Beyond ResearchKit: User Engagement with Phendo, a Novel App for Self-Tracking and Research

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Introduction
Smartphone apps for self-tracking of chronic disease hold promise both for patients trying to manage their condition and researchers aiming to characterize diseases and behavior patterns at scale. In 2015, Apple introduced ResearchKit, a platform to facilitate app-enabled research through streamlined survey functionality and wide recruitment of study participants through electronic consent. Studies that use ResearchKit have been successful over traditional studies in enrolling a large number of participants, but opportunities remain to overcome the limitations of passive recruitment, in which a ResearchKit app is released but not actively marketed, and for app engagement via active contribution of data consistently over the study period1-3. For example, the mPower study on Parkinson’s disease had 48,104 app downloads but only 898 study participants, of which 150 were patients (0.3%), used the app for at least 5 days within the 6-month study2. Fostering engagement (broadly defined as the quality of experience in using a technology that makes it appealing to continuous use) is critical for realizing the full potential of research and general tracking apps. In this study, we explore the impact of active recruitment strategies as well as the use of specific app functionalities on user engagement. The context for this work is Phendo, an app-based study to capture and characterize endometriosis, a prevalent disease (estimated to affect 10% of women) and systemic chronic condition with a high burden on quality of life, from the standpoint of patients.

Methods
Phendo aims to capture directly from patients a wide range of variables about endometriosis through time. It was developed as a ResearchKit-based tracking app. The design of the app, in particular, identifying the range of variables to track, along with determining their temporal granularity for patients to track (e.g., momentary assessment vs. day-level) was carried out through a user-centered, participatory process with endometriosis patients via 5 focus groups with 27 adult women with the disease5. We incorporated a number of features beyond the vanilla ResearchKit capabilities: customized user interface of surveys to allow users to enter multiple responses to a survey question; smart notifications triggered only when a user has not tracked any data as well as “positive” notifications to encourage returning users, calendar-based review and insights screen that provide a personalized timeline of tracked data; and a Citizen screen showing how much their individual data contributed to the overall study. For this study, we explore three novel functionalities and their traction with study participants: (i) customizable surveys to track medications, hormones, supplements, foods, and exercises; (ii) ability to track specific variables on a moment-by-moment basis (repeatedly if needed) throughout the day and other variables at the day-level; and (iii) ability to track all variables retroactively. The app is available on the iTunes Store for use on iPhone, and as such passive recruitment is available. For active recruitment, we created a website (citizenendo.org) and a social media presence, maintained a blog, and engaged with patient advocacy groups and celebrities who advocate for the disease to promote Phendo. We focus on the first 100 days of the app since its launch (11/13/2016-2/20/2017).

Results
1,184 women with self-reported endometriosis diagnosis from 39 countries consented to the Phendo study, during which time no participants opted out. Participant demographics follow the adult US female population who use apps6: 56.7% have at least a college degree, live in suburban (46.4%) or urban (38.1%) areas, and are White non-Hispanic (82.5%). Their median age is 29 years old, and their age at endometriosis diagnosis was consistent with epidemiological characterization of the disease7. Fig. 1 shows the impact of active recruitment efforts on enrollment. In the first 100 days since the launch of the app, participants each tracked 1 to 80 days, and 50% of them tracked 6 days at least. Participants made use of the customizable surveys: 84.5% used at least 1 customized variable, and on average created 6 variables across the food, exercise, medications, supplements, and hormones categories. Overall, participants tracked both day-level (e.g., “Do you have your period today?” and “What did you do to self-manage today?”) and moment-level variables (e.g., “Are you experiencing any GI/urinary issues now?”) (Fig. 2). We note the variability in amount of tracking both at the moment- and day-level, indicating that participants made sure to track only what is relevant to them or what they deem useful to let researchers know (e.g., menstrual periods were tracked more than sexual activity). Fig. 3 shows the times at which participants engaged with the app.
to track (i.e., local time at which participant used their phone). They used the app throughout the day for momentary tracking, whereas they answered day-level questions at the end of the day (7pm is default notification time). 53% of actively tracking participants made use of retroactive tracking. Within the same day, they tracked retroactively primarily for moments (graph not shown) (e.g., tracked a moment that occurred in the morning at 4pm). But they also tracked retroactively up to several days in the past (Fig. 4), mostly for day-level questions.

Discussion
Beyond ResearchKit’s many benefits, ways to retain and engage patients are needed. We found that active recruiting was critical to not only gather interest but also to target the right population of study participants (in our case, women with endometriosis). Aligning tracking functionalities with the way in which participants experience the disease showed promise in engaging participants: they made heavy use of customized tracking and both moment and day-level surveys, with specific patterns of tracking throughout the day. Furthermore, ability to track retroactively was shown convenient and useful to participants. When used retroactively, moment-level tracking was done within the same day, while day-level tracking went back 1-2 days in time, suggesting users are reasonable in their recall. These patterns are encouraging: these functionalities enable more data points to be tracked, and there is likely validity to them given the short retroactive tracking times. Although we focus on a specific condition, engagement functionalities are applicable to other chronic disease populations that experience a wide range of symptoms dynamically over time.

References
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