Precision VISSTA: Bring-Your-Own-Device (BYOD) mHealth Data for Precision Health

Arlene E. Chung, MD MHA MMCi[1], Kimberly Glass, PhD[2,3], Jacob Leisey-Bartsch[4], Lucas Mentch, PhD[4], Nils Gehlenborg, PhD[3], David Gotz, PhD[1]
[1]University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; [2]Brigham & Women's Hospital, Boston, MA, USA; [3]Harvard Medical School, Boston, MA, USA; [4]University of Pittsburgh, Pittsburgh, PA, USA

Introduction

A Bring-Your-Own-Device (BYOD) model for contributing mobile health (mHealth) data enables real-world data collection as patients go about their daily activities. To date, most mHealth research studies provision a specific wearable device (i.e., Fitbit) and have a constrained study period during which data is collected. A BYOD mHealth model allows for capturing data from patients' routine lives and has efficiencies at scale, allowing researchers to better understand patient trajectories in a real-world deployment of devices. There are growing examples of BYOD data contribution for the purposes of research including the PCORnet Inflammatory Bowel Diseases (IBD) Partners (formerly Crohn's and Colitis Foundation of America) patient-powered research network,[1] and NIH's All of Us Research Program,[2] where participants can currently contribute their Fitbit data.

IBD Partners allows for a wide range of wearable devices and apps to be connected to our research platform. This facilitates mHealth data contribution for those who participate in our longitudinal Internet cohort study. These mHealth contributors can connect different devices over time and can view their data trends in the IBD Partners patient portal. Participants also contribute self-reported survey data on health outcomes, such as disease activity, as well as on patient-reported outcomes such as depression and anxiety.

While BYOD has many benefits, there are also challenges due to the diversity of both devices/apps and usage patterns that come with real-world data generation. As this BYOD data contribution model is still an emerging one, there is little known about how many patients will choose to contribute their mHealth data, and how those patients may differ from those who do not. We examine which brands are represented across mHealth contributors within the cohort, the patterns for device wear-time (usage) among these participants, and blocks of missingness where devices/apps were not used. In this oral abstract, we present an overview of the characteristics of a BYOD mHealth study, Precision VISSTA, which is an NIH-funded study that seeks to develop preprocessing, machine learning, and data visualization methods for mHealth data to generate precision health recommendations for patients with IBDs as the initial use case.

Methods

Descriptive statistics were used to summarize sample characteristics and to examine patterns across mHealth data for physical activity and sleep. Two-sample t-tests were used to evaluate differences between mHealth data contributors versus those who were not for disease activity (Simple Colitis Activity Index (SCAI) for ulcerative colitis; Simplified Crohn's Diseases Activity Index (SCDAI) for Crohn's diseases) and patient-reported outcomes for depression, anxiety, sleep disturbance, social relationships, and pain interference.

Results

Of the 10,090 patients enrolled thus far, 437 patients have contributed mHealth data. ~71% of patients who contributed mHealth data were female, 91% were White, the majority were between the ages of 18-60 years old (18.5% 18-25 years, 44.6% 26-40 years, 30.9% 40-60 years), and 78.3% had a college or graduate school education. Of those who connected device(s)/apps to contribute mHealth data, 62% had Crohn's disease and 36% had ulcerative colitis. For distribution of device/app brands across the cohort, 67% were Fitbit, 10.3% Garmin, 5.6% Strava, 5.2% Under Armour, 4.1% Jawbone, 2.1% Moves App, 1.8% RunKeeper, 1.3% Withings, 0.8% Microsoft, 0.6% Map My Fitness, 0.6% Misfit, 0.4% Fatsecret, and 0.2% Nike+.

Figure 1a visualizes various patterns of step count data in two patients as an example; blocks of missing data are shown in white. Patterns differ across the day of the week for some participants, while others have more heterogeneity in their step count patterns. The majority of participants have contributed between 6 months to 3 years of mHealth data (Figure 1b) and the size of blocks of missing data ranged from one day to ≥4 weeks (Figure 1c).

On average, participants had 5,384 total steps per day and 6.8 hours of total sleep per night. Approximately 29% of who contributed mHealth data had at least 150 minutes of moderate-to-vigorous physical activity per week. We observed differences in outcomes for mean IBD disease activity scores for those who contributed mHealth data versus those who did not (SCAI=2.9 vs. 3.1, p=0.003; SCDAI=124.7 vs. 140.7, p<0.0001). For mean patient-reported outcome scores in the domains of pain interference, depression, anxiety, fatigue, social relationships, those who contributed mHealth data had better scores than those who did not [49.75 vs. 51.40, p<0.0001 for pain interference; 49.48 vs. 50.23, p<0.0001 for depression; 51.12 vs. 51.99, p<0.0001 for anxiety; 53.84 vs. 54.30, p=0.01 for fatigue; 50.85 vs. 49.24, p<0.0001 for social relationships (higher score is better for social relationships; lower score is better for pain interference, depression, anxiety, and fatigue)].

