My Journey Compass

A Preliminary Investigation of a Mobile Tool for Cancer Patients

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My Journey Compass Overview

Multi-year engagement based in Rome, GA

- Working with the two hospitals, cancer clinic, and cancer navigators

Partnering with Microsoft and Georgia Department of Community Health

- Using HealthVault as depository for health records

Monitoring breast cancer patients' usage of tablets and PHRs

- 100 Participants, logging usage data for one year

Initial Study

Exploratory study on the utility of My Journey Compass tablet for cancer patients

- 12 participants, 1 month of use

Outcomes:

- Surprising technology uses
- Generalizable techniques to improve engagement with health tools
- Challenges pointing to future research directions
- Influences to local health system

Imagine the doctor told you that you have breast cancer…

What does that mean?

I have to schedule a surgery?

What kind of cancer did she say I have again?

How long did she say I will need to get radiation?

http://raleighmidtownchiropractic.com/headache-and-migraine/

You spend the next two weeks trying to learn everything you can about cancer and your treatment plan…

How does surgery and radiation work?

What will I look like after the lump is removed?

Should I consider plastic surgery?

http://theocdmama.blogspot.com/2013/08/the-updated-meal-binder.html

You finished surgery a couple of weeks ago and your radiation treatment begins next week…

What do I need to do to prepare for radiation?

What side effects should I expect?

How do I schedule my treatment sessions?

http://www.cancer.gov/cancertopics/coping/radiation-therapy-and-you/page3

Patient Responsibilities

- ✓ Obtaining medical information
- ✓ Sharing health information
- ✓ Coordinating treatment across multiple providers

http://www.visualphotos.com/image/2x3379182/runner_jumping_hurdle

Background

Mobile phones in emergency department

- Increased awareness
- Helped to reduce feelings of anxiety
- Empowered patients to take a more active role in understanding their healthcare

Pfeifer Vardoulakis, L., Karlson, A., Morris, D., Smith, G., Gatewood, J., and Tan, D. Using mobile phones to present medical information to hospital patients. *CHI 2012*.

http://www.koaa.com/news/red-cross-telethon-scheduled-for-thursday/c

Background

Tablet application for hospital patients

- Provided patients with doctors' names and photos and up-to-date medical information from EHRs
- Patients believed that application would improve their own satisfaction and healthcare engagement

Vawdrey, D. K., Wilcox, L. G., Collins, S. A., Bakken, S., Feiner, S., Boyer, A., & Restaino, S. W. A tablet computer application for patients to participate in their hospital care. AMIA 2011.

Wilcox, L., Feiner, S., Liu, A., Collins, S., Restaino, S., Vawdrey, D. Designing Inpatient Technology to Meet the Medication Information Needs of Cardiology Patients *IHI 2012*

Background

HealthWeaver Mobile

- Allowed patients to access necessary health resources at any time or location
- Improved patients' confidence in their ability to manage their own health information

Klasnja, P., Hartzler, A., Powell, C., Phan, G., and Pratt, W. HealthWeaver Mobile : Designing a Mobile Tool for Managing Personal Health Information during Cancer Care. *AMIA 2010*, 392–396.

http://www.breakingnews.ie/ireland/stolen-iphones-tracking-software-leads-gardai-to-thieves-569935.htmlc

Atypical Features

Mobile, Open Platform

Interface Customized by Participants

Integration into Existing Health System

http://ibnlive.in.com/news, http://footage.shutterstock.com/

Cancer Navigators

Address emotional, financial, and logistical challenges often overlooked by the traditional medical system

- Jacobs, M., Clawson, J., and Mynatt, E.D. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. CSCW 2014.

Ideal research partners

- Expert knowledge of patient needs
- Existing framework for meeting, working with, and developing relationships with patients

