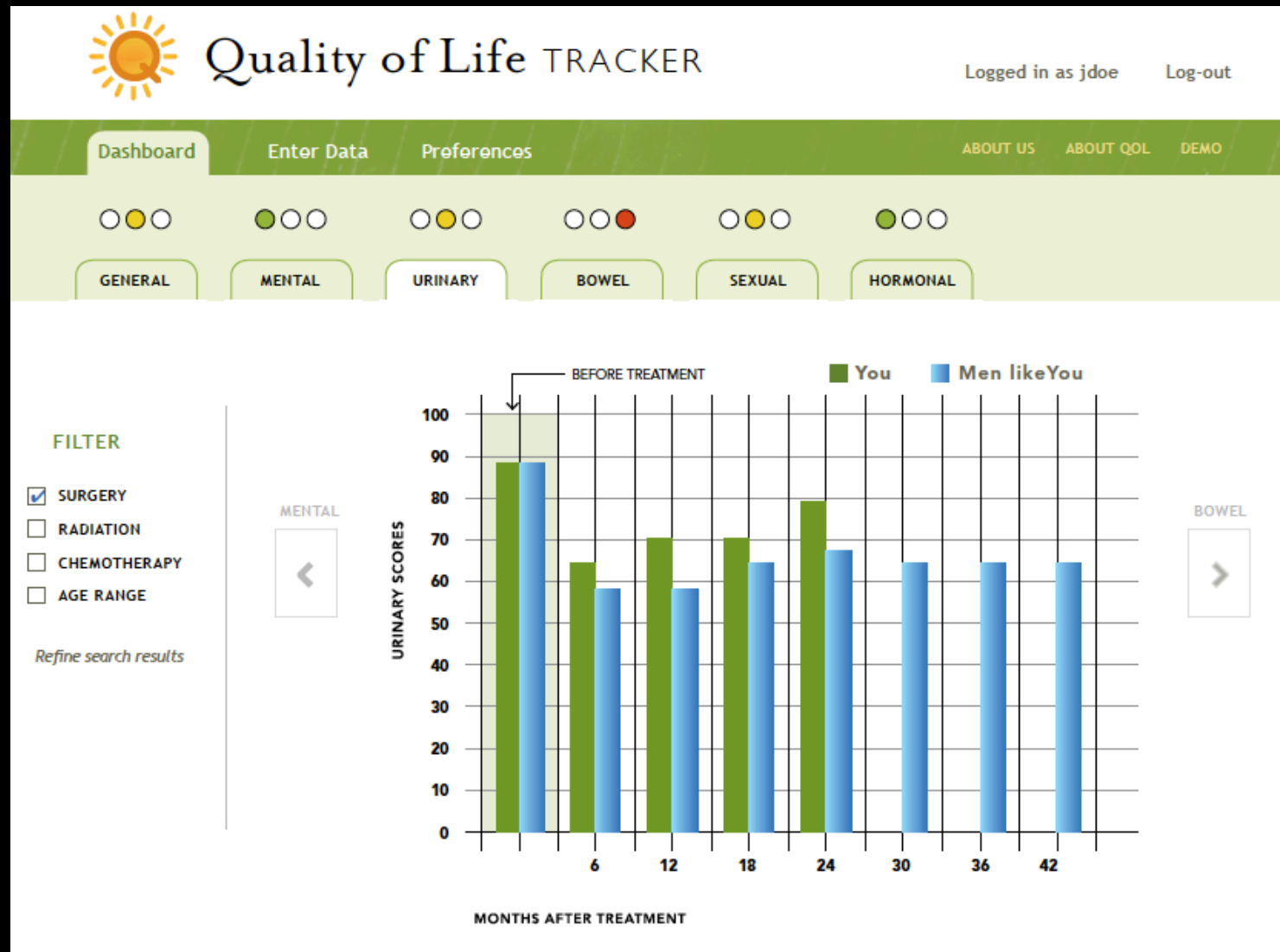
- 2-year National Cancer Institute (NCI) grant
 - *“Understanding & promoting health literacy through a QOL dashboard of prostate cancer symptoms following treatment”* (Gore, Hartzler, Dalkin)
- Visual dashboard to track QOL
- Prostate cancer support groups
- Goals
 - Focus group to identify dashboard elements
 - Patient & clinician testing for concordance
 - Pilot testing in clinic