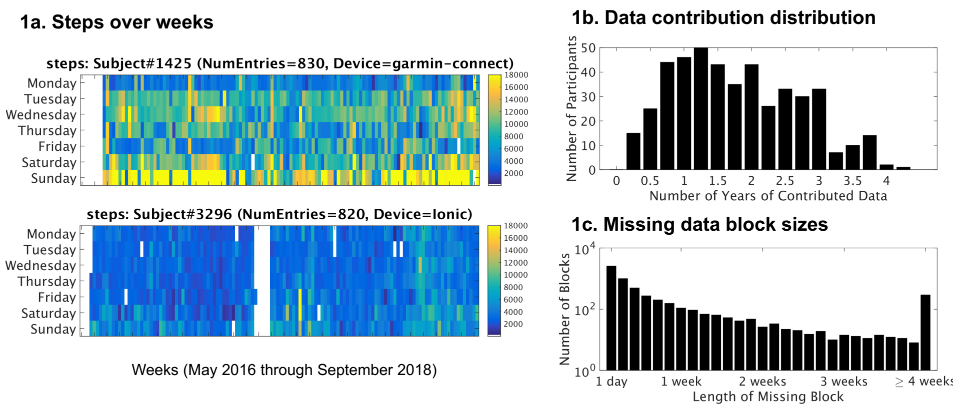

Figure 1. Example of step patterns and distribution of data contributions and missing data block size.

When mHealth data is examined in aggregate for an individual and for the cohort, there are both common patterns (such as weekday vs. weekend patterns in sleep; see Figure 1a) and systematic differences between brands (Figure 2a and 2b). For some sleep variables, such as deep sleep, changes in the algorithms that process sleep data can also be seen (i.e., August 2017 in Figure 2b).

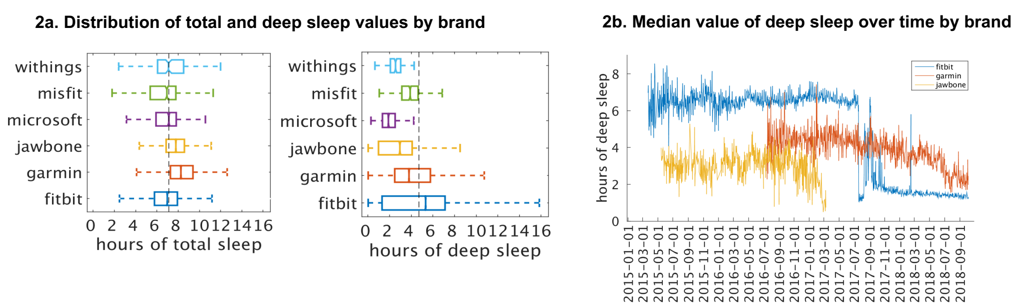

Figure 2. Patterns of sleep across brands.

Conclusions

Thus far, ~4% of the IBD Partners Internet cohort have contributed mHealth data using our BYOD model across various brands. Participants were mostly female, educated, and less than 60 years old. The majority have either Fitbit or Garmin devices. Those who track and contribute mHealth data have significantly better disease activity scores and patient-reported outcomes. However, the difference in scores may not all be clinically significant. When examined in aggregate across the population, there are systematic differences across brands of devices/apps for physical activity and sleep. Our analyses suggest that simple visualization techniques can expose important features of mHealth data, such as changes in software algorithms that process the data. Ongoing work seeks to address challenges in preprocessing to deal with missingness and sparsity and the batch effects seen across brands of devices/apps.

References

1. Chung AE, Sandler RS, Long MD, Ahrens S, Burris JL, Martin CF, et al. Harnessing person-generated health data to accelerate patient-centered outcomes research: the Crohn's and Colitis Foundation of America PCORnet Patient Powered Research Network (CCFA Partners). J Am Med Inform Assoc. 2016 May;23(3):485-90.
2. *All of* Us Research Program expands data collection efforts with Fitbit. 2019 [cited 11 March 2019]. Available from: https://allofus.nih.gov/news-events-and-media/announcements/all-us-research-program-expands-data-collection-efforts-fitbit