



Improving Medical Outcomes through At-Home, Longitudinal Health Monitoring

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Abstract

Ubiquitous Computing and Human-Computer Interaction health researchers motivate their work with the promise of improving health outcomes for patients. Although computing devices are producing more health data than ever, turning this data into actionable insights remains a challenge. In this Doctoral Colloquium submission, I argue that to improve health outcomes, medical systems must not only produce health data, but also provide interpretations of that health data personalized to the individual in order to deliver effective, actionable feedback. To illustrate this approach, I introduce two projects: Beacon and ExerciseRx-CP. Beacon is a system that screens for minimal hepatic encephalopathy through a novel critical flicker frequency (CFF) measure. I use Beacon's CFF measure as an illustration of defining ways to interpret new health data by incorporating personal baselines and longitudinal measurements. ExerciseRx-CP is a system that uses real-time feedback of exercise tracking to encourage physical activity among adolescents with cerebral palsy. I use ExerciseRx-CP as a way to show how motion data can be interpreted on multiple levels (e.g., raw sensor signals, subrepetition motion, and aggregated repetition metrics) to deliver different feedback mechanisms. Finally, I describe how an *enabling activities* framework can help Ubicomp researchers characterize activities necessary for translational research, promote more translational research to be conducted our community, and ultimately create greater impact as a field.

CCS Concepts

• **Human-centered computing** → Ubiquitous and mobile computing; **Human computer interaction (HCI)**; • **Applied computing** → Health informatics.

Keywords

Health data, Translational research, Interactive systems

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1 Problem Statement

Over the last five decades, computing devices have become more personal, moving from static fixtures to accompanying people on-the-go and even worn on-body [40]. This trajectory has also given rise to the use of personal informatics systems [20] for collecting increasingly dense amounts of health data [18]. People collect this data with the promise that it will increase understanding of their health [13], motivate and support behavior change [1], and improve management of their condition [23], leading to improved health outcomes. However, despite having more data than ever, turning data into actionable insight remains a challenge [8, 30]. In this work, I propose taking a preventive medicine approach to interpreting and processing this data in order to derive useful feedback. Preventive medicine is an approach to healthcare that aims to proactively mitigate the development of diseases [19]. In the United States, it is estimated that one third of all deaths are considered to be potentially preventable through measures such as not smoking and maintaining a healthy diet [41]. This approach involves strategies that are described as taking place on three levels [9], enumerated in Figure 1.

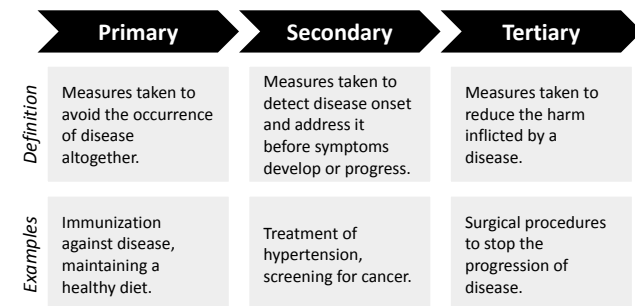


Figure 1: Levels of preventive medicine strategies.

The preventive medicine approach prioritizes strategies that promote the health of the individual, through individual-level interventions and lifestyle choices. This approach contrasts with that of a population health approach that seeks to improve the health outcomes of groups of people by considering systemic issues such as poverty, education, and access to health care [16]. The COVID-19 pandemic has demonstrated the value of primary level preventive medicine, reminding the global population of basic health measures such as handwashing, social distancing, and mask wearing [10]. Moreover, preventive measures have been shown to increase quality of life in those with chronic diseases [32].

Because the preventive medicine model recommends measures to be taken by the individual, such as smoking less or engaging

in more physical activity, recommendations are typically made relative to the individual's own baseline [25, 27]. We suggest that, in the same way that these recommendations are made, medical devices should consider the baselines of the individual. However, because of the density of data available to these medical devices, they can form more sophisticated baselines that consider multiple factors, including changes over time and the context in which measurements are taken. In my interpretation of this approach towards designing medical devices, I present the following thesis statement.

