

Title: Mobile Patient-Reported Outcomes for Value and Effectiveness (mPROVE)

Principal Investigator: Jane Jih, MD, MPH, MAS

Prior Principal Investigator: Ida Sim, MD, PhD

Team Members:

- Riley Bove MD (UCSF)
- Simona Carini MA (UCSF)
- Patrick Carter MPAS (The Commons Project)
- Tiffany Chinn (UCSF)
- Mitchell Feldman MD MPhil (UCSF)
- Anthony Louie MBA (UCSF)
- Eric Meeks (UCSF)
- Nicolette Miller (UCSF)
- Tung Nguyen MD (UCSF)
- JP Pollak PhD (The Commons Project)
- Narender Sara MS, MBA (UCSF)
- Jason Satterfield PhD (UCSF)
- Billy Zeng MD (UCSF)

Inclusive Dates of Project: 09/01/2019 – 08/31/2024

Federal Project Officer: Kevin Chaney, MGS

Prior Federal Project Officer: Chun-Ju (Janey) Hsiao, PhD

Acknowledgment of Agency Support: This project was supported by Agency for Healthcare Research and Quality.

Grand Award Number: U18HS026883

## **STRUCTURED ABSTRACT**

**Purpose:** The purpose of this project was to develop and pilot Mobile Patient-Reported Outcomes for Value and Effectiveness (mPROVE) system in English and Chinese for patient self-care and shared decision-making in an adult primary care practice.

**Scope:** We sought to develop patient-facing mPROVE app in English and Chinese to collect and track PROs for adult patients with depression, type 2 diabetes or hypertension. The mPROVE app uses the EPIC electronic health record (EHR) MyChart patient portal credentials to authenticate users. Using SMART-on-FHIR technology, PRO results are visualized via the BRIDGE data dashboard within the Epic EHR which was developed by an academic-based software engineering team. In between clinic visits, if a patient's PRO exceeds a clinical threshold, their primary care clinician receives an EHR staff message alert. Furthermore, clinicians can view a patient's entered mPROVE data via the BRIDGE electronic data dashboard accessible with the EPIC EHR.

**Methods:** With an interdisciplinary team including The Commons Project, a non-profit tech solutions organization, we used participatory design sessions, field testing, workflow prototyping, and pilot usability testing with patients and primary care clinicians to develop the mPROVE system.

**Results:** We developed a feasible and acceptable mPROVE Android app in English and Chinese. We enrolled 5 patient-clinician dyads in usability testing that demonstrated real-time integration of PROs collected for a patient-facing smartphone app in a primary care workflow.

**Key Words:** chronic disease, patient-reported outcomes, SMART-on-FHIR, data visualization

## **PURPOSE**

Due to delays and other constraints because of the COVID-19 pandemic, the purpose of the project was modified to:

**Aim 1. Develop the mPROVE system in English and Chinese for patient self-care and shared decision making.**

- a. Using participatory design methods, develop and test patient-facing Android app for collecting and displaying traditional-format PRO surveys
- b. Develop and test a clinician-facing PRO dashboard for clinician actions and shared decision-making

**Aim 2. Integrate mPROVE into UCSF's Epic EHR and into the workflow of three DGIM clinic sites.**

- a. Integrate mPROVE into Epic using SMART-on-FHIR technology
- b. Prototype and optimize workflows and policies for patient self-care and for shared decision-making

**Aim 3. Conduct usability testing with 5-10 patient-clinician dyads to identify barriers and facilitators to implementation.**

## **SCOPE**

Background. Patient-reported outcomes (PROs) provide valuable information to both patients and clinicians for patient-centered care. For patients, capturing and reviewing their own PROs between clinic visits allows them to monitor and self-manage their health in real time. For clinicians, PROs provide a far more complete picture of their patient's health status than what the patient recalls during in-person clinic visits and can lead to improved health outcomes. Making the patient health experience visible and actionable is especially important for the care of multiple chronic conditions (MCC), which impact people where they live, work, and play over spans of years. Patients and clinicians can co-manage chronic illness with meaningful shared decision-making only if both parties share an accurate understanding of the patient's overall health experience.

