Mitigation of Demographic Imbalances Resulting from Bring-Your-Own-Device Study Design

Mitigation of Demographic Imbalances in Bring-Your-Own-Device Study

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The prevalence of digital health technologies such as smartphones and smartwatches in recent times demonstrates the potential to augment the present health care system via revolutionizing disease prevention, detection, and treatment. Widespread usage of these digital technologies brought forward an opportunity to collect a large volume of data in research studies through a Bring-Your-Own-Device (BYOD) approach, in which participants who already own a specific technology may voluntarily sign up for the study and provide their digital health data. Although BYOD study design facilitates the collection of a large volume of data from a wide range of study populations with minimum cost and resources for the researchers, it may not support collecting data from a representative sample of the target population where the developed technologies are intended to be deployed. The results generated by the data from a non-representative sample may result in biased study results and consequently, biased technology development (artificial intelligence or machine learning models). In this position paper, we highlight demographic imbalances discovered in recent BYOD studies, including our own, and we propose a Demographic Improvement Guideline to address these imbalances to increase the effectiveness, usability, and value of artificial intelligence in personal informatics systems.

CCS CONCEPTS • Social and professional topics • User characteristics • Race and ethnicity

Additional Keywords and Phrases: bring-your-own-device, wearable device, mHealth

1 INTRODUCTION

Digital health technologies, including smartphones and wearable devices, can provide a unique opportunity for the researchers to collect a high volume of physiological and activity data in naturalistic settings that is more representative of

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a person's health state during their daily life than data collected in a clinical setting [7]. The feasibility of acquiring such data outside of the clinic has led researchers to adopt new study designs for their study via incorporating digital health data collection tools and developing digital biomarkers. Digital biomarkers are digitally collected data from smartphones or wearables (e.g., mean resting heart rate) that are transformed into indicators of health outcomes (e.g. fitness, risk of infection) and can be used to provide biomedical insights or improve health decision-making [6]. Out of the new study designs with digital health technologies, the "Bring-Your-Own Device" (BYOD) study design has become increasingly popular as it allows researchers to collect a large volume of data at a low cost and with fewer resources from participants who already own personal smart devices such as smartphones and wearables. The COVID-19 pandemic has further motivated researchers to collect digital health data using the BYOD study design to track illness, either for COVID-19 detection or to support remote monitoring [2,11,15]. Researchers use artificial intelligence (AI), specifically machine learning (ML) algorithms, to develop health status (e.g., infection status, disease severity) detection models via learning from digital health data.

1.1 Representativeness on ML models

ML algorithms rely on data to learn and train models, and consequently, these algorithms are susceptible to biases that result in poor predictions during the actual deployment if the study population used in the training phase are not representative of the population where the model is intended to be deployed [13]. Therefore, one key aspect of a generalized ML algorithm development is the data collection process, via ensuring that a representative random sample of the target population is used to train and develop these algorithms to reduce biases [14]. BYOD studies are particularly susceptible to bias in the data collection process because the study cohort is often limited to people who already own wearables and their socioeconomic and other demographic factors (race, ethnicities, gender, etc.) might be different than the population where the developed tools are ultimately intended to be used in practice. As a result, BYOD studies, might exclude the underrepresented population and result in a nonrepresentative study population that lacks key socioeconomic and physiologic circumstances that can covary with race, ethnicity, or both. For example, disease prevalence and pathophysiology often vary by race and ethnicity (e.g., COVID-19 infection and mortality rates [8,16], cardiovascular disease [9,21], manifestations of metabolic disease [10,22,23], and sleep irregularities [4,5]), which can result in inferior performance in the deployment phase of the newly developed technologies. To address such bias, representative digital health data are needed to develop generalizable ML models that perform equally under deployment as they are in the initial testing phase.