To improve health outcomes, medical systems should not only produce health data, but also provide interpretations of that health data personalized to the individual in order to deliver effective, actionable feedback.

In this Doctoral Colloquium submission, I will illustrate this thesis statement through showing how this process of designing systems that provide personalized interpretations has been implemented in two example projects. First, I will introduce Beacon, a system that enables at-home, repeated screening for minimal hepatic encephalopathy (MHE) and an example of secondary preventive medicine. Then, I will introduce ExerciseRx-CP, a system for promoting consistent physical activity among adolescents with cerebral palsy (CP) and an example of tertiary preventive medicine. Finally, I will reflect on insights shared across both projects in building the system deploying them in home settings. Taken together, my work contributes pragmatic approaches to deploying systems in the real world that lead to improved health outcomes.

2 Related Work

2.1 Chronic Liver Disease Background

Cirrhosis, or scarring of the liver, is a severe outcome of liver disease responsible for over 48,000 deaths in the United States in 2021, the 9th-leading cause of death that year [24]. Over 80% of cirrhotic patients develop neurocognitive impairments known as hepatic encephalopathy (HE) [37]. These impairments can fluctuate over time, ranging from minimal hepatic encephalopathy (MHE) to overt hepatic encephalopathy (OHE), affecting nearly all aspects of life. While the guidelines for diagnosing OHE are generally well-defined, our work focuses on improving screening for MHE, when treatment is easier and more effective than for OHE. Studies have demonstrated that, if administered in the early stages of MHE, lactulose and rifaximin can significantly improve the quality of life of patients [2, 29, 33]. On the other hand, if not controlled, MHE can develop into OHE, resulting in severe consequences such as coma or death. We seek to improve early detection of MHE by making testing more accessible and enabling patients to take more frequent tests, both in clinical and home settings. Upon detection of MHE, all parties involved are better informed: the patient can make applicable lifestyle changes, such as adjusting their diet [3], making sure to be careful when climbing stairs [31], and not operating heavy machinery [4]; caretakers can pay more attention to their patients; and providers can prescribe relevant drugs, such as lactulose or rifaximin.

2.2 Cerebral Palsy Background

Cerebral palsy (CP) is a neurological disorder that appears in infancy or early childhood as a result of damage or abnormalities in the brain that permanently affects body movement and muscle coordination. The motor skills of individuals with CP are characterized using the Gross Motor Function Classification System (GMFCS), which categorizes people into five different levels [26]. CP is a non-reversible condition, and in general, children will not improve their GMFCS level after the age of 5 years old [7]. Although prior work has studied the benefits of physical activity in helping manage the implications of CP [22, 36], physical therapy alone does not increase physical activity in the long term. Further work on motivation and behavioral interventions is needed for sustained physical activity and lasting impact [6]. People with CP face a range of significant barriers to getting the physical activity they need. In addition to the significant financial cost of physical therapy (PT) sessions, particularly with specialists that tailor their sessions for people with CP [15], access to PT is generally limited due to factors such as transportation and insurance coverage [11]. Even for individuals who are able to receive PT, they struggle to stay motivated to practice their prescribed exercises at home [28, 34]. While PT solutions have been developed for at-home use by providing video libraries and text instructions, they are generally not applicable or adaptable to this patient population.

3 Methodology and Core Ideas

Across both projects, I have adopted a mixed methods approach towards user-centered design. Through the first two stages of the user-centered design process, in understanding the context of use and specifying user requirements, I have found that it is helpful to engage all stakeholders. For Beacon, I have engaged not only the liver disease patients, but also caretakers and loved ones in addition to hepatologists that work with this patient population. Similarly for ExerciseRx-CP, I have engaged with not only the adolescents with CP, but also their families as well as their physical therapists. This formative work has helped inform the design of these systems and understand its role in facilitating interactions with all of these stakeholders. This step has primarily involved qualitative methods.

In the latter two stages of the user-centered design process, designing solutions and evaluating against requirements, I have found that this is an iterative process within just these two stages. Many iterations are first dedicated to determine what is technically and functionally possible before moving to incorporating it into a design that is suitable based on user requirements. As a result, this stage involves first many quantitative results, using metrics such as accuracy and power consumption, before leading to qualitative findings, in which users report their experiences with the system.