Context. As more Americans have MCC, there is a growing need to bring PROs into the primary care setting where most patients with MCC receive their care. However, the systematic use of PROs in primary care has been limited by logistic and methodological challenges on PRO collection, patient engagement, and clinical workflow integration. The Mobile Patient-Reported Outcomes for Value and Effectiveness (mPROVE) project will use stakeholder engagement and novel technology to address central challenges around patient engagement, reaching diverse populations, fostering collaborative patient-provider interpretation, and workflow integration.

Settings. The setting for this work is the University of California San Francisco's (UCSF) Division of General Internal Medicine (DGIM), which serves a racially and ethnically diverse population of 25,000 primary care patients with over 70,000 visits annually. UCSF uses the Epic electronic health record (EHR) and its MyChart patient portal. Because only 43% of UCSF DGIM patients use MyChart and because MyChart does not

support character-based languages, using only MyChart to collect PROs will have insufficient reach. With over 75% of Americans including those in underserved populations owning a smartphone, it is now not only feasible but essential to use personal mobile technologies as the first-line method for patients to collect and view PROs *in situ* of daily life and in their preferred language. Furthermore, to make PRO results available to clinicians in their workflow, SMART-on-FHIR technology can be used to launch a PRO results dashboard inside an embedded window within the patient's EHR encounter without requiring a separate login.

Participants. The DGIM patient population reflects the ethnic and cultural diversity of the San Francisco Bay Area. More than 50% of patients are racial/ethnic minorities (21% Asian, 10% African American, 9% Latino, 13% other). DGIM patients speak over 47 different languages with 15% speaking a language other than English. The most common non-English language is Chinese (Cantonese/Mandarin).

## **METHODS**

Study Design. The major components of the mPROVE project were: 1) selection of PROs most useful for holistic primary care of patients with MCC; 2) participatory design and testing of the mPROVE app and PRO dashboard; and 3) integration, prototyping and deployment of the mPROVE system into UCSF's EHR and into DGIM workflow. We then conducted a 6-week usability testing of the mPROVE system with Android patient-facing app with patient-clinician dyads.

Data Collection. Our patient eligibility criteria for the project were: 1) age 18 or older; 2) speak English or Chinese (Cantonese); 3) have a diagnosis of depression, type 2 diabetes mellitus or hypertension (HTN) using ICD-10 codes as noted on the problem list and/or visit diagnoses; and 4) uses an Android smartphone device. Clinician eligibility criteria included physician or nurse practitioner serving as a primary care clinician at the study site.

We conducted patient recruitment for participatory design sessions and field testing using a convenience sample of patients from the study site. For the usability testing, we identified potentially eligible patient participants using the EHR and asked clinicians to identify who should be excluded. We then send patients a letter signed by their clinician with an option to opt out of the study by mail. If we do not receive an opt out response in 10 days, we will contact the patient by phone. After patient participants consented to the usability testing, we then approached primary care clinicians to join the study by email. All study activities were conducted in the preferred language (English or Chinese (Cantonese) of the participant.

Intervention. The patient-facing mPROVE app was developed in partnership with a global non-profit technological solutions developer, The Commons Project. The mPROVE app was developed using the Agile development method, an iterative software development methodology utilizing extensive collaboration between independent teams, for both iOS and Android platforms in English and Chinese. Given the necessary integration of all components of the mPROVE app, a weekly standing video conference call was established early in the project that is attended by TCP representatives including the mPROVE developer team, UCSF research team and BRIDGE data visualization team.

BRIDGE is a data visualization dashboard incorporated within the existing EHR infrastructure allowing clinicians to view a comprehensive snapshot of a patient's self-reported data, in addition to the trends in this data over time. This is the first and only data visualization tool connected the Epic EHR at the study site. BRIDGE is a Substitutable Medical Applications and Reusable Technologies utilizing Fast Health Interoperability Resources (SMART on FHIR) application that launches from within the EPIC EHR at the study site. All of the patient's PRO data via completed collection surveys in the mPROVE app are summarized as data points over time. Moreover, this visualization displays data from surveys in context with other data from the EMR. Additionally, there is a time scale allows a clinician to see whether PROs are getting better, worse, or stable for the patient - especially during introduction of new changes such as starting a new medication. Should a patient enter in data within the mPROVE app that exceeds a clinically significant threshold, BRIDGE will be triggered to send a message to their primary care clinician's EHR in-basket notifying them of this change. For BRIDGE, the SMART-on-FHIR approach was used as a work around UCSF Epic EHR system's structures, specifically allowing the import of data entered into the mPROVE app in the EHR without Epic approval.

