Scaling Up HCI Research: from Clinical Trials to Deployment in the Wild.

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ABSTRACT

In this paper, we describe two case studies of research projects that attempt to scale up HCI research beyond traditional small evaluation studies. The first of these projects focused on evaluating an interactive web application for promoting problem-solving in self-management of type 2 diabetes mellitus (T2DM) in a randomized clinical trial; the second one included deployment in the wild of a smartphone app that provided individuals with T2DM with personalized predictions for changes in blood glucose levels in response to meals. We highlight lessons learned during these two projects and describe four different design considerations important for large scale studies. These include designing for longevity, diversity, adoption, and abandonment. We then discuss implications for future research that targets large scale deployment studies.

CCS CONCEPTS

• Human-Centered Computing; **• Human Computer Interaction (HCI)**; **• HCI design and evaluation methods**; **• User studies**;

KEYWORDS

User studies, clinical trials, deployment in the wild, health, mHealth, self-management

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1 INTRODUCTION

Technologies for health and wellness have become an area of active research within Human-Computer Interaction (HCI) (e.g., [3],[8],[9],[13]). Given the continuing increase in the prevalence of chronic diseases, innovative interactive technologies can have an important positive impact on individuals' health. However, demonstrating the potential of this impact may require conducting large scale studies with diverse user populations. Traditionally, research within HCI community favors innovation in design rather than large-scale evaluations; a typical evaluation study reported in a CHI paper includes dozens of participants and lasts weeks. These smaller studies, while an important first step in understanding the potential impact of new technologies [18], leave out critical questions that arise when new technologies are deployed in the real world with diverse user populations and over long periods of time.

In this paper, we describe two case studies of research projects that attempted to scale up HCI research beyond traditional small-scale evaluation studies. In the first of these projects, we deployed a novel intervention for problem-solving in self-management of type 2 diabetes (T2DM) with 111 individuals with T2DM recruited from low income communities in the New York Metropolitan area in a Randomized Clinical Trial (RCT). These participants, randomly selected for the intervention arm of the trial (with another 107 in the control arm), were asked to use the application, Mobile Diabetes Detective (MoDD) for up to 1 year. In the second of these projects, we deployed a smartphone app GlucOracle that provided individuals with T2DM with personalized predictions for changes in their blood glucose (BG) levels after eating their meals. GlucOracle was deployed with App Store and Google Play and thus far has been downloaded over 4000 times. Both of these projects began as innovative interactive solutions for diabetes self-management, as is typical for HCI research, and both were deployed on a scale that exceeds that typical for the HCI community.

Overall, we found that this scale of deployment demands specific considerations during the design phase. In particular, our experience suggests the importance of designing for several critical, yet often overlooked factors, including: 1) longevity: anticipating that interactive solutions must continue to be operational and relevant for several years needed to complete the study, 2) diversity: accounting for potentially vast differences in values, experiences, and perspectives of their users, 3) adoption: taking concrete steps to recruit and retain users, and 4) abandonment: designing solutions that gradually and gracefully fade as users meet their objectives and decrease their reliance on technology. In the rest of this paper, we describe lessons learned from our case studies and their implications for future efforts at increasing scale of HCI research projects.

2 CASE STUDIES: MOBILE DIABETES DETECTIVE AND GLUCORACLE

2.1 Mobile Diabetes Detective

Mobile Diabetes Detective (MoDD) is a web application with text messaging grounded in theories of problem solving in diabetes self-management [16] and in the patient empowerment and activation model [4]. Using MoDD, individuals record their daily blood glucose readings either by typing them directly into the MoDD website, or by sending them to MoDD through text messaging. Based on these daily readings and associated temporal context, MoDD identifies daily blood glucose patterns that are systematically higher or lower than ranges recommended by the American Diabetes Association (ADA). MoDD organizes these readings into patterns (upon waking, before or after meal, before bed, etc.), displays them to the individuals in a way that highlights deviation between average readings for each pattern and ranges recommended by ADA, and asks individuals to engage in problem solving process that includes the following steps: 1) select a glycemic control pattern they wish to work on (for example, "High blood glucose after breakfast"); 2) identify a potential behavioral trigger – a behavior that is a known contributor to the selected pattern (for example "Lack of protein for breakfast"); 3) select an alternative healthier behavior and set an action-oriented goal related to this behavior (for example, "Include a table spoon of peanut butter or a boiled egg with breakfast"); and 4) implement the new behavior while monitoring for possible changes in the selected blood glucose readings (here, changes in blood glucose after breakfast) and progress towards achievement of blood glucose target range. MoDD was designed using the participatory design approach with educators and individuals with diabetes recruited from Federally Qualified Health Centers (FQHCs) in New York City.

