Lessons Learned From a Yearlong Deployment of Customizable Breast Cancer Tablet Computers

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Overview

36 Breast cancer patients



Customized tablet computers



Multi-year engagement with Harbin Cancer Clinic



Partnered with
Microsoft and
Georgia Dept. of
Community
Health



Monitored patients' tablet usage for one year

Motivation

Challenges:

Feeling overwhelmed
Understand treatment options
Finding transportation to treatment
Unexpected complications

Responsibilities:

Share health information with others
Make clinical decisions
Symptom tracking
Financial management

Questions:

How does surgery and radiation work?
What will I look like after surgery?
What side effects should I expect?
How do I schedule my treatment sessions?

Existing tools

 Increase patient awareness, reduce feelings of anxiety [Vardoulakis et al. 2012]

 Provide patients with up-to-date medical information [Vawdrey et al. 2011]

 Improve patients' confidence in their ability to manage their own health information [HealthWeaver Mobile, Klasnja et al. 2010]

My Journey Compass

How can we develop holistic technology to support patients' cancer journeys?

- Curated set of digital resources:
- Existing documentation and online tools
 - Funded by ONC grant

Research Project

- 1. Needs Assessment
- 2. Tablet Design
- 3. Initial Study¹
- 4. Yearlong deployment
- 5. Analysis of usage data

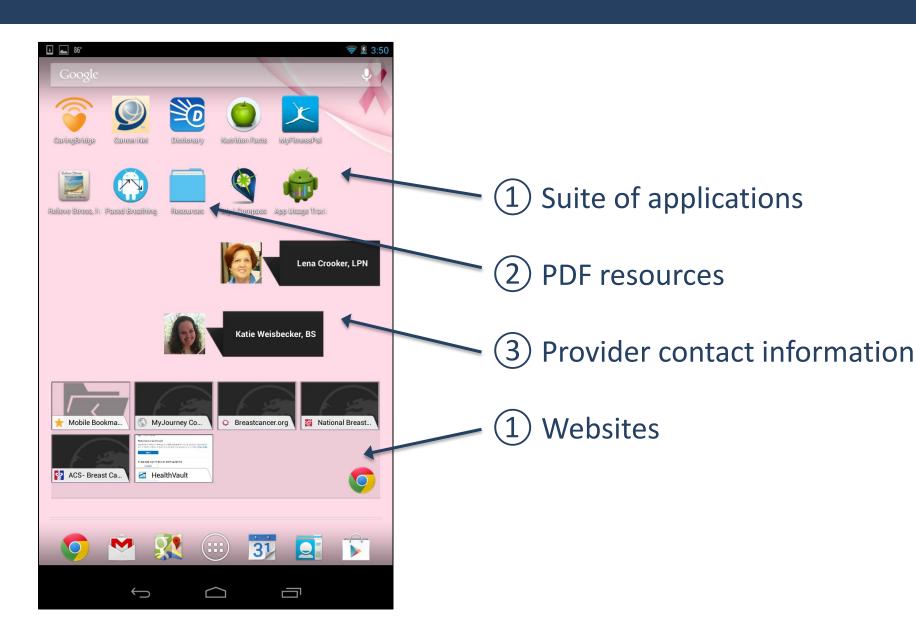
^{1.} Maia Jacobs, James Clawson, and Elizabeth Mynatt. 2014. My Journey Compass: A Preliminary Investigation of a Mobile Tool for Cancer Patients. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14).

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About My Journey Compass



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Three key features:







Mobile device

Open, modifiable platform

Integrated into health system

Integration into Health System

Participants recruited after first consultation with oncologist by cancer navigators

Every participant who received a tablet set up a training session with cancer navigators

Cancer Navigators

Address emotional, financial, and logistical challenges not addressed 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



Data Collection

36 participants

- 26-80 years old (median = 60)
- 35 female, 1 male
- Mostly from rural, northwest Georgia

Monitored tablet usage

- Application name
- Date and time application was opened
- Duration of time the application was used

Interviewed 25 participants about their experiences

Tablet Usage

Average usage: 2.6 hours/week

239 applications used

29/36 participants used the tablet regularly, with gaps in use lasting less than two weeks

14 participants continued to use My Journey Compass after completing active treatment.

Tablet Usage

Variety of uses:

- Communication support with doctors
- Tool for supporting others
- Relaxation/entertainment tool
- Organization and memory aid
- Tool for enhancing support system communication

Contributions

Discuss three motivating factors led participants to integrate technology into their daily lives.

Describe participants' usage patterns and the insight these patterns provide into ways flexible health tools may support patients' health needs.

Discuss benefits of using a customizable platform for encouraging long-term engagement with health technology

Identify lessons learned through this deployment to guide the design of future technologies

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Lessons Learned

1. Integrating health and non-health resources encourage participants to return to health resources when needed.

2. Customizable tools reveal insight into patients' goals and values.

3. We must expand our definition of health resources.

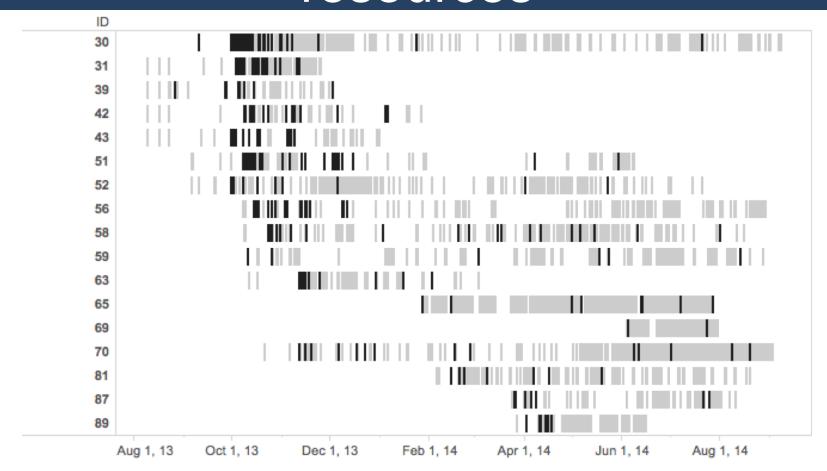
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Integrating health and non-health resources



17 participants used the tablet regularly with sporadic usage of the health resources

Integrating health and non-health resources

"I'm going to use [the tablet] more for other things than research or cancer stuff. Unless they say 'you have to do a new treatment', then I'll go and research that."

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Patient Customization

Thirty-five participants added applications

178 unique applications were added to the tablets (average 9 per patient)

Allowed participants as they could add personally meaningful resources.

- Photographs of family members
- Religious applications
- Games, books to reduce stress
- Recipes on YouTube

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Expanded Definition of Health Resources



→ Reduce stress during chemotherapy



You Find healthy recipes for dietary changes



→ Share health information with family and friends

Moving Forward



Curated set of resources for all patients(My Journey Compass)



Customized set of resources per patient NIH R01



Adaptive technology as patient needs, behaviors change



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