3.1 Beacon: Core Idea

Beacon is a system that enables liver disease patients to administer a test for measuring their own critical flicker frequency (CFF). CFF is defined as the frequency at which a flickering light appears steady to the user, and has been shown to be related to one's neurocognitive state [17, 35]. As a cirrhotic patient develops MHE, their CFF measure will begin to decline. Through Beacon, patients are able to monitor their neurocognitive state and make better informed

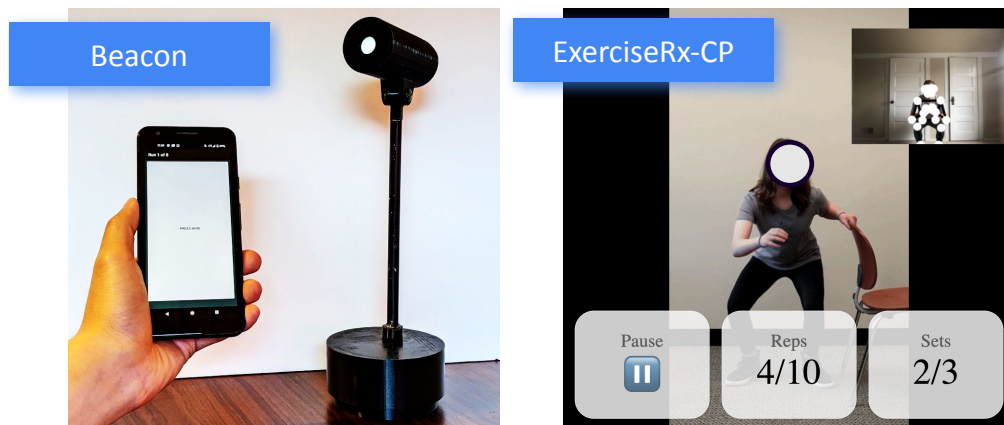


Figure 2: Left: The Beacon system, consisting of a physical hardware device and accompanying smartphone app. Right: A screenshot of the ExerciseRx-CP app, showing an instructional video, form tracking feedback, and automatic repetition counting.

choices, such as whether or not to operate heavy machinery. This capability has value not only for screening in clinical settings, but it also presents the potential for more frequent monitoring in home settings. Our work in Beacon is motivated by this latter potential benefit.

3.2 ExerciseRx-CP: Core Idea

ExerciseRx-CP is a system that encourages adolescents with CP to engage with physical activity through real-time feedback and progress tracking. Because CP manifests in distinct ways between people, we designed this system with an emphasis on enabling physical therapists to prescribe specifically tailored exercises for each patient. Through these two features, interactivity and personalization, ExerciseRx-CP motivates adolescents with their exercise while also providing their physical therapists with deeper insight into their exercise habits and trends.

4 Evaluation

As described in the Methodology section, I take a mixed methods approach towards user-centered design. Correspondingly, my evaluations involve analyses of both qualitative and quantitative data. On the qualitative front, I conduct surveys and interviews to understand both user's needs (formative) and experiences (reflective). I use thematic analysis to distill learnings and takeaways from the interview transcripts. I also collect quantitative data from both users and systems and use standard statistical techniques for determining outcomes. Beyond the specific analysis methods I employ, I have also prioritized collecting data in naturalistic situations. Namely, for both projects, I have deployed systems into participants' homes. In this section, I will primarily report on qualitative findings from these deployments. All studies described were approved by our Institutional Review Board.

4.1 Beacon

4.1.1 Completed Work. Motivated by at-home monitoring, we have prioritized form factor (*i.e.*, to mitigate medical device stigma)

and cost in developing Beacon. We have thus far designed and iterated on the Beacon device according to these goals, leading to the current implementation shown in the left panel of Figure 2. The system consists of a hardware device for rendering the light stimulus, paired with a cross-platform smartphone app over Bluetooth Low Energy that enables users to provide input (*i.e.*, to indicate when they see the desired stimulus). Over the course of iterating on the device, additional considerations in manufacturability and scalability have been introduced: the need to make more physical devices has motivated redesigns of the 3D housing to streamline assembly, and enabling remote monitoring has necessitated building up a robust software infrastructure.