We recently completed a randomized controlled trial of MoDD with 218 participants, with 111 individuals in the intervention arm. The trial lasted over 5 years; each participant in the intervention arm was asked to use MoDD for up to 1 year. More details on the design and the study are available elsewhere [7],[15],[20].

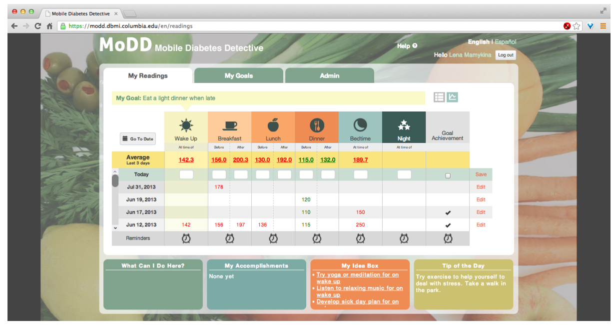

Figure 1: MoDD: blood Glucose viewing page

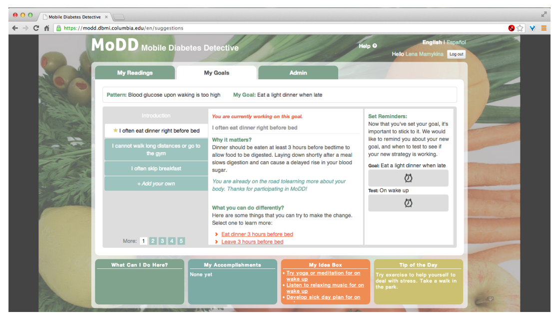

Figure 2: MoDD: behavior assessment and goal-setting page

2.2 Glucoracle

GlucOracle is a smartphone app designed for both iOS and Android for providing in-the-moment meal-time decision support using personalized forecasts for changes in BG levels in response to meals. To achieve that, GlucOracle asks users to log their meals by photographing each meal and providing a short textual description, and BG levels before and 2 hours after eating meals. GlucOracle uses these data to train a personalized computational model of BG regulation [2]. Once the model is trained, for all newly captured meals, GlucOracle displays a forecasted range of future BG levels between the lowest and highest points of a continuous stream of predicted BG levels within 3 hours after the meal (2 3). The users can then decide whether to continue with the planned meal, or whether to change it, for example by adding or removing foods, record a new meal, and review corresponding change in the forecasted BG. Because the computational model uses macronutrient amounts as inputs, and to ensure timely delivery of forecasts, GlucOracle uses individuals' own estimate of nutrition in meals to generate forecasts. However, it uses nutritional assessments by Registered Dietitians (RDs) to train the computational model. We released GlucOracle on App Store and Google Play in April 2017; thus far, it has been downloaded over 4000 times. More details on GlucOracle design and evaluation are available in our prior publications [10],[11].

3 LESSONS LEARNED AND IMPLICATIONS

In this section we discuss lessons learned from our experience deploying both MoDD and GlucOracle with over 100 and over 4000 users respectively in studies that lasted several years each.

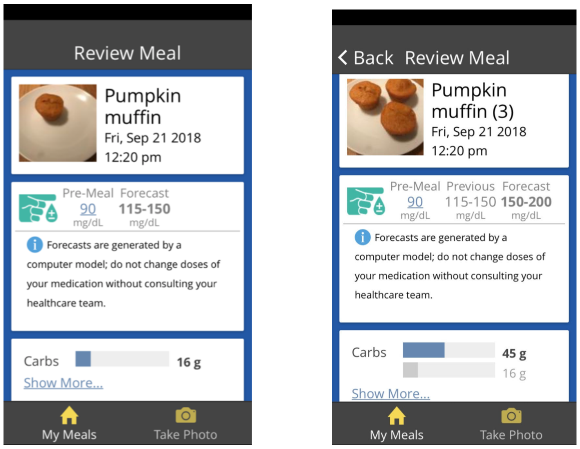

Figure 3: Personalized BG forecasts: on the left, the user photographs one pumpkin muffin fries and views the forecast; on the right, the user increases the amount of pumpkin muffins and views comparison between the two forecasts.

