Interface Between Electronic Systems and Humans: View From Outside of Medicine

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Key Question

How do we create technology that encourages sustained patient engagement?

"Often, the causes of [information] system failures cannot be explained in purely technical terms. Rather, the complex network of relationships among people in an organization strongly affects the success of a technology."

Wanda Pratt, Madhu C Reddy, David W McDonald, Peter Tarczy-Hornoch, and John H Gennari. 2004. Incorporating ideas from computer-supported cooperative work.
Journal of biomedical informatics 37, 2: 128–37

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

Understand the practices of cancer navigators

Understand the "breast cancer journey" from a holistic care perspective

Design and evaluate personalized and adaptive support by breast cancer patients

CANCER NAVIGATORS
Reassurance Resources Renewal

Funded by GA DCH and ONC: Rome Challenge Project, Consumer Mediated Health Information Exchange #12036G-ARRA

NCI Creating Interactive of Models Healthcare Journeys to Improve Patient-Care (R01CA195653)

Vision for Patient-Centered Care

Cancer Journey Framework

	Responsibilities *Patient work; health tasks placed on patients*	**Challenges** *Barriers to care*	**Personal Journey** *The effects of cancer on one's personal, daily life*
Screening and Diagnosis	• Communicating the disease to others	• Information gaps • Emotional impacts • Dealing with others' reactions	• Attitude changes • Major life events
Information Seeking	• Information filtering and organization • Clinical decisions • Preparation	• Overwhelming amount of information • Understanding treatment options	• Coping strategies
Acute Care and Treatment	• Symptom management • Support management • Compliance • Managing clinical transitions • Financial management	• Inability to work • Transportation • Lack of support • Reluctance to ask for help • Unexpected complications	• Relationship changes • Responsibilities of daily life • Social behavior changes • Loss of independence • Asserting control • Health milestones • Personal goals
No Evidence of Disease	• Continued monitoring • Giving back to the community • Health behavior changes	• Worry about recurrence	• Survivor identity • Return to normal

- Gillian Hayes, Gregory Abowd, John Davis, Marion Blount, Maria Ebling, and Elizabeth D Mynatt. 2008. Opportunities for pervasive computing in chronic cancer care. Pervasive Computing: 262–279.
- Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2014. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. CSCW 2014.
- Maia Jacobs, James Clawson, and Elizabeth D. Mynatt. 2017. Articulating a Patient-Centered Design Space for Cancer Journeys. EAI Endorsed Transactions on Pervasive Health and Technology 3, 9: e5.

Overall Approach

1 Holistic

Patients face numerous physical, practical, and emotional challenges in parallel

2 Personalized

Cancer diagnosis, treatment plan, SES, and daily responsibilities all influence patients' experiences