CANCER NAVIGATORS
Reassurance Resources Renewal

...because people shouldn't have to journey alone

Research Phases

1. Needs Assessment
2. Tablet Design
3. Initial Study

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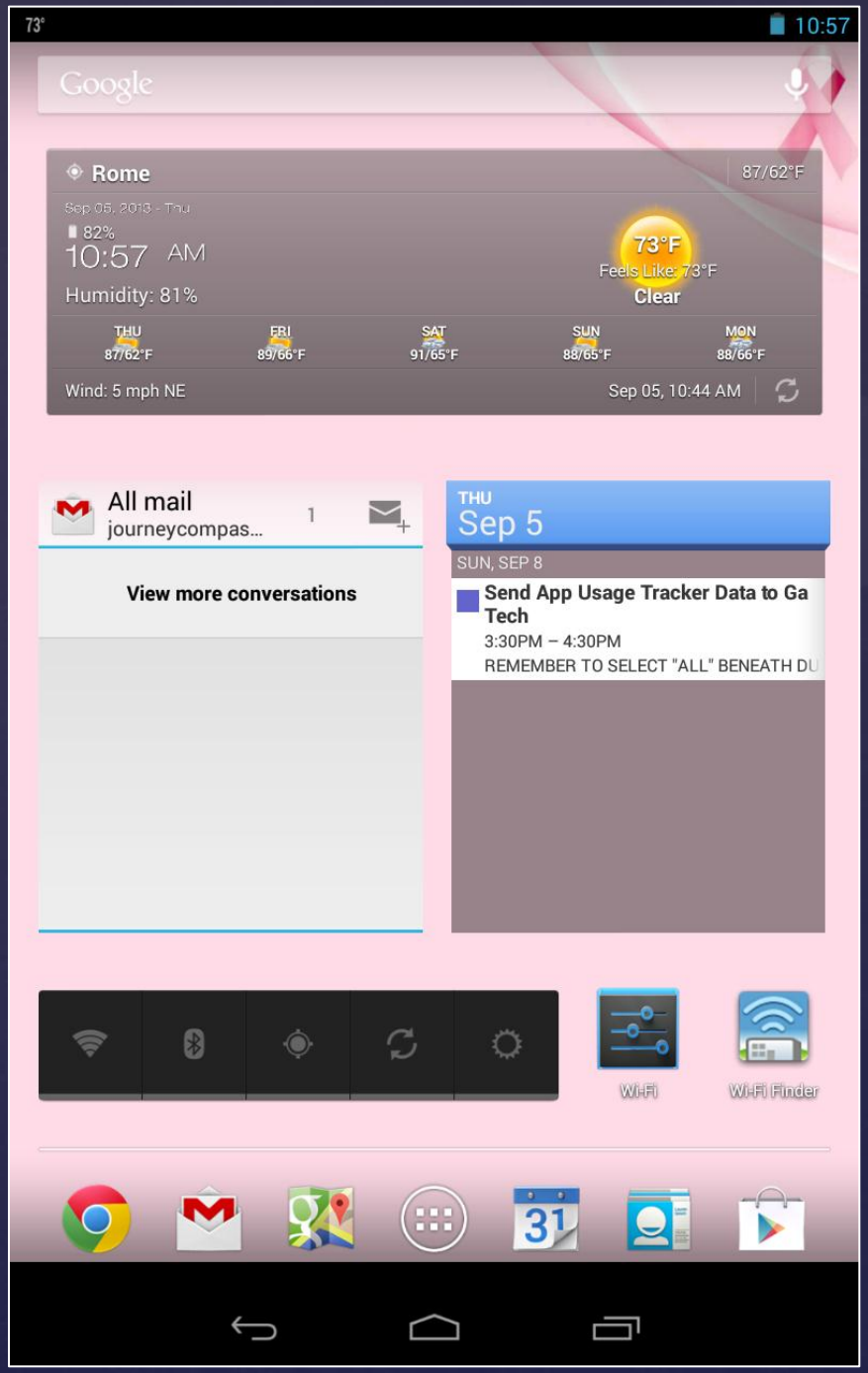
2. **Tablet Design**
3. **Initial Study**

