

Informing Acceptability and Feasibility of Digital Phenotyping for Personalized HIV Prevention among Marginalized Populations Presenting to the Emergency Department

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Abstract

For marginalized populations with ongoing HIV epidemics, alternative methods are needed for understanding the complexities of HIV risk and delivering prevention interventions. Due to lack of engagement in ambulatory care, such groups have high utilization of drop-in care. Therefore, emergency departments represent a location with those at highest risk for HIV and in highest need of novel prevention methods. Digital phenotyping via data collected from smartphones and other wearable sensors could provide the innovative vehicle for examining complex HIV risk and assist in delivering personalized prevention interventions. However, there is paucity in exploring if such methods are an option. This study aimed to fill this gap via a cross-sectional psychosocial assessment with a sample of N=85 emergency department patients with HIV risk. Findings demonstrate that although potentially feasible, acceptability of digital phenotyping is questionable. Technology-assisted HIV prevention needs to be designed with the target community and address key ethical considerations.

Keywords: HIV, health disparities, equity, digital phenotyping, wearable sensors

1. Introduction

New human immunodeficiency virus (HIV) infections have had overall declining rates in the United States since 2015 (Centers for Disease Control and Prevention [CDC], 2021b). Progress is largely due to efficacious biomedical (e.g., pre-exposure prophylaxis [PrEP]) and behavioral (e.g., cognitive behavioral therapy for health behavior uptake and adherence) HIV prevention interventions (Rotheram-Borus et al., 2009). Despite the national decline, key groups continue to experience an HIV epidemic. Specifically, racial/ethnic minorities (Black, Hispanic, and Indigenous people), transgender women, men who have sex with men, and persons using drugs continue to have increasing incidence (Centers for Disease Control and Prevention [CDC], 2021a, 2021b) For these groups, HIV is not occurring in a siloed manner. Specifically, marginalization (e.g., discrimination; stigma) drives the co-occurrence of psychosocial challenges including mental health, substance use, poverty, and interpersonal violence – all drivers of HIV risk (Smith et al., 2022). Such interacting factors (i.e., syndemic theory; Singer et al., 2017) drive HIV risk behavior and lead to suboptimal access, uptake, and adherence to biobehavioral HIV prevention

(Babel et al., 2021; Grulich & Bavinton, 2022; Maticotta et al., 2020; Nydegger et al., 2021; Shoptaw et al., 2013). Thus, available efficacious interventions are not reaching the groups that would benefit from HIV prevention services the most. Finding alternative environments and methods to reach and provide HIV prevention intervention services to key populations is critical. Further, it is necessary to find novel ways to understand the complex life context in which ongoing HIV epidemics are occurring.

One potential alternative venue to engage key populations with HIV risk is the emergency department. Groups experiencing discrimination, stigma, and other marginalization lack access to regular health care (Baah et al., 2019; Biancarelli et al., 2019; Jackson et al., 2016; Kachen & Pharr, 2020; Richardson & Norris, 2010). Due to the lack of engagement in ambulatory care, such groups have high utilization of drop-in care via emergency departments (Lewer et al., 2020; Moravek et al., 2017; Parast et al., 2022; Sánchez et al., 2007). Recent work confirms that individuals with HIV risk behaviors and related psychosocial drivers of risk behaviors (e.g., mental health issues, substance use) are more likely to frequent the emergency department (Bonar et al., 2016; Harmon et al., 2021; Pringle et al., 2013). Therefore, emergency departments represent a location to