3.1 Design for longevity: active ingredients in HCI research

Health behavior change is a long process [18]. Consequently, studies that focus on behavior change often take months and sometimes years: a typical clinical trial can last for 3 to 4 years. This presents the requirement that the intervention and the technology that delivers it continue to be operational and relevant within this timeframe. Furthermore, to ensure validity of the trial findings, the intervention needs to remain unchanged for the duration of the study. Given the rapidly changing landscape of computing technologies, particularly mobile technologies, this requirement may present a considerable challenge. Technology platforms and software packages used to develop applications age and may become obsolete, or transition to new versions, sometimes incompatible with the older ones, thus requiring essentially redeveloping the entire application or jeopardizing the study. Furthermore, user preferences for platforms and applications may shift as new technologies become available and once preferred platforms become increasingly irrelevant. All this makes for a dynamic technological landscape that can make even routine maintenance and upkeep of interventions both labor intensive and costly. Perhaps not surprisingly, interventions that make their way into clinical trials often use more robust, well-established technologies, such as text messaging [14] and commercially available trackers [17]. This presents stark contrast with smaller scale HCI studies in which innovative prototypes are rarely expected to continue to function after the study is completed.

In the context of our case-studies, we clearly observed this with both MoDD and GlucOracle. MoDD was originally designed in 2012 as a web-based application to meet the technological needs and constraints medically underserved individuals with T2DM experienced at that time. Furthermore, because it was intended for mixed-literacy populations, we designed it for a large screen, rather than as a mobile app, which may be harder to use for individuals with poor vision and lower dexterity, common in T2DM. However, since the time of its original design and implementation, smartphone adoption has increased exponentially, and smartphones have become the predominant platform for consumer applications, including those for health and wellness. This suggested that MoDD may require considerable redesign and re-development to make it compatible with contemporary platforms and preferred devices. In the case of GlucOracle, it was developed as a hybrid smartphone app using React framework, an open-source JavaScript library for developing user interfaces that enables easy access to native smartphone capabilities, such as accessing the phone's camera to take pictures of meals. This continuously evolving framework has great advantages for research projects as it helps to simplify the development process; however, its nimble and evolving nature requires continuing updates to the app to keep its features operational.

These observations have several implications for other researchers who plan to conduct large scale longitudinal deployment studies of innovative technological interventions. For example, given the inevitable decay of technical platforms, it suggests the need to be explicit about design principles that can be carried from one technical platform to another, rather than on their implementation. This is consistent with literature in behavior change that stresses the importance of "active ingredients" such as rewards or goal setting that can be implemented in many different forms [22]. For example, MoDD specifically focused on structuring design around the step-wise problem-solving process, and GlucOracle focused on delivering meal-time personalized forecasts for changes in BG as their active intervention ingredients. However, given that HCI research often specifically focuses on the form in which behavior change interventions are delivered, open questions remain as to how to formulate HCI contributions in the way that is less dependent on technical platforms.

3.2 Design for diversity: "kitchen sink" or testing mechanisms

When conducting a study with hundreds of participants in a clinical trial or deploying an app in the wild with potentially thousands of users, one should expect to encounter individuals with vastly different values, circumstances, social settings, behavioral patterns, preferences, and styles. Designing behavioral interventions that accommodate such diversity can be challenging: what works for one person may not work for another [5]. This may be particularly the case with economically diverse communities and for populations with diverse levels of computing literacy [26]. Yet constraining recruitment to homogeneous groups of individuals with shared characteristics is problematic in clinical trials and impossible in the wild [32]. To accommodate such diversity, behavioral interventions often take the "kitchen sink" approach and include a variety of different features and functions with the hope that everyone will find something that works for them. This approach, however, makes it near impossible to determine which part of the intervention had the desired impact and is worth replicating in the future.

In our own work, we had to grapple with this diversity in both MoDD and GlucOracle. Qualitative interviews with individuals who participated in the MoDD trial showed that no single pattern of use dominated. Different individuals found vastly different ways to use it to meet their needs. Some particularly valued the visual representation of trends in their blood glucose levels, which helped them to get daily bearings and set the stage for choices regarding daily activities, such as meals and exercise. Others never looked at visualizations and mostly used text messages with reminders for self-management activities to keep them "on track". In GlucOracle, some users valued the simplicity of meal logging features that were consistent with their busy lifestyles and wished for further simplifications, while others lamented lack of richer features for capturing slower meals with multiple courses and wished for a way to take multiple pictures during a single meal.

There are multiple directions for accommodating this diversity of perspectives inevitable in large studies without compromising insightfulness of study findings. For example, researchers could use more nuanced study designs to examine the impact of different features or version of interventions. Specifically, factorial study designs are particularly well-suited for evaluating complex interventions [6]. Similarly, Sequential Multiple Assignment Randomized Trials (SMART) can help to evaluate different doses or forms of the intervention and even to tailor interventions to different user characteristics [19]. In addition, future research could examine systematic differences in psycho-social characteristics of individuals participating in studies, thus constructing psycho-social phenotypes, and use these phenotypes to tailor behavior interventions in a way clinical phenotypes are used to tailor medical treatment [1].

