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## Predictors of Willingness to Use a Smartphone for Research in Underserved Persons Living with HIV

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### Abstract

**Objectives**—The burden of HIV/AIDS is borne disproportionately by a growing number of racial and ethnic minorities and socioeconomically disadvantaged individuals. Developing mHealth interventions for the everyday self-management needs of persons living with HIV (PLWH) can be challenging given the current constraints of the U.S. healthcare system, especially for those from underserved communities. In order to develop effective, evidence-based mHealth self-management interventions, we need a better understanding of the factors associated with mHealth research. The purpose of this study was to assess factors associated with PLWH's participation in research using smartphones.

**Methods**—We conducted a prospective cohort study (parent study) to examine the relationships among HIV self-management, age, gender and mental wellness. Relevant to this study, we analyzed the relationship between self-reported use of smartphones, willingness to use a smartphone for research, and other predictor variables including: HIV stigma, social isolation, social integration functions, and depression. We selected these variables because previous work indicated they may influence smartphone or mHealth use and because they also tend to be elevated in PLWH.

**Results**—We found increased age, HIV stigma and social isolation were negatively associated with smartphone use, which supports the use of smartphones for conducting research with PLWH but also suggest that age, stigma, social integration functions and social isolation need to be considered in research involving PLWH.

**Conclusions**—Findings here support smartphone use in research involving PLWH. However, future mHealth interventions targeting PLWH should take into account the inverse relationship between smart phone use and age, HIV stigma, and social isolation, and other predictor variables

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Alisson Webel: Conception and design of the study, drafting the manuscript

All authors approved the final version to be published and agree to be accountable for all aspects of the work.

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## Keywords

mHealth; smartphone use; self-management; persons living with HIV; stigma

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## Introduction

HIV imposes a significant burden on the health and quality of life of approximately 1.2 million Americans living with the disease [1]. The burden of HIV/AIDS is borne disproportionately by a growing number of racial and ethnic minorities and socioeconomically disadvantaged individuals [2]. Significant racial disparities exist in HIV incidence and care in the United States [3-6]. In 2011, 48.7% of new HIV diagnoses were among Blacks and 31.3% were among Latinos [7]. Blacks represent approximately 14% of the U.S. population, but accounted for an estimated 44% of new HIV infections in 2009. The HIV infection rate among Blacks is almost eight times as high as that of Whites (69.9 vs. 9.1 per 100,000) [8]. The HIV infection rate among Latinos was three times as high as that of Whites [9, 10]. In addition, HIV disease progression and survival are worse among racial/ethnic minority patients [11]. These disparities underscore the importance of developing health interventions targeted for the needs of racial and ethnic minority groups.

HIV has changed from an acute illness to a chronic disease. The success of HIV medications and treatments has significantly changed the course of the disease [12]. While AIDS-related illnesses are no longer the primary threat, a new set of HIV-associated complications have emerged, resulting in a chronic disease that, for many, will span several decades of life. Current HIV treatment does not fully restore immune health and multi-morbidity (e.g., cardiovascular disease, bone disease and cancer) is associated with HIV disease [13-15]. In view of the change in the course of the disease, persons living with HIV (PLWH) are living longer but experiencing more symptoms associated with the disease and its treatment. More than a quarter of adults living with HIV are 55 years of age and older and the number is growing [16]. As the population of PLWH ages, there is a sharply increased risk of poorer everyday functioning and HIV-related disability, which supports the need to manage adverse symptoms in this population [17]. Yet targeting the everyday symptom-management needs of PLWH can be challenging because chronic disease management is difficult to support given the current constraints of our healthcare system (e.g., limited provider time, fragmented health information system), especially for those from underserved communities.

mHealth is the use of consumer-grade hardware -- such as cellular phones, tablets, smartphones and other wireless devices -- for the delivery of health services and information [18]. The ubiquitous nature of mobile technologies in daily life creates opportunities for health behavior management tools that were not previously possible [19]. mHealth can rapidly assess and modify health-related behavior and transform patients' decision-making about their health [18]. Smartphones can house mHealth applications (apps) designed to be used by patients and providers for diagnostics, behavioral prompts, reminders, and illness monitoring and self-management programs that extend beyond the traditional limits of a physical clinic. For example, a mobile behavioral sensing system was used by a small group of schizophrenia patients and found to be a feasible and acceptable approach for collection

of behavioral data through the passive ascertainment of the patients' location, activity, and exposure to human speech as they went about their day [20]. Electronic patient monitoring devices have also been used to improve HIV Antiretroviral Therapy in a small group of PLWH who were sent SMS reminders to take their medications upon missing a scheduled dose [21].