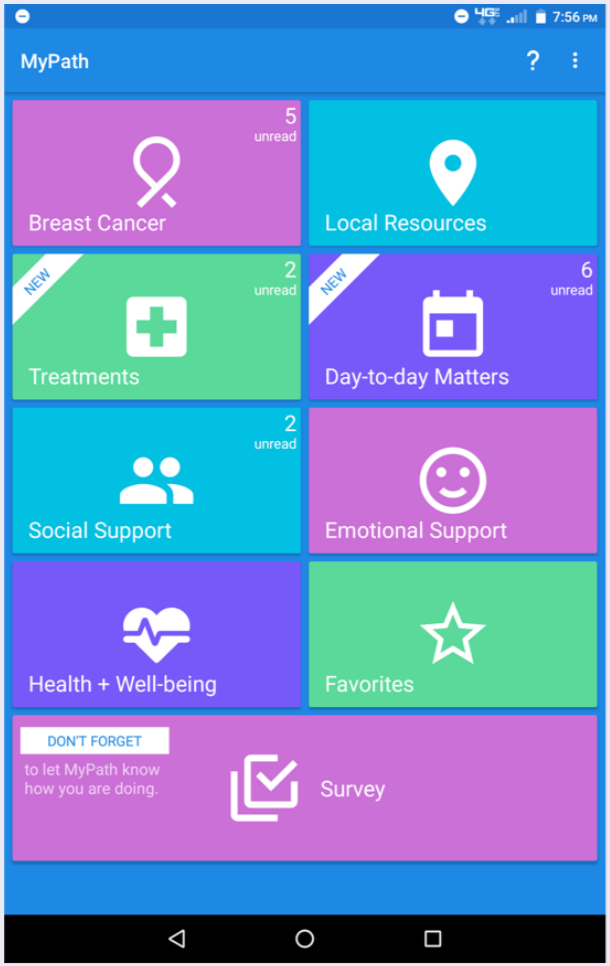
3 Adaptive

Patients' goals, needs, and priorities change over time

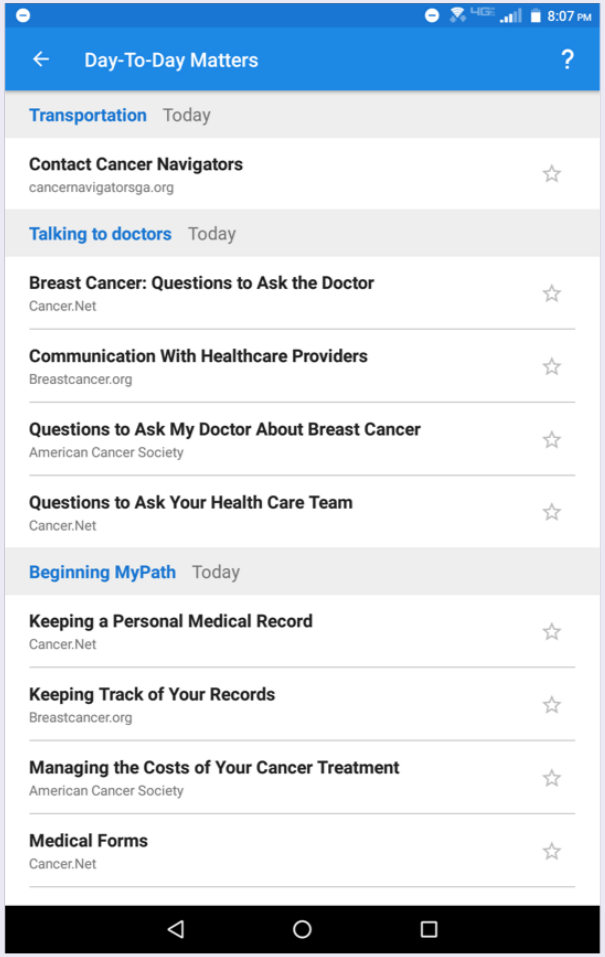
Core Features:

- Mobile device
- Open customizable platform
- Integrated into health system
- Simple AI system to index vetted resources against diagnosis, treatment and PROs