Tablet Design

- Design Team
  - Oncologists, cancer navigators, breast cancer survivors, director and executive director of two local cancer centers
- Selected application, PDF resources, and websites useful for breast cancer patients
- Nexus 7 tablet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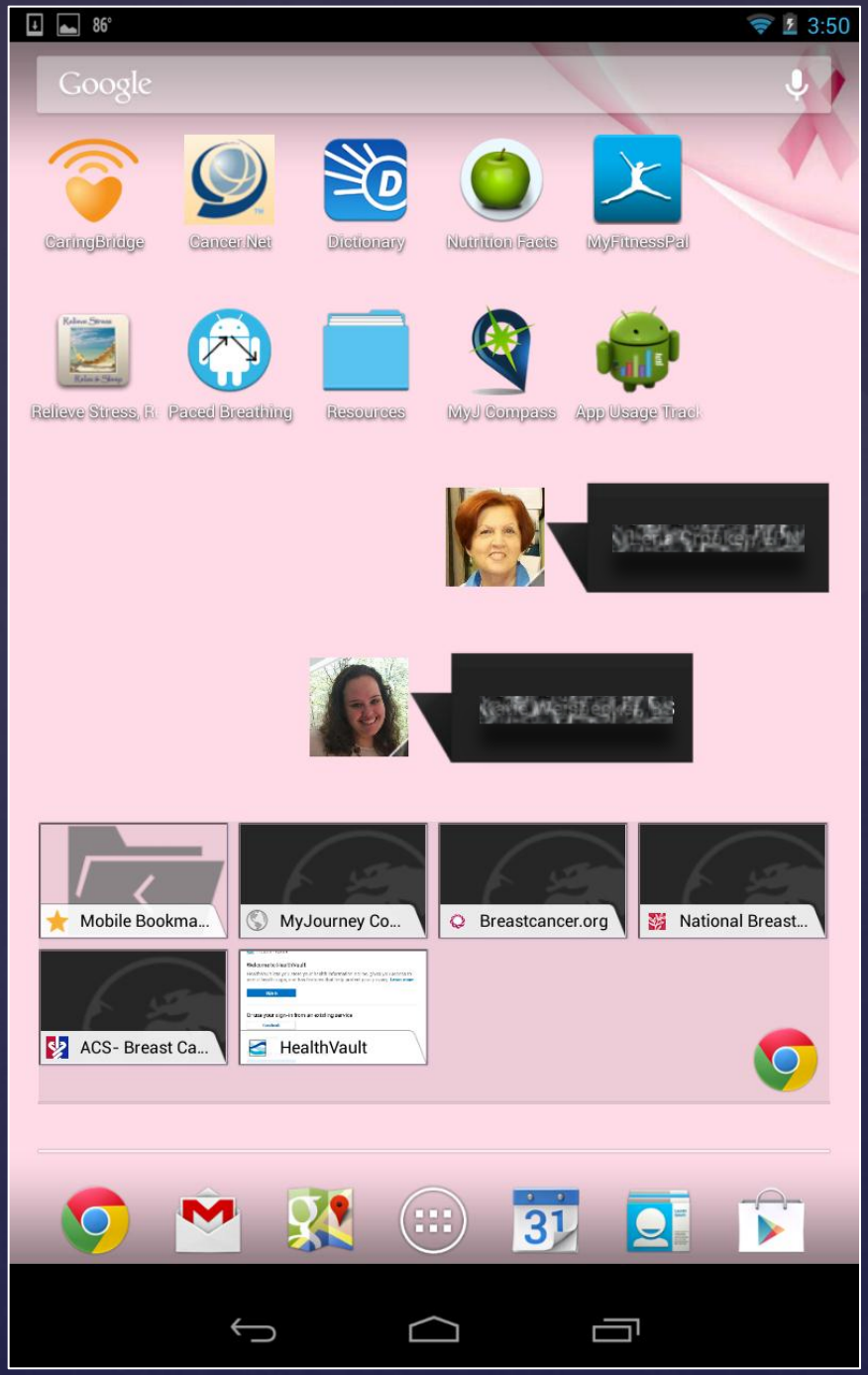
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App Usage Track
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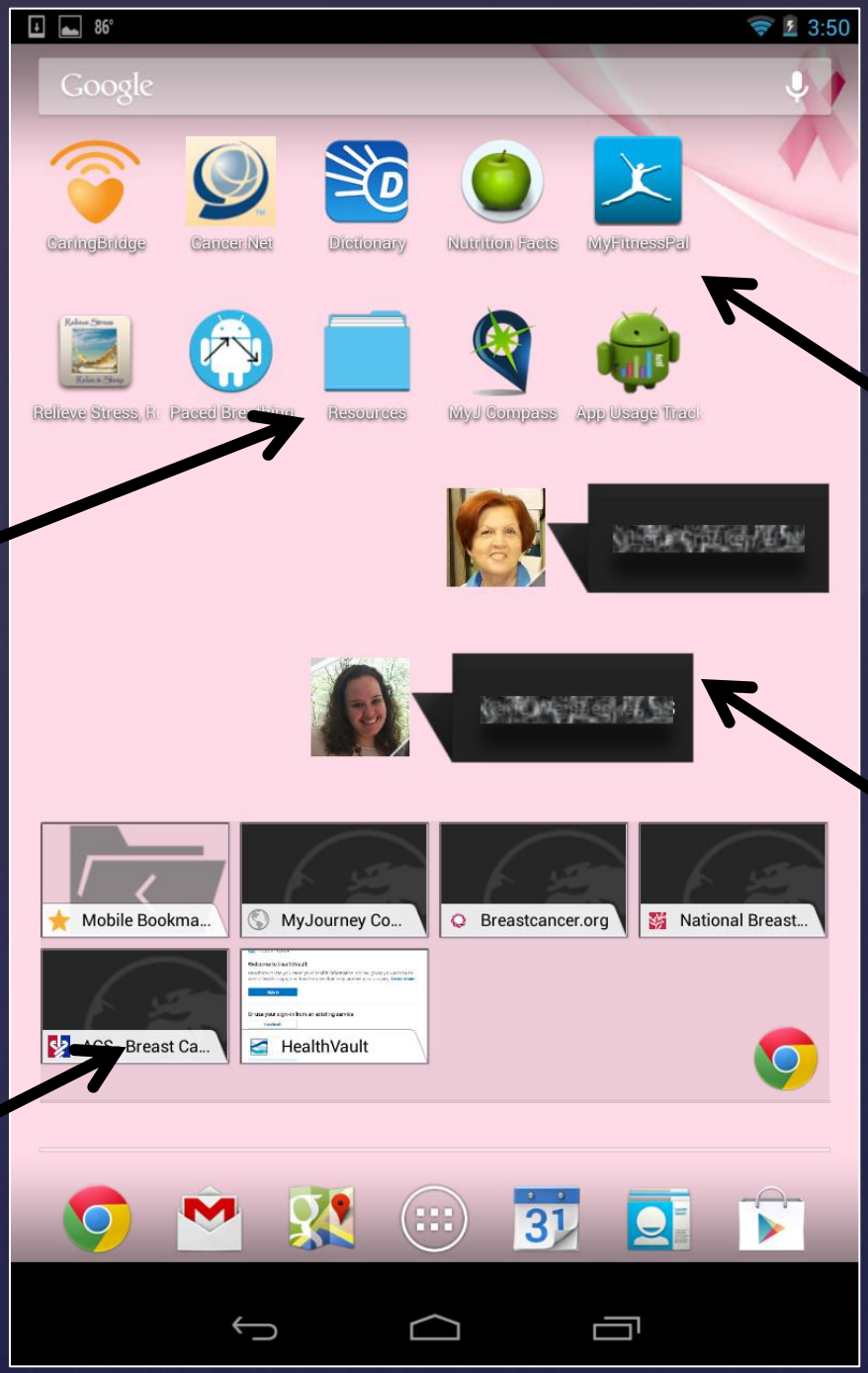
MyJourney Co...
Breastcancer.org
National Breast...
ACS- Breast Ca...
HealthVault