The potential for information and communication technology, such as mobile apps, to enhance health behaviors through the provision of support (information, education, reminders, etc.) for behavior change has been well-documented over the last decade [22-29]. A growing body of research confirms the benefits of empowering PLWH consumers with information and decision-making support [30-36]. Patient participation in their health leads to increased satisfaction as well as positive behavior change patterns translating into improved clinical outcomes [37-39]. Individuals who use mobile apps to help manage their health may perceive these tools as more private, potentially increasing patients' willingness to disclose unhealthy behaviors and seek support tools [40, 41]. This may be particularly important for diseases, such as HIV, that remain stigmatized and require substantial, complex, daily self-management.

mHealth also has the potential to bridge a divide in healthcare delivery among underserved racial and ethnic minority groups. The use of mobile technology has made a significant impact on communication, access, and information/resource provision to minority and underserved populations [42]. Nearly 2/3 of Americans are now smartphone owners, particularly those from racial/ethnic minority and low socioeconomic groups [43]. Of telecommunication technologies, mobile phones are one of the widest reaching, with 90% of African Americans, 92% of Latinos and 90% of Whites in the US owning mobile phones as of 2014[44]. In 2010, African Americans and Latinos, who are collectively of lower socioeconomic status in the US, use SMS at higher rates (79% and 83%, respectively) than Whites (72%), with adoption of mobile technology across all groups increasing over time[45]. Furthermore, emerging evidence suggests that underserved populations use smartphones as their primary method for accessing the Internet [46]. The use of mHealth can reduce economic disparities and personalize healthcare [47, 48], which can be particularly relevant to PLWH because a majority of these persons are from underserved and minority groups [2, 49, 50].

Finally, mHealth can facilitate research participation by underserved PLWH through tailoring of information, messaging, and support; thus enhancing user control [51]. mHealth can also passively collect data on the PLWH's location, activity, and other important variables, minimizing subject burden and lost data. However, conducting research with PLWH can pose challenges including perceived HIV stigma, guilt or shame by being asked certain questions, or fear of criminalization[52-54]. mHealth, in particular the use of smartphones, can minimize these challenges through more anonymous data collection. However, little is known about smartphone use among minority PLWH and the factors associated with their willingness to use smartphones for research participation. Therefore, the purposes of this study were to: 1) describe current smartphone use in a predominately minority sample of PLWH and 2) to assess demographic and social factors associated with PLWH's willingness to use a smartphone for participation in a research study.

## Methods

We conducted a prospective cohort study (parent study) to examine the relationships among HIV self-management, age, gender, and mental wellness [55-58]. In this cohort study, ( $n=102$ ), participants completed two data collection visits, one year apart. To ensure a representation of both women and older adults, subjects were purposively enrolled into four strata: men <50 years, men 50 years, women <50 years, and women 50 years. As part of the cohort study, participants completed a battery of measures including a self-report survey, 7-day actigraph and physical activity measures, heart rate variability testing, anthropomorphic measures (height, weight, waist-to-hip-ratio), vital signs, and serum measures [55, 59]. The data presented in this analysis come from the second data collection time point of this study at which time 93 participants completed all study measures.

Relevant to this study, we analyzed the relationship between self-reported use of smartphones, willingness to use a smartphone for research, and other predictor variables including: HIV stigma, social isolation, social integration functions, and depression. We selected these variables because previous work indicated they may influence smartphone or mHealth use [60, 61] and because they also tend to be elevated in this sample [56, 58]. All procedures were approved by the University Hospitals, Case Medical Center Institutional Review Board.