For patient participants, the 6-week usability testing involved 1-hour onboarding meeting to learn how to use the mPROVE app and fill out patient-selected baseline surveys in the app and a survey focused on technology literacy. For the first three weeks of the usability study period, patients self-selected surveys about their health on the mPROVE app and complete the surveys once a week. If patients had visit with your primary care clinician in the 6-week study period, patients will receive a push notification to fill out some of the same surveys about their health on the mPROVE app right before the visit. For the last three weeks of the usability study period, patients can use mPROVE as often as they wish to track symptoms. Patient participants received \$50 gift card for completing study activities for the first 3 week of the study period and another \$50 gift card for completing the debriefing interview at the end of the 6-week study period.

For clinician participants of usability testing, clinician participants received an interactive 15-minute video conferencing-based onboarding that included an overview of the mPROVE system and how to access and use the BRIDGE data visualization tool embedded in Epic. Clinicians were made aware that should a patient enter in data within the mPROVE app that exceeds a clinically significant threshold, BRIDGE will be triggered to send a message to their EHR in-basket notifying them of this change. Clinicians were encouraged to monitor patient's data using BRIDGE as often as they wish. If clinicians had a visit with a patient enrolled in the mPROVE study during the 6-week study period, clinicians received a secure text message sent by the study PI to encourage them to view BRIDGE before and during the visit. Clinician participants received a \$50 gift card for completing the debriefing interview at the end of the 6-week study period.

Measures. The mPROVE app includes PROs asking about their physical function, anxiety through the General Anxiety Disorder-7 (GAD-7) questionnaire, depression through the Patient Health Questionnaire-8 (PHQ-8), fatigue, sleep, cognitive function, and pain in regard to how it affects a patient's ability to complete daily tasks.

Limitations. The initial aim was to develop the patient-facing mPROVE app in Android and iOS. However, due to unforeseen technical challenges later on in the study, study and technical staff leadership made the decision to rebuild the mPROVE app natively within the Android platform and removed the option of having an iOS available version. Field testing of the app was done for both the Android and iOS platforms while the later usability testing was only performed on the Android platform which severely limited the eligible patient population as iOS is the dominant smartphone platform in the San Francisco Bay Area.

## **RESULTS**

Principal Findings, Outcomes and Discussion. Patient field testers were recruited from a newly formed DGIM Technology Testing Panel of patients interested in giving feedback on emerging digital health technologies and programs from the study site. Patient field testers (iOS n=8; Android n=7) completed two-week testing with high user satisfaction including PRO response app visualization. Identified usage barriers included repetitiveness of PRO questions and lack of push-notifications at time of field test. Resolution of technical problems found in field testing resulted in delays ranging from one week to one month in duration. Authentication and login-redirect issues preventing users from entering the app to enter data were the most commonly encountered technical errors by field test participants. Testers who encountered authentication issues would be delayed for 1-2 weeks depending on which error was causing the issue during that specific instance. The most time-consuming errors to fix were periodic, iOS failures that resulted in the iOS version of the mPROVE app unusable, ultimately requiring the developer team to release a new version of the app containing a fix in the coding of the app. The team ultimately decided to rebuild the mPROVE app natively within the Android platform.

Usability testing of this newly built mPROVE Android application occurred in English and Chinese on the Android platform only. We enrolled 5 patient-clinician dyads (with one patient bilingual in English and Chinese) to engage in usability testing with 4 patient participants completing the usability testing study period. One consented patient participant was lost to follow up after more than one unsuccessful attempt to have patient use MyChart credentials to authenticate to the mPROVE server. Patient feedback from the usability period included authentication challenges (e.g., needing to revalidate MyChart credentials more than once), perceived limited utility of the mPROVE app largely due to lack of primary care clinician communication during the usability testing period, and perceived limited impact on chronic disease self-management behaviors given patient-reported well controlled depression, diabetes and/or hypertension and/or high degree of self-awareness. Clinician participants reported little to no self-initiated engagement in the BRIDGE data