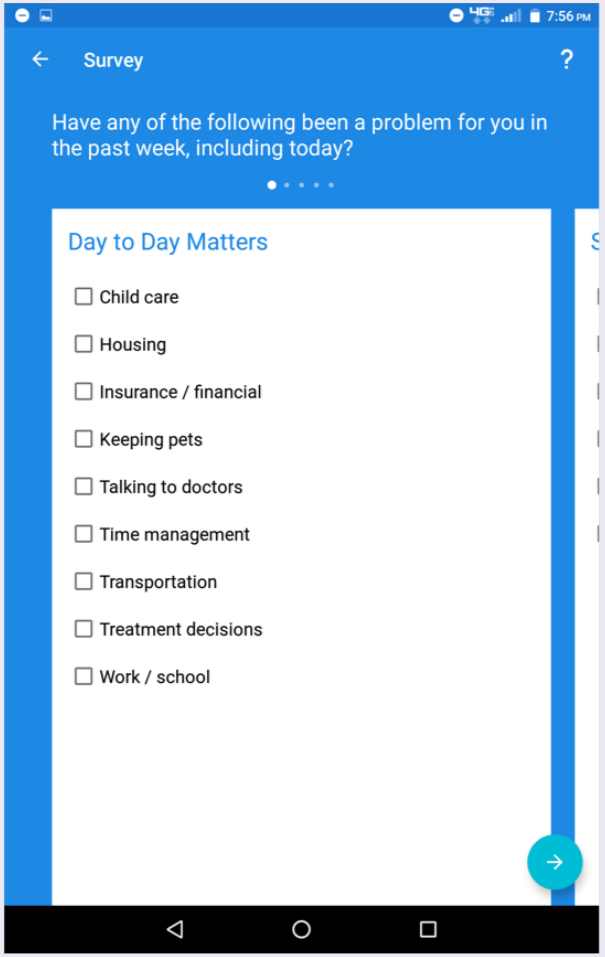
MyPath Patient Interface



MyPath main page

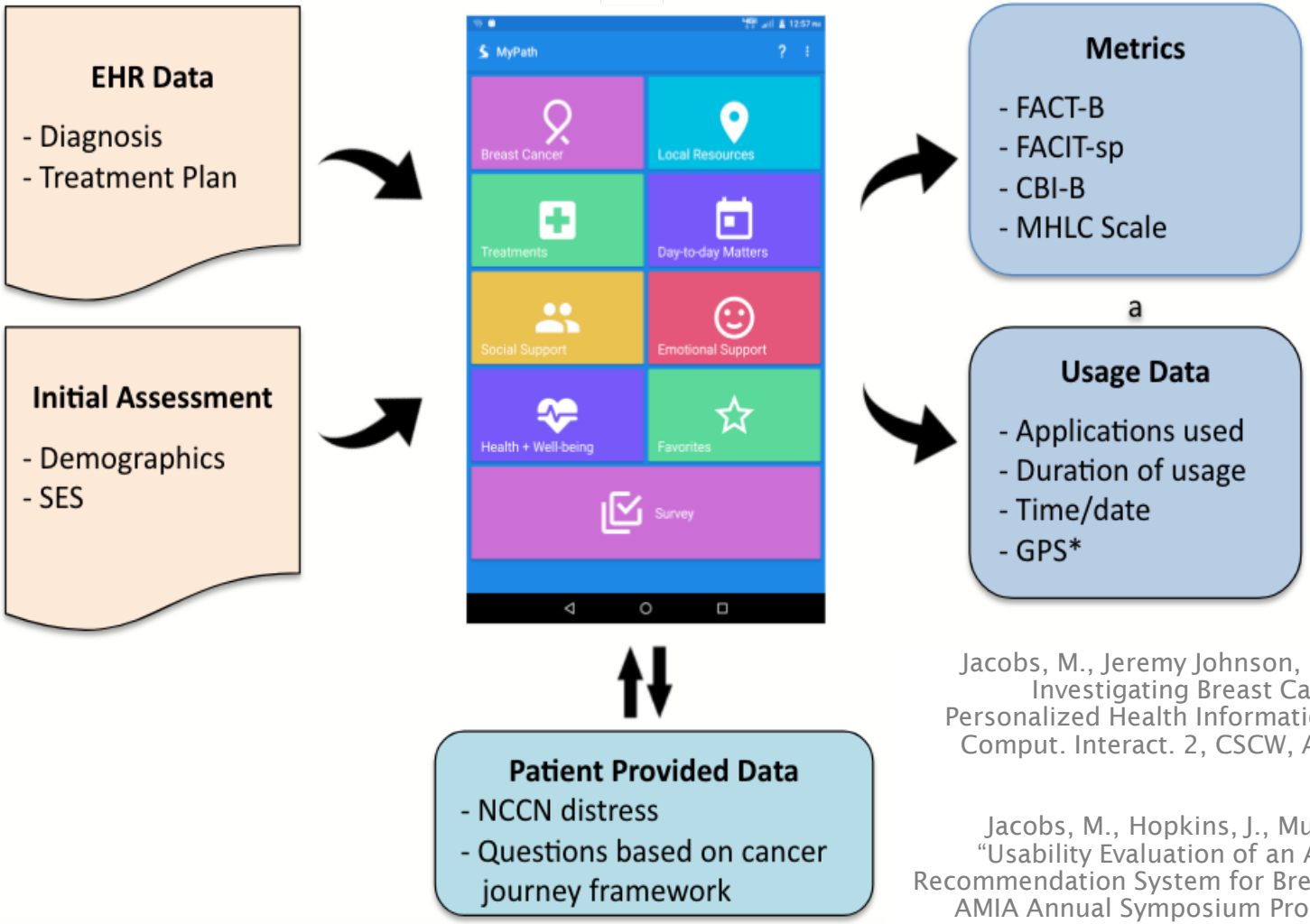


Day-to-Day Matters category with a set of personal resource recommendations



MyPath survey

MyPath Information Flow



Jacobs, M., Jeremy Johnson, Mynatt, E.D. MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information. Proc. ACM Hum.-Comput. Interact. 2, CSCW, Article 78 (November 2018

Jacobs, M., Hopkins, J., Mumber, M., Mynatt, E. "Usability Evaluation of an Adaptive Information Recommendation System for Breast Cancer Patients," AMIA Annual Symposium Proceedings. Vol. 2019.

Human Experience Challenges

Engagement

- Holistic
- Relevance
- Longitudinal
- Personalized
- Adaptive

Confidence

- Technology embedded in trusted relationship
- “It knows me”
- Tech can foster *over* confidence

Coordination

- Information gaps. How can technology be a trusted proxy
- Inform patient outreach

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