### Sampling and Recruitment

Subjects were recruited from an HIV Research Registry housed in the Frances Payne Bolton School of Nursing at Case Western Reserve University in Cleveland, Ohio, at three Ryan White- funded HIV clinics (out of five in Cleveland) and two service organizations using IRB-approved letters to participants on the research registry and flyers directed at PLWH at the clinics and service organizations (posted by research study staff). We chose these sites for recruitment because they provide clinical and support services to the majority of HIV care and services to PLWH in Northeast Ohio. To be eligible for the study, interested parties needed to be adult (18 years of age), have a confirmed HIV diagnosis, currently prescribed HIV antiretroviral therapy, and English speaking. Due to study procedure restrictions, subjects were excluded if they had a diagnosis of insulin dependent diabetes or if they had a cardiac pacemaker. These exclusion criteria were applied because in the parent cohort study, subjects wore a holster monitor for which insulin dependent diabetes and cardiac pacemakers are contraindicated [55]. Our sample size and sampling methodology was determined based on the primary hypothesis of the parent study[56] that older adults would experience greater stress and isolation as compared with younger PLWH and that these outcomes would vary by gender. Accordingly, we initially recruited 102 PLWH in four equivalent strata (27 males < 51years of age, 27 males 51years, 30 females < 51years, 18 females 51years). All participants were invited back one year later, to participate in the second data collection visit, from which these data are derived.

### Procedures

Potential participants were screened via telephone by a trained research assistant to determine initial eligibility and consented to medical chart abstraction to confirm study

eligibility. All eligible subjects were scheduled for an enrollment appointment at the research offices at Case Western Reserve University. At this appointment, study staff verbally explained the study procedures and verified informed consent for study participation in writing. Subjects next completed a release of medical information from their HIV clinic (to confirm study eligibility) and completed several self-report measures assessing demographics, social factors, and potential for smartphone use on the web-based data management tool REDCap [62]. Those unable or unwilling to complete the survey on REDCap were interviewed by a research assistant who also entered these responses simultaneously into REDCap. Data were collected during the hours of 9am and 7pm between December 2012 and April 2013. Participants were compensated with a \$50 cash card for their time.

## Measures

### Demographic characteristics

Demographic characteristics (gender, age, race, marital status, education level, monthly income and health insurance status) were obtained by self-report. We also measured the following social factors using validated and psychometrically-sound scales, including: HIV stigma using the HIV Stigma Scale [63], depression using the Center for Epidemiologic Studies Depression Scale (CESD) [64], social isolation using the Hawthorne Friendship Scale [65] and social integration functions using the Lubben Social Network Scale-6 (LSNS-6) [66]. The LSNS is a brief instrument designed to gauge social isolation in older adults by measuring perceived social support received from family, friends and neighbors.

### Smartphone Use: Willingness to Use Smartphones

The investigators developed a 13-item scale that assessed participants' potential for using smartphones in three domains: (1) current smartphone use (e.g., ownership, comfort with, how often each day the participant used apps, times of text messaging and numbers of emails on their smartphones each day); (2) healthcare communication (i.e. dichotomous questions asking if the participant used their phone to communicate with their health care team, to receive appointment reminders, and to manage their health); and (3) willingness to use a smartphone for research purposes (e.g., if they would participate in studies that asked them to complete questions on their smartphone, if they would receive health information via smartphone and if they would play health-related games on a smartphone). The present analysis focused on this last domain and specifically the question "would you want to participate in a research study that asked you questions each day via a smartphone"?

### Data Analysis

Data were first summarized, scale psychometrics checked, and distributions analyzed. We then used descriptive statistics (e.g., frequencies, means and standard deviations) to characterize our study sample. We conducted correlation analyses (Pearson for continuous variables and Spearman for continuous and categorical variables) to assess any relationships among demographic and social factors, and smartphone use. We also conducted a multiple regression analysis to examine whether the variables significantly predicted the four social factors of stigma, depression, social isolation and social integration functions and a logistic

regression analysis to obtain a final model describing the predictors of smartphone use including willingness to use a smartphone for research purposes (dependent variable: smartphone use). We adjusted the analysis to include only smartphone users to examine if they were willing to use their smartphone for research purposes and how their willingness was correlated with other factors. In our regression analysis, we used backwards elimination to select variables [63]. In backwards elimination, the least significant effect that did not meet the level for staying in the model was removed using Wald Chi-Square Test. The process was repeated until no other effect in the model met the specified level for removal. Level of significance was set at  $\alpha=0.05$  for all analyses.