visualization tool citing competing time-related challenges. One clinician received multiple EHR in-basket messages alerting that patient data exceeded a clinically significant threshold; when the clinician attempted to launch BRIDGE, there was a technical issue with BRIDGE and Epic due to a recent upgrade and BRIDGE did not launch. This clinician also reported that the patient had known active depressive and anxiety symptoms that was under behavioral health specialty care. All clinicians cited that a more focused approach to mPROVE app use that is patient and clinician driven – such as trying to see if medication changes improved mood or reduced pain over a specified time period could be a scenario in which mPROVE could be an asset. Otherwise, clinicians noted the potential time and data burden of receiving ongoing patient data without a specified context could overwhelm the clinical workflow. There was one patient-clinician dyad that had an in person primary care visit during the 6-week usability study period. The patient did not receive a push notification to complete surveys (due to technical issue). The separate patient and clinician debriefing interviews for this dyad revealed that the primary care visit focused on acute issues leading to a recent emergency room visit. PRO data entered into the mPROVE app was not on the agenda and was not discussed. These findings suggest that the concept of mPROVE system could optimize its impact and utility in very specific use cases that require consistent interaction and communication between patients and their primary care clinicians.

To support study recruitment for usability testing, we conducted an online survey of technology behaviors, preferences and literacy among the newly formed DGIM Technology Testing Panel composed of nearly 500 DGIM patients that speak English and/or Chinese. Survey respondents received \$5 e-gift card for completing the survey. We received a total of 223 responses including 30 responses from Chinese-language preferring patients. Initial analyses show that the survey respondents were highly educated (50% with an advanced degree) with over 40% with an annual household income of \$150,000 or more. Survey respondents had high technology literacy and access to internet and iOS devices were the dominant form or reported technology devices as only 11.6% of survey respondents reported using an Android smartphone. These initial findings suggest that directed, intentional engagement and recruitment of more diverse patient populations to such testing panels and development of patient-facing technologies are needed to prevent widening of the digital divide and exacerbating health disparities particularly by socioeconomic disadvantage. We are finishing our analyses and working towards preparing a manuscript reporting these results to the Journal of Participatory Medicine.

Conclusions, Significance and Implications. The mPROVE project was able to develop a feasible and acceptable mPROVE Android app in English/Chinese and to initially demonstrate how the mPROVE system (patient-facing app and EHR-embedded data visualization tool with in-basket message alerts for out-of-range data) may work in an active, large primary care practice. However, the most significant implication of this project are the lessons learned in undertaking a project with this technological approach. Our project encountered challenges and barriers into 3 categories: individual, organization/environmental and technical. Individual challenges and barriers included rapid team turnover during a world-wide pandemic and different work culture and communication styles in new teams without prior experience collaborating. Organizational and environmental challenges including evolving informational technology governance and technology security practices and opaqueness of the EHR. Technical challenges including server outages, “babysitting” the mPROVE system with any updates to the EHR, app store and server upgrades. To that end, we are in the final stages of a manuscript reported on the lessons learned from the mPROVE project that we plan to submit to the JMIR Formative Research. SMART-on-FHIR allows for a good means to work around existing EHR and other restrictions in existing health data systems, but its benefits are significantly weakened without an optimization of existing institutional technical infrastructure and policies, especially as it pertains to interfacing with the EHR.

## **LIST OF PUBLICATIONS AND PRODUCTS**

1. Jih J, Satterfield JM, Louie A, Carini S, Zeng B, Nguyen T, et al. Development of a Bilingual Smartphone Application and Electronic Health Record Data Dashboard to Collect and Display Patient-Reported Outcomes for Chronic Disease Management in Primary Care. In: Journal of General Internal Medicine. Denver, Colorado; 2023. p. S640.
2. Louie A, Sim I, Carini S, Satterfield J, Jih J. Development of an English/Chinese Smartphone Application and Electronic Health Record Data Dashboard to Collect and Display Patient-Reported Outcomes for Chronic Disease Management in Adult Primary Care. In San Francisco, CA; 2023.

3. Louie A, Carini S, Pollak J, Meeks E, Sara N, Bove R, N Miller, Zeng B, Satterfield J, Nguyen T, Feldman M, Sim I, Jih J. The Experience of an Academic-Technology Collaboration to Design and Implement a Smartphone App Collecting Patient-Reported Outcomes with an Electronic Health Record Data Visualization Dashboard in an Academic Health System, in preparation.
4. Louie A, Chu E, Vasudevan A, Nguyen A, Jih J. Creating Diverse Patient Testing Panels Towards Health Equity, in preparation.