PDF Resources

Suite of Applications

Navigators' Contact Information

Websites

Initial Study

Participants recruited after first consultation with oncologist

Patients keep tablets, encouraged to add or delete applications of their choosing

12 patients, 11 female, age range from 39 - 80

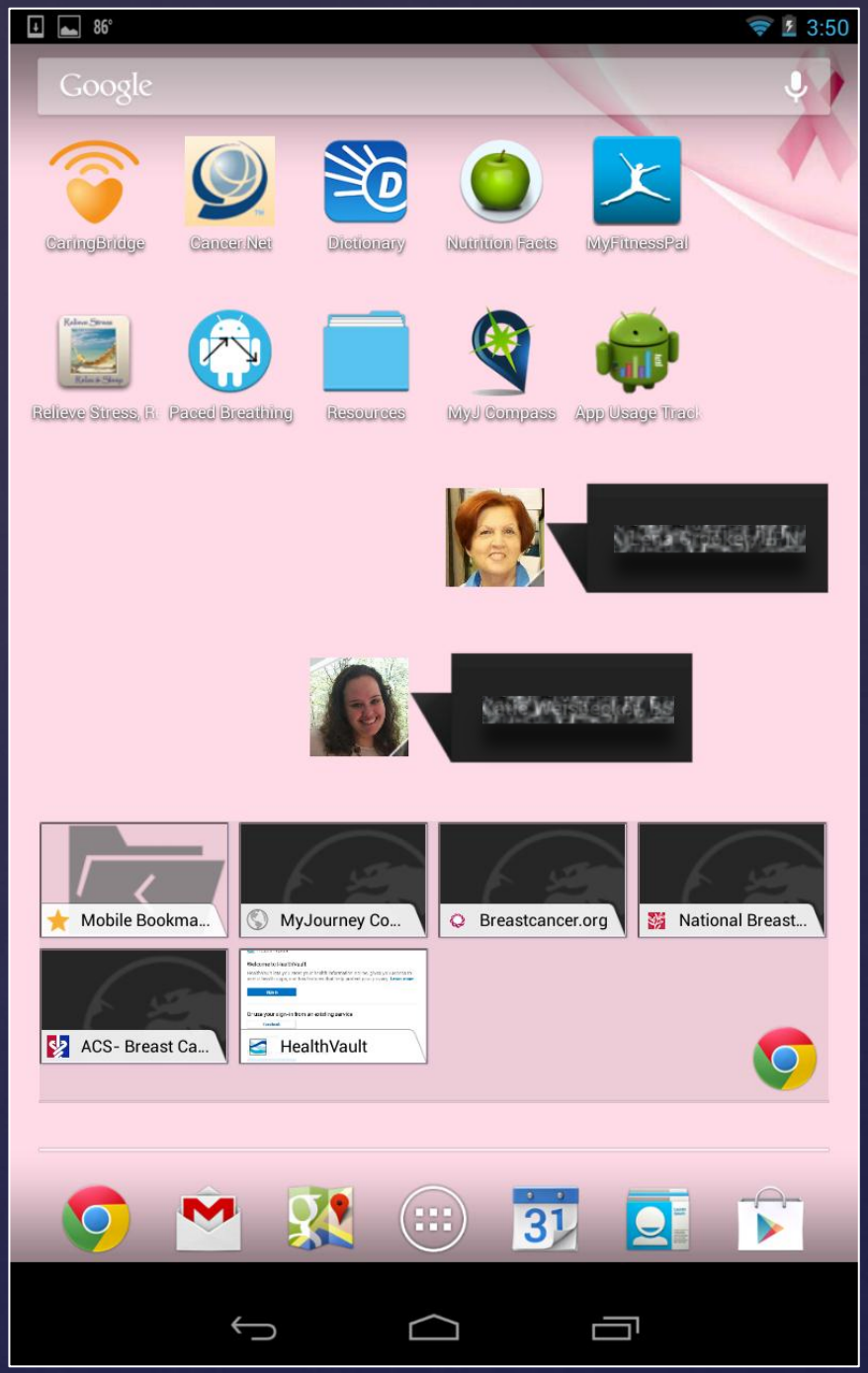
Interviewed after one month

- Focus on usage patterns and motivations for adoption

Findings

Findings

Communication support with doctors



Findings

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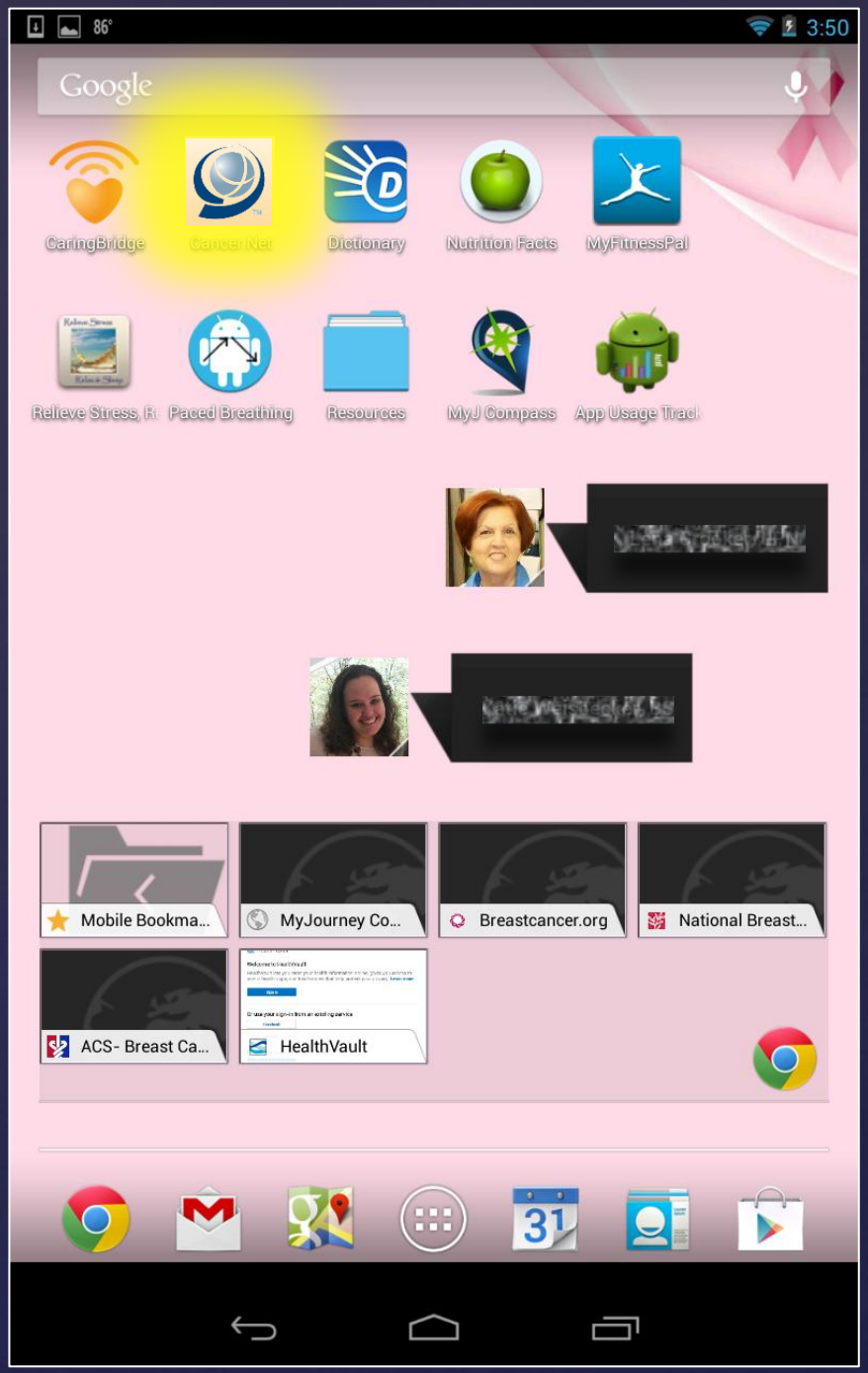
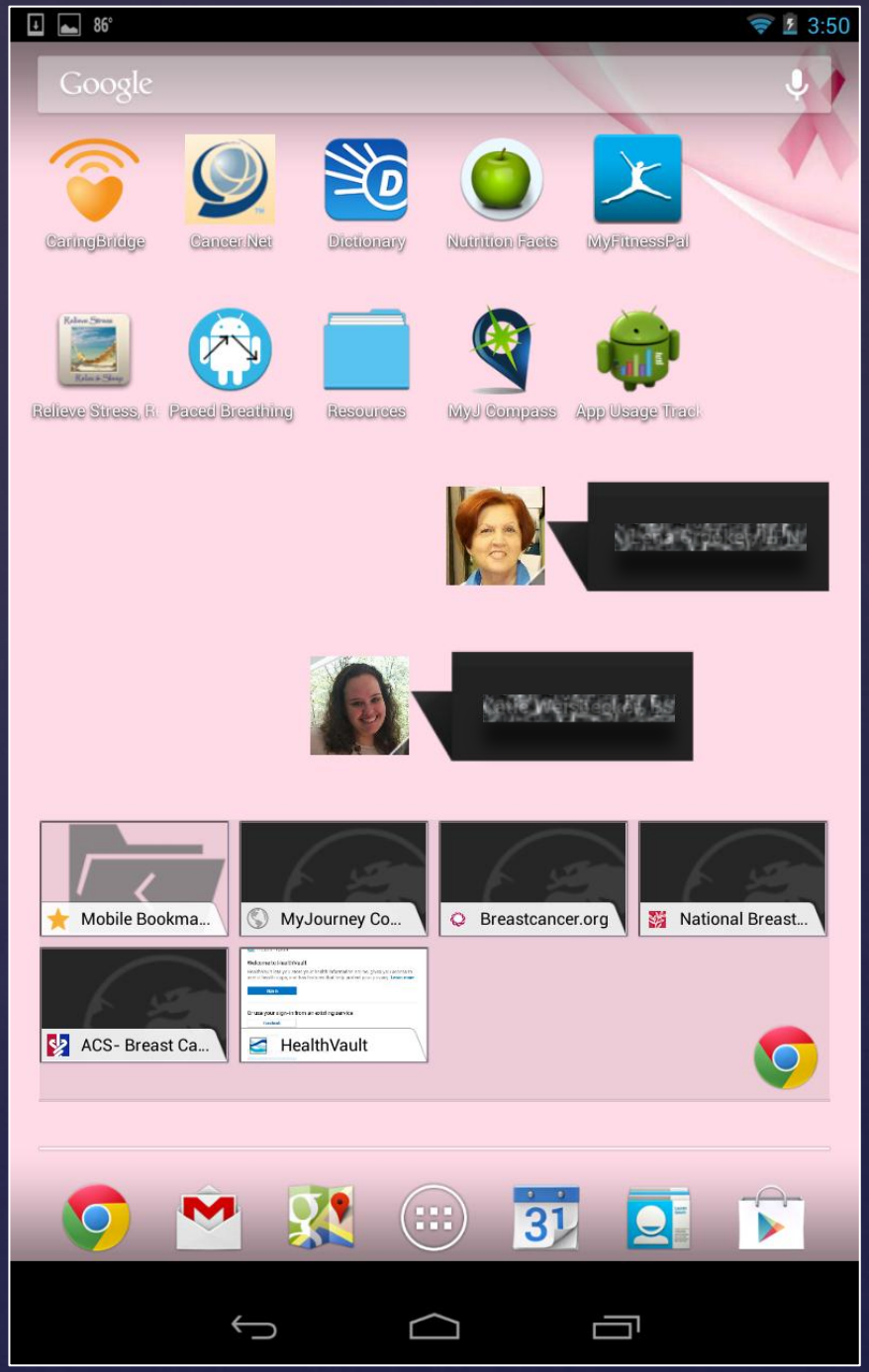