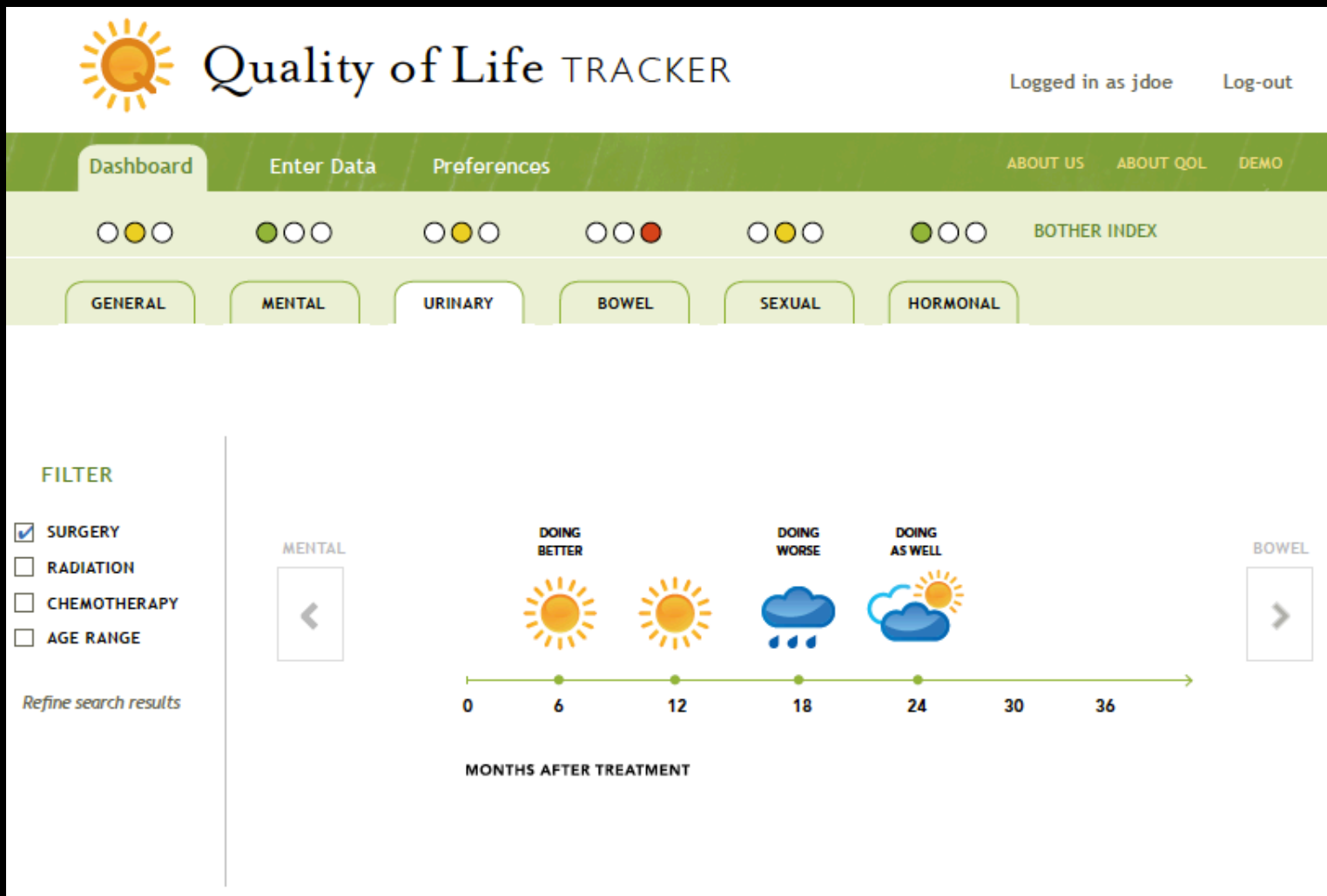
Line graph



Bar chart



Pictograph



Summary

- What patients want from a QOL dashboard
- Differences in patient vs. clinician preference
- Insights into clinical integration
- Status
 - Currently preparing for pilot testing
 - PCORI proposal under review
 - Next step is submitting R01

Outline

- Background
- Patient expertise sharing project
- Peer mentoring project
- Quality of life dashboard project
- Contributions

Summary of Projects

1. Patient expertise sharing

Nature of patient expertise & how patients share it

2. Peer mentoring project

Facilitate peer mentoring through social matching

3. Quality of life dashboard project

Share quality of life data in meaningful ways

Contributions

- Value of patients' experiential wisdom
- Range of designs to facilitate sharing in peer networks
- Interdisciplinary reach
 - Expands knowledge on breadth of patients' needs
 - Bridges understanding across domains (eg, expertise sharing, mentoring)
 - Fuels efforts to leverage social support through peer matching
- Helping people help each other empowers

Thank you



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