Introduction

• Self-tracking of disease is increasingly popular among patients and general public for monitoring wellness, managing chronic conditions, and self-discovery of symptom patterns.1
• Smartphones are well suited to capture diverse and rich data about patients as they self-track their disease.2
• Opportunities exist to better understand how self-tracking data support characterization of disease dimensions of endometriosis over time.
• We aim to characterize the patient experience of disease by collecting patient-reported data through an smartphone app.

Methods

• Patients (all women with official or doctor-suspected endometriosis) informed design of Phendo through five focus groups (27 women), two surveys (1,246 respondents), and one-on-one interviews (20 alpha testers)3.
• Phendo, built on Apple’s ResearchKit, is designed as research study with electronic consent and secured data storing.
• Phendo allows users to track customizable set of signs and symptoms (pain locations, GI and urinary, moods), medications, menstruation, exercise and diet triggers, and activities of daily life.
• World Endometriosis Research Foundation EPHect Questionnaire (EPHect) is provided through electronic portal within Phendo.4
• With initial data collected, we 1) examined dynamic disease variation in users’ self-tracking data and 2) compared subset of Phendo data to the same users’ EPHect results across several disease dimensions.

Results

• Phendo, launched in Late November 2016, is currently used by over 1,700 patients from 49 different countries.
• Average age of participants is 29 – in line with age of endometriosis diagnosis.5
• EPHect completed by a subset of 196 Phendo users.
• Phendo allows for tracking disease-related variables moment-by-moment as they occur and at the day level.
• Visually appealing survey format in Phendo engages users in tracking their disease.

Results Cont.

• Greater diversity of medication classes and greater use of opioids reported in Phendo as compared to EPHect.

Figure 2. Top 9 medications (excluding hormones) by ingredient in Phendo vs. EPHect

• Greater range and granularity of activities present in Phendo as compared to EPHect.
• Problems with activities related to employment (working, sitting down) reported most commonly in Phendo (on average at least 1 out of every 2 days).

Figure 3. Difficult daily activities in EPHect (freq, over past 3 months) vs. Phendo (mean freq. per day)

Discussion and Conclusions

• Data collected through Phendo congruent with existing disease knowledge, supporting validity of app-based self-report.
• Range of disease related variables captured through Phendo vs. EPHect demonstrates importance of self-report in adding to existing knowledge about endometriosis.
• Given dynamic nature of disease, Phendo promising tool to capture temporal variation in signs and symptoms of the disease.
• Phendo provides a complement to more standardized questionnaires like EPHect, helping to build a rich set of data, which is necessary to fulfill the promise of precision medicine for endometriosis.
• For more information and updates, sign up for our email listerv at www.citizenendo.org

Figure 1. Phendo allows for tracking symptoms moment-by-moment and once a day.

Figure 4. Case example (N=1) of variation in disease-related variables through time.