Findings

Tool for supporting others



Findings

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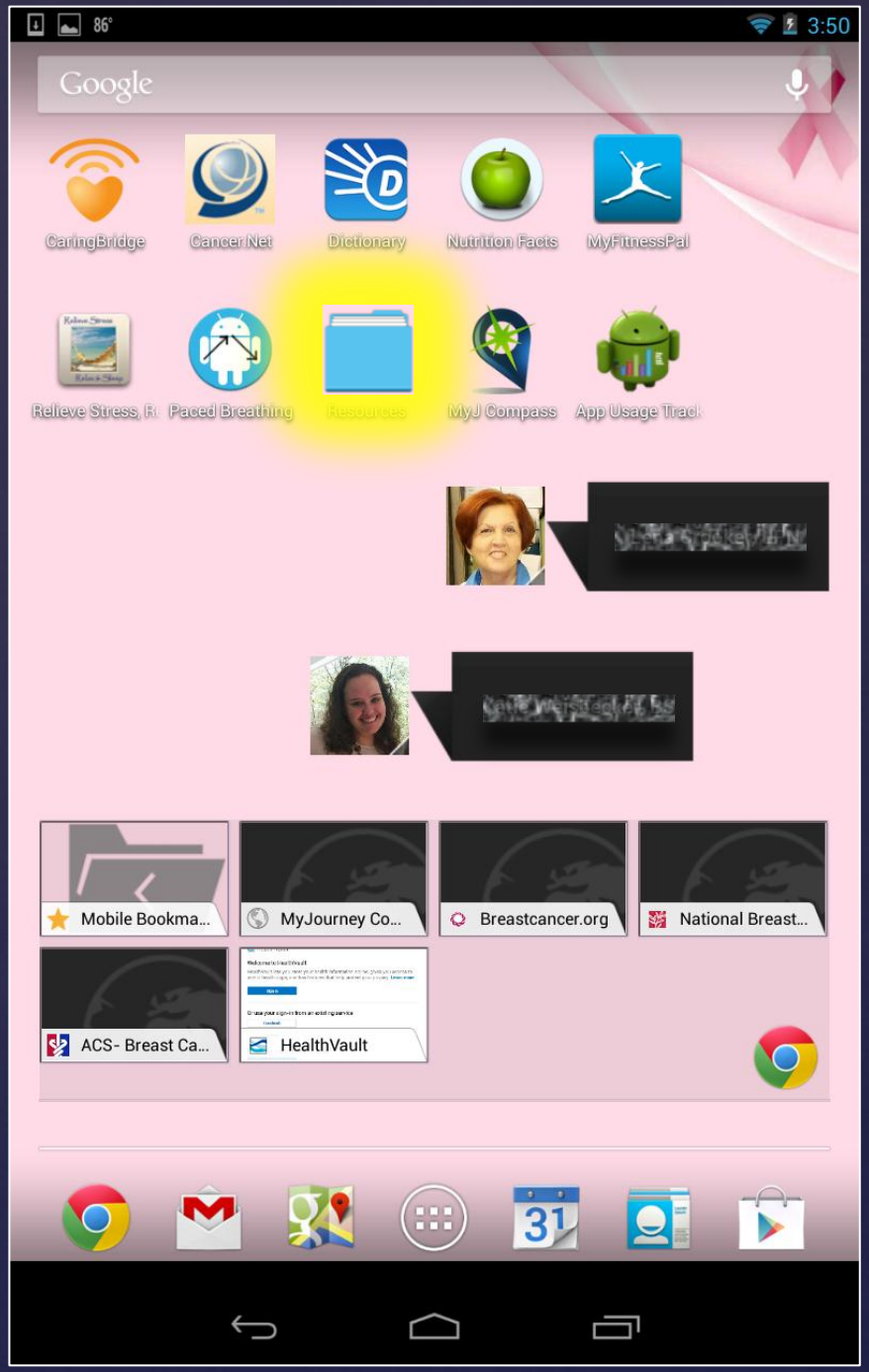