## Results

### Sample

Our final study sample included 93 PLWH. Mean age was 48 years ( $SD\pm 9.36$ ). The mean age of men was 40 years ( $SD\pm 8.08$ ) in the under 50 group and 54 years ( $SD\pm 3.63$ ) in the 50 or over group. The mean age of women was 41 years ( $SD\pm 8.76$ ) in the under 50 group and 55 years ( $SD\pm 4.71$ ) in the 50 or over group. Demographics of our study participants are reported in Table 1. Of the 93 participants, 84 (90.3%) had cellphones but only 29 (31.2%) had smartphones..

*HIV Stigma Scale* scores ranged from 13-52 with higher scores indicating higher levels of perceived HIV stigma. Mean stigma score across participants was 22.08 ( $\pm 8.49$ ). The CESD Scale ranged from 0-60 with a score of 16 suggesting a clinically significant level of psychological distress. In our study sample, the mean depression score was 16.40 ( $\pm 11.57$ ). The social isolation score ranged from 0-24. Scoring of the scale is as follows: 0-11 -Very socially isolated; 12-15- Isolated or with a low level of social support; 16-18 - Some social isolation or some social support; 19-21- Socially connected; 22-24: Very or highly socially connected. The mean social isolation score in our study was 17.19 ( $\pm 5.32$ ). The LSNS-6 is a brief measure of social engagement including family and friends with a scale ranging from 0 to 30 with a score  $<12$  are at risk for social integration functions. In our sample, the mean social integration functions score was 15.49 ( $\pm 6.14$ ).

### Current Smartphone Use

Regarding a current use of smartphones, the median number of apps used each day was 6.5 (IQR=18), the median number of text messages sent or received per day was 10 (IQR=45), and median number of emails received or sent on their smartphones per day was 10 (IQR=23). Regarding healthcare communication among smartphone users, 53.33% of participants used their smartphones to communicate with their health care team, 31.25% to receive appointment reminders, and 28.13% to manage their health.

There was an association between HIV stigma and comfort using smartphones ( $p=0.036$ ). Study participants who are more comfortable using smartphones are less likely to report HIV stigma ( $r = -0.405$ ). There was also a significant association between social isolation and willingness to use a smartphone for research among study participants ( $p=0.031$ ). Study participants who were more willing to use a smartphone for research, reported less social

isolation ( $r = 0.383$ ). The results of a multiple regression analysis indicated that the two predictor variables of comfort using a smartphone ( $\beta = -0.099$ ,  $p = 0.027$ ) and depression scores ( $\beta = 0.420$ ,  $p < 0.001$ ) explained 50.38% of the variance for the outcome of HIV stigma.

The current use of a smartphone was significantly correlated with age, monthly income, and total social integration function score. After using a backward elimination method [63], we deleted the monthly income from the model. Findings from our logistic regression analysis showed that for every one year increase in age, the log odds of the use of a smartphone compared to the non-use of a smartphone decreases by 0.101 ( $p < 0.001$ ). Moreover, for every one-unit increase in total social integration function score, the log odds of a smartphone use, compared to non-use of a smartphone, increased by 0.106 ( $p = 0.026$ ). A higher total social integration function score indicates that on average the individual has more people to perform social integration functions. The results can be found in Table 2.

### Willingness to Use a Smartphone for Research

Regarding willingness to use a smartphone, 81.25% of smartphone users responded that they would like to participate in a research study that requires them to answer questions each day via a smartphone. Findings from our logistic regression analysis demonstrated that for every one unit increase in total social isolation, the log odds of the willingness to use of a smartphone for research compared to the unwillingness to use of a smartphone for research increased by 0.233 ( $p = 0.048$ ). Higher social isolation scores indicate greater social connectedness by the *Hawthorne Friendship Scale*. (Table 3)

