Research Statement

Maia Jacobs

Advances in engineering approaches and scientific evaluations of technology for personalized healthcare are needed to combat the growing burden and complexity of managing chronic diseases. Approximately half of the adult population in the United States has been diagnosed with a chronic disease, requiring healthcare to extend its reach from medical centers and into the home and everyday settings. This shift has quickly made personal health informatics, a class of tools that support individuals' personal health management, a critical component of care. Advances in personal health informatics are largely being driven by computing research, through the development of technologies that help individuals learn about and manage their health in the context of daily life. Personal health informatics is widely considered to be an important strategy for improving chronic disease survivorship rates in the future, but developing effective tools is a challenging and complex task. These technologies must offer the flexibility and robustness to conform to individuals' evolving health situations. Existing tools typically focus on a small subset of goals or tasks, such as symptom tracking or exercise monitoring, placing the burden on patients to integrate information from disconnected sources and repeatedly find and incorporate new resources as their healthcare needs change. Further, few studies have utilized the experimental rigor necessary to determine how interactions with personal health tools impact health outcomes and the daily experiences of chronic diseases management.

In my work, I am creating new computing approaches for mobile health tools that consider the holistic and changing needs of individuals over time. Specifically, I am leading the design and evaluation of mobile health tools that offer personalized, adaptive health information to breast cancer patients. Through a randomized control trial, I will provide scientific evidence that interactions with personal health tools positively influence healthcare experiences. Further, my evaluation will identify the usage patterns and system features that correspond to improved health metrics. This work, supported by the National Cancer Institute, has garnered national attention, being recognized in the 2016 report to the President of the United States from the President's Cancer Panel[1], which discusses the importance of patient engagement as a strategy for improving cancer-related outcomes. Below, I describe the contributions of this work in more detail.

An important, open question in the design of novel systems that support individuals' continuous health management needs is *how do patients' needs and goals change over time?* While studies have identified a variety of patient challenges, few consider how individuals' priorities shift over time as their health changes. Through multiyear engagements with both breast cancer survivors [3] and healthcare professionals [2,4], I

[1] "Improving Cancer-Related Outcomes with Connected Health: A Report to the President of the United States from the President's Cancer Panel." 2016. https://prescancerpanel.cancer.gov/report/connectedhealth/Part2Obj2.html.

first worked to understand the complexities of cancer care and patients' cancer experiences. Through this work, I created a comprehensive framework of the cancer experience, presenting a robust set of patient information needs and challenges, and identifying the scope of support necessary across common phases of breast cancer care.

Another important question when considering how technology can support personal health management is *will patients adopt a mobile health tool, and how will use of the tool connect to the challenges of managing cancer?* Often evaluations of health tools focus on behavior changes over a limited period of time. Through a yearlong technology probe, I confirmed that newly diagnosed patients were willing to adopt a novel mobile health tool into their daily lives, independent of factors such as age or technological expertise. Further, participants remained engaged with the system even after finishing treatment, allowing me to identify technological features that encourage continuous, long-term engagement with health tools [1].

Both of these formative studies highlighted a significant challenge individuals face while managing their health. An overwhelming number of resources exist for cancer patients, and finding trusted tools to support one's specific needs is an extremely difficult task. I am now leading the development of MyPath to reduce this burden. MyPath is a mobile application that integrates electronic health record data, online resources for patients, and patient input to present personalized health information to breast cancer patients. Interaction with and information from MyPath adapts as each patient progresses from diagnosis through treatment and post-treatment survivorship. In addition to the development efforts, I am leading a randomized controlled trial comparing MyPath to non-personalized mobile support to determine how use of the technology correlates to changes in patient engagement and quality of life. My study will demonstrate how advances in mobile computing can improve the health and wellbeing of individuals managing cancer, while providing a model for developing future informatics systems that consider dynamic health needs and goals of individuals.

Together, these studies address two critical needs in personal informatics research: the development of tools that offer integrated and personalized support for chronic illness management and the scientific knowledge establishing the impact of these tools on health outcomes and health management experiences. My research has led to a comprehensive framework of the cancer journey, the identification of mobile technology features that encourage long-term engagement, and the development and evaluation of a novel application that connects individuals with personalized and adaptive health resources. In my future research, I will continue to address challenges raised by my research, developing information tools that provide dynamic assistance across health contexts. I will turn my attention to creating tools that support illness trajectories that are characterized by greater variability and unpredictability, such as degenerative diseases. When considering the development of tools for these contexts, natural computational problems arise, such as the development of patient classifications that utilize comprehensive journey data to offer automated personalized support. Such problems fall under the frameworks of machine learning and natural language processing. The 2017

RisingStars in EECS workshop would provide an important opportunity to develop these ideas and collaborations with colleagues and mentors.

References

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)*.
2. Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2014. Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey. *Proceedings of the SIGCHI Conference on Computer Support Cooperative Work (CSCW '14)*, 1467–1478.
3. Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2015. A Cancer Journey Framework: Guiding the Design of Holistic Health Technology. *Conference on Pervasive Healthcare (Pervasive Health '15)*.
4. Maia Jacobs, James Clawson, and Elizabeth D Mynatt. 2015. Comparing Health Information Sharing Preferences of Cancer Patients, Doctors, and Navigators. *Proceedings of the SIGCHI Conference on Computer Support Cooperative Work (CSCW '15)*, 808–818. http://doi.org/10.1145/2675133.2675252