3.3 Design for adoption: engaging communities and stakeholders

It may be tempting for the developers of innovative applications to focus on the design and the features of the intervention and to assume that if they get the design right, their users will enthusiastically adopt the application. In reality, however, adoption of even the most useful technologies is often complicated and is rarely straightforward and involves much effort beyond the design of the technology itself. Much is written about implementation of large software products and the importance of creating social and organizational structures, training, and advocacy to promote adoption (e.g., [25],[30]). Similar issues arise with deployment of interventions for health and wellness.

We have experienced these challenges in both projects described here. GlucOracle's release in the app store was timed to coincide with the publication of the paper describing its computational engine [2]. Both the paper and the app were covered in multiple press releases issued by our university. Perhaps as a result, GlucOracle received almost 1000 downloads in the first week since its release. However, subsequently, its download rate decreased dramatically and required a continuous advertisement campaign to keep it steady. MoDD encountered a different challenge: the participants for this trial were recruited from FQHCs and had generally low access to computing technologies and low computing literacy. These individuals often required extensive training in the use of a computer and a mouse, which presented additional demands on study coordinators.

This observation suggests that conducting large scale research studies requires careful planning and consideration not only for the intervention itself, but also for its dissemination strategy. This challenge is greatly reduced for research that leverages existing technologies that already enjoy popularity and loyalty from their users. Not surprisingly, many interventions for health and wellness leverage popular social media platforms, such as Facebook [23]. Dissemination of new technologies may require creating excitement and recruiting advocates from relevant social groups and communities. For example, online health communities that focus of particular diseases and condition can provide great support for technologies they view as beneficial to their members. This, however, requires building strong ongoing partnerships with such communities and engaging them in the design process. Similarly, community-based participatory research (CBPR, [29],[24]) offers a set of approaches for engaging community stakeholders in the design of innovative interventions that address real needs of these communities and create foundation for engagement and adoption.

3.4 Design for abandonment: redefining engagement

Success of behavior change interventions often relies on their ability to inspire engagement from users. Indeed, if users do not engage with interventions, they are unlikely to experience the benefits. Lack of engagement is a common challenge reported in studies of interventions for behavior change in health [31],[27]. This may be particularly the case for interventions that rely on self-monitoring data, foundational for discovery problem-solving, and decision and action support [21]. However, engagement is a complex topic that may require careful consideration. Specifically, in the context of technologies for health and wellness, questions remain as to the appropriate degree of engagement and expected changes in engagement overtime. Should designers of these interventions focus on promoting higher and more prolonged engagement, or should they focus on developing new habits and behaviors, which would naturally lead to abandonment of solutions after users reach their goals? And if abandonment is the goal, how should it factor in the evaluation metrics?

We faced these questions in both MoDD and GlucOracle studies Specifically, with GlucOracle, qualitative interviews with its users showed that it was common for users to start with a burst of intensive engagement in the first days or sometimes weeks of use. During this time, individuals recorded all or most of their meals and often found forecasts insightful and informative. However, with continuous use, forecasts became predictable and, eventually, less useful. Few interviewed users could imagine continuing using GlucOracle with the same intensity overtime; instead, they saw it as a tool that could be used periodically and when needed, for example when introducing new dishes or eating out. This perspective, however, challenges the typical view of sporadic and declining use as a negative reflection on the usefulness of the applications.

To address these challenges, HCI community may need a more nuanced treatment of engagement and ways to conceptualize and study different trajectories of engagement with interventions. For example, when decline in use is accompanied by increase in competence, sustained changes in behaviors, and improvements in health indicators, such decrease may be natural and even desirable. This, however, requires new approaches to formulating and testing hypotheses that include engagement together with other outcomes. Recent publications in HCI have begun to address these questions, but more work is needed to develop robust approaches for understanding engagement [12],[28].

4 CONCLUSIONS

In this paper we discussed our experiences deploying innovative interactive solutions for promoting health and wellness that go beyond typical HCI studies, and lessons we learned from deploying these solutions in clinical trials and in the wild. While this paper outlines multiple challenges that inevitably accompany large-scale longitudinal studies, such studies are critically important in examining ways individuals use innovative technologies overtime and in the context of their real lives. We encourage researchers in the HCI community to continue exploring opportunities to test their innovative design ideas with diverse user populations and in the context of unconstrained used in the wild.

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