In parallel with device development and iteration, we have also conducted studies in a lab setting with healthy participants, then in a clinical setting with chronic liver disease patients, to validate that the system measures the CFF phenomenon it is designed to [38, 39]. Currently, we are conducting an at-home study to evaluate the efficacy of taking measurements over extended periods of time. Thus far, 23 participants have completed our 6-week study.

Through this study, we have first determined that it is feasible to take measurements on a daily basis, and that the protocol is not too overly burdensome. Furthermore, we have found that the measures are stable over time in the absence of clinical events. Finally, through exit interviews with patients after their 6-week experience, we have continued to confirm that these patients do seek insight into their condition.

4.1.2 Future Work. Based on our experiences from this work, we have identified two areas for next steps. The highest priority line of work is to make the data we are collecting actionable, for both patients and providers. As part of this investigation, we have begun to design and prototype visualizations for patients to provide feedback on. We anticipate that the needs of providers will be different with regards to patient data presentation.

Another area of work is to streamline the measurement process for patients. Currently, in each at-home study session, patients are asked to complete multiple measurements, each with a different

protocol. The shortest protocol has taken around 2 minutes on average, while the longest protocol has taken around 7 minutes on average. The difference in burden by each of these protocols motivates this next step: how can we make taking a measurement a quicker process? How can we use trends over time such that patients do not need to take measurements on a daily basis?

4.2 ExerciseRx-CP

4.2.1 Completed Work. The ExerciseRx-CP prototype, as shown in the right panel of Figure 2, is a cross-platform progressive web application. It uses the BlazePose [5], a convolutional neural network optimized for running in real-time, to track body pose landmarks and detect exercise repetitions. Using this prototype, we have thus far conducted a pilot at-home study with 5 adolescents with CP. In this study, each participant was prescribed 3 to 5 exercises by a physical therapist, and they were asked to complete exercises 3 to 5 days for five weeks. At the end of the five weeks, participants were invited to participate in a remote exit interview to discuss their experience using the app and their engagement in physical activity as supported by the app.

Through this study, we have determined that it is feasible for these adolescents to complete their exercise prescriptions. This feasibility is even more significant because all of the participants reported that they previously did not exercise at all. Other than the convenience of the app, allowing for easier access to exercise, repetition counting and progress tracking were cited by participants as the most useful features.

4.2.2 Future Work. Through our exit interviews with these participants, we have also identified several areas of improvement. The longitudinal aspect of our study also revealed challenges related to sustained engagement. Participants felt that the number of choices in exercise selection was too low. Furthermore, they also felt that the app was not particularly visually appealing, and desired more of a gamified experience. Finally, interviews with physical therapists have helped prioritize the need to enable providing feedback on movement quality. These insights are guiding our next steps in this ongoing project.

5 Contribution

Through these two projects, I have made contributions to their respective medical fields (e.g., hepatology and sports medicine) in the form of new approaches and techniques. These projects have also led to contributions to the UbiComp community through the design and technical innovations developed. Furthermore, I am developing a framework to characterize the *enabling activities* necessary to conduct translational research. In this framework, I refer to these enabling activities as those that may not by themselves constitute research contributions, but are nevertheless necessary both to support research contributions and also for progress toward the greater goal of translational impact. Similar to findings from Mack et al. [21] in considerations around accessibility in research methods, I observe that research publications are often limited to reporting portions of a research journey perceived as most relevant to the body of knowledge in their respective research communities i.e., learnings that are considered *research contributions*. Although a distinction between enabling activities versus research contributions occurs even within

a single discipline, such as the bench-to-bedside models used in medicine [12, 14], I believe that multidisciplinary research with an ultimate goal of translational impact highlights and amplifies this distinction. As a result, researchers must work to articulate overall progress within framings of research contributions expected by a particular community, but readers may then find papers lacking in details or context of a project's overall execution. Through this framework, I share my experiences in navigating the challenges of executing enabling activities, with the goal of benefiting future UbiComp researchers pursuing multidisciplinary research contributions toward translational impact.

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