## Discussion

As HIV/AIDS has become a chronic disease, we have seen a corresponding increase in the number of people, particularly older adults, living with HIV. This is a population who may be at increased risk for stigma and isolation and are likely to experience increased health needs [55]. mHealth has the potential to mitigate isolation and improve self-management of health and illness, yet research on the development and efficacy of theory-driven mHealth tools is scant/lacking [64, 65]. We investigated the relationships among smartphone use, HIV stigma, social isolation, social integration functions, and depression in the context of future research participation in PLWH. Although depression was not an independently significant predictor of current smartphone use, depression and comfort using smartphones were significant predictors of HIV stigma, and HIV stigma was significantly associated with comfort using smartphones. These findings suggest that there may be an indirect effect of depression on smartphone use that is mediated through HIV stigma. Moreover, we found increased age, HIV stigma and social isolation were negatively associated with smartphone use suggesting that future mHealth research studies targeting this population should be, in part, tailored to these unique needs of PLWH. This may include tailoring of instructions on how to complete mHealth study protocols for older or more isolated PLWH or adding these variables as potential moderators [60] to the many ongoing clinical trials evaluating the efficacy of mHealth to improve health outcomes for this population [34-36].

Findings from this work support the thoughtful and systematic use of smartphones for conducting research with PLWH and also suggest that age, stigma, social integration

functions and social isolation need to be considered in research involving PLWH. Currently there are a number of mHealth apps for PLWH [66], but few have been developed by using information systematically gathered from potential app users or healthcare providers regarding desired content and features of a mobile app and barriers that need to be overcome in order to scale up such apps [67]. Of the limited number of studies specifically focused on mobile apps for PLWH, one study identified the preferences for a mobile app in HIV positive young mothers [68], but did not systematically evaluate the app after its development. In another study, researchers developed a mobile app consisting of a music program to improve adherence to antiretroviral medications for adult PLWH, but did not engage the intended end-users in the development of the intervention [69]. Further, neither of these studies evaluated the potential moderation of age, stigma, social integration and social isolation on the efficacy and effectiveness of these promising mobile apps. Although mobile phone apps are increasingly being used for the care of HIV and other sexually transmitted diseases, most available apps have failed to attract user attention and engagement [70]. In a 2012 review of existing HIV apps, researchers found that apps were infrequently downloaded (median 100 to 500 downloads) and not highly rated (an average customer rating 3.7 out of 5 stars) [66]. Based on this review, less than 0.3% of the more than 29,000 health-related apps available for iPhone and Android consumers were dedicated to HIV/STD information and prevention [66]. Given the dearth of well-developed mHealth tools and the willingness of underserved PLWH to use these tools for future study, this work supports the further development and evaluation of mHealth tool to enhance the self-management behavior of PLWH.

Willingness of PLWH to use smartphones for any phase of research (data collection, confirming appointments, intervention delivery) will depend on both their comfort with the technology and the trust the participants have in the researchers. Previous researchers have detailed the importance of trust for research engagement [71], and adding technology to the equation will require the research team to include the targeted end-users in the design of the interventions. Our findings show that stigma and age influence willingness to use smartphones for research and so purposefully engaging older PLWH who have higher levels of stigma in the design phase, will underpin the research team's success.

Findings from this work are important to help support the research and use of mHealth for all PLWH. Mobile delivery has five key advantages over traditional face-to-face delivery models: (1) participant control of the delivery to provide an efficient, flexible, and convenient way for study participants to receive the health information under investigation; (2) consistency of delivery (high fidelity) of the intervention under investigation; (3) decreased time burden on the delivery of the information/intervention under investigation; (4) reduction in monetary and time costs associated with travel and in-person consultation with research staff; and (5) the ability to self-monitor one's own health status and tailor the intervention under investigation to one's own needs[72]. These advantages eliminate major contributing factors to existing HIV self-management intervention, especially for those from underserved populations. Yet more research on the efficacy of these developmental interventions, and their effectiveness in socially marginalized PLWH, is needed.



## Limitations

Limitations of our study include drawing our sample from one geographic location. Although our population was demographically representative of the growing HIV epidemic in the U.S. [50], there may be unique aspects of HIV care in this location that limit generalizability of our findings. We used a cross-sectional, descriptive research design, making it impossible to characterize the directionality of smartphone use, HIV stigma, social isolation, social integration functions and age.