Findings

Uses

Relaxation/entertainment tool, personal uses, tool for supporting others, organization and memory aid, communication support with doctors, enhancing support system communication

Motivations for Adoption

Privacy, customization, balance of information, mobility

Factors influencing low adoption

Privacy

Concerned about identity, not data security

"To be real honest with you there are not a whole ton of people that have shared the fact that I even have cancer… Most people's response is 'oh my god' but I'm not one of those 'oh my god' people. That just makes me feel strange when they do that, so I just won't tell them." – P7

http://www.ontravel.com/2011/02/gadgets-and-gear-restricted-internet-access-and-better-photography-tips/

Privacy

Participants could bring their medical resources to public areas while maintaining discretion

"You're sitting in an office and people know why you're there. Even if it's the general surgeon they know why you're there because you have the big cancer folder. So this is great because it's discreet."
– P9

http://www.ontravel.com/2011/02/gadgets-and-gear-restricted-internet-access-and-better-photography-tips/

Customization

Participants told that they could use the tablet however they liked

Health served as a gateway into personal use and customization

Led to unexpected uses

http://www.prevention.com/health/health-concerns/healthier-heart-30-days

Customization

"One of the best things about it was being able to take it to chemo and have it and plug in my earphones and if I wanted to listen to music or if I wanted to read a book or whatever it is. It just made the whole thing a lot more relaxed and easier." – P6

Customization

Allows tool to remain relevant and useful as new healthcare applications and resources become available

Could be important for keeping users engaged with health tools once the novelty of the health device fades

Leads to a broader ranges of uses

Factors Influencing Low Adoption

Age and low technology literacy did not hinder tablet adoption or use

Technology burnout did lead to low adoption

"I sit in front of a computer all day and when I get home that's probably the last thing I want to do is turn on another computer." – P2

http://www.medway.gov.uk/leisureandculture/libraries/healthyliving.aspx

Changes to the Health System

Creation of the education navigator position

- Provided participants with technology support
- Allows the navigation organization to expand its own technology fluency

http://cancernavigatorsga.org/myjourney-compass/

Key Takeaways

Provide an example for, and discuss the benefits of, **combining personal and health technologies**.

Provide **insight into four factors that motivated** our participants to **use** the tablet

Provide evidence for the importance of **integrating new health management technologies into existing healthcare systems**

Future Work

Continue to examine usage patterns of participants throughout the year

Examine correlations between tablet usage and cancer stages

Identify gaps in ability for existing tools and applications to support patients through their cancer journeys

Thank You

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