1.2 Demographic Imbalances in BYOD Studies

Like other fields that have discovered that bias in data used to train models has led to biased models, we fear that digital health will face similar challenges if the bias inherent in BYOD studies is left unaddressed [13,18]. In our recent viewpoint paper [24], we sought to raise awareness of demographic imbalances in several BYOD studies and propose a guideline based on our own BYOD case study to directly improve the demographic balance of BYOD digital health studies. To mitigate this demographic imbalance and to ensure the inclusion of participants from underserved communities, we developed the Demographic Improvement Guideline [24] and correspondingly altered our recruitment process for our own BYOD study, CovIdentify [17,25], when we discovered demographic imbalance in the study. Many BYOD studies acknowledge demographic imbalance as a limitation, and we believe a concerted effort is needed to enact change to reduce bias in digital health data used in research.

2 DEMOGRAPHIC IMPROVEMENT GUIDELINE

This guideline [24] is relevant to BYOD studies in which sampling bias resulting in demographic imbalance could challenge the validity and generalizability of a BYOD study's conclusions. The method can be implemented iteratively in the study design and execution process and includes the following steps:

"(1) Identify the population(s) at risk of being omitted from the study for whom the technology may ultimately be used and determine if BYOD study design is appropriate for the research question.

(2) If the BYOD study design is insufficient for addressing issues associated with demographic imbalance, modify the study design using internal and external resources to improve dissemination of information and improve engagement with the target population(s).

(3) Launch study and monitor study demographics in real time to adjust downstream efforts accordingly."

Researchers should reassess their study population demographics iteratively to ensure that target distributions are achieved and re-strategize accordingly.

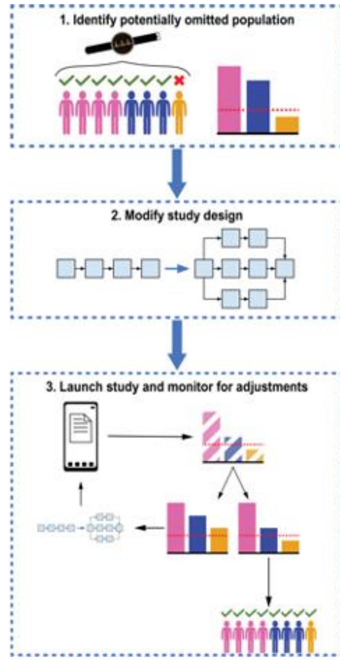

Figure 1: Visualization of Demographic Improvement Guideline [24].

3 IMPLEMENTATION OF DEMOGRAPHIC IMPROVEMENT GUIDELINE

With the COVID-19 pandemic unfolded, we launched our own BYOD study, CovIdentify (Institutional Review Board No. 2020-0412), in April 2020. The study aimed to collect wearable data and self-reported symptoms via the CovIdentify platform [25] for developing ML algorithms to detect and track COVID-19 and influenza-like illnesses from wearable device data and symptoms data, with a long-term vision of developing an intelligent diagnostic testing allocation strategy using digital biomarkers extracted from personally owned commercial wearable devices under resource-limited conditions (limited testing, rural areas, etc.). Following informed consent, participants were able to donate their wearable device data (e.g., Fitbit, Apple Watch) and reported daily symptoms for 12 months via a downloadable app, email, or text message. Following the rapid launch of the study, exploratory data analysis revealed significant differences between the demographics of CovIdentify and the demographics of COVID-19 positive cases and deaths in the U.S. based on the 2020 U.S. Census [26]. The communities hit hardest by the COVID-19 pandemic, including Black/African American and Hispanic/Latinx communities, had the lowest representation [24]. Consequently, we designed and implemented our demographic improvement guideline, which resulted in a 250% increase in the representation of Black/African American participants and a 49% increase in the Latinx/Hispanic population within 4 months of the implementation [24].

4 DISCUSSION

In this position paper, we discuss the need for representativeness of the target population in digital health studies using a BYOD study design while developing ML models from the collected wearable data to ensure the equitable performance of AI or ML models. We explore demographic imbalances in BYOD studies and propose a Demographic Improvement Guideline to address these imbalances, with a real-world implementation example with our own CovIdentify study. We believe that integrated efforts and funding in this space can improve equitable digital health study design and data collection.

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