In our study, we were unable to compare the participants' reports about their smartphone usage and their willingness to use their phone for health research because we only collected data on participants' willingness to use their smartphone if they actually had a smartphone. This is a limitation of our study because smartphone use and willingness to use a smartphone are distinct and people do not necessarily do what they intend to do. Also, the confidence associated with people reporting their willingness to use a smartphone for health communications when they already own a smartphone by comparison with people who do not own a smartphone or any mobile phone is likely to be different. Future work should evaluate whether there is a difference between smartphone and non-smartphone users. Because we adjusted the analysis to include only smartphone users to explore the willingness of the use of a smartphone for research purposes, the small sample size might limit generalizability, which requires further research with a larger sample. Additional, longitudinal multi-site research designed to investigate this directionality is necessary in order to design and test tailored mHealth interventions to improve the health and wellness of PLWH in the U.S. and around the globe.

## Conclusion

mHealth has the potential to mitigate isolation and improve self-management of PLWH, yet research on the development and efficacy of theory-driven mHealth tools is needed [64, 65]. We investigated the relationships among smartphone use, HIV stigma, social isolation, social integration functions, and depression in the context of future research participation in the development of mHealth tools for PLWH. We found increased age, HIV stigma and social isolation were negatively associated with smartphone use suggesting that future mHealth interventions targeting this population should be, in part, tailored to these unique aspects of PLWH. Findings from this work support the use of smartphones for conducting research with PLWH but also suggest that age, stigma, social integration functions and social isolation need to be considered in this research.

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### Highlights

- mHealth has the potential to mitigate isolation and improve self-management of persons living with HIV, yet research on the development and efficacy of theory-driven mHealth tools is needed
- Increased age, HIV stigma and social isolation were negatively associated with smartphone use which supports the use of smartphones for conducting research with persons living with HIV.
- Future mHealth interventions targeting this population should be, in part, tailored to these unique aspects of PLWH.

### Summary Points

- Developing mHealth interventions for the everyday self-management needs of persons living with HIV can be challenging given the current constraints of our healthcare system, especially for those from underserved communities.
- mHealth has the potential to mitigate isolation and improve self-management of persons living with HIV, yet research on the development and efficacy of theory-driven mHealth tools is needed
- Increased age, HIV stigma and social isolation were negatively associated with smartphone use support the use of smartphones for conducting research with persons living with HIV.
- Future mHealth interventions targeting this population should be, in part, tailored to these unique aspects of PLWH.

**Table 1**Demographic Characteristic ( $n=93$ ).

<b>Demographic Characteristic</b>	<b>N (%)</b>
<i>Gender</i>	
Male	52 (55.91)
Female	39 (41.94)
Transgender	2 (2.15)
<i>Race</i>	
African American/ Black	81 (87.10)
White (Non-Hispanic)	11 (11.83)
<i>Marital Status</i>	
Single	66 (70.97)
Divorced	11 (11.83)
Domestic Partnership	7 (7.53)
<i>Education Level</i>	
11 <sup>th</sup> grade or less	20 (21.51)
High School or GED	24 (25.81)
Some college or technical school	23 (24.73)
<i>Monthly Income</i>	
No monthly income	14 (15.05)
\$600-\$799	38 (40.86)
\$1000 or more	20 (21.51)
<i>Health Insurance Coverage</i>	
None	14 (15.05)
Medicaid	49 (52.69)
Medicare	30 (32.26)
Ryan White Care Act	25 (26.88)



**Table 2**  
**Final model predicting smartphone use among adults living with HIV**

Variable	B	SE	P value	Odds ratio	95% CI
Intercept	2.413	1.491	0.106	—	—
Age (years)	-0.101	0.030	<0.001	0.904	0.853 to 0.958
Total social integration functions	0.106	0.048	0.027	1.112	1.012 to 1.221

**Table 3**  
**Final model of willingness to use a smartphone for research purposes**

Variable	B	SE	P value	Odds ratio	95% CI
Intercept	-2.455	1.920	0.201	—	—
Total isolation	0.233	0.118	0.048	1.262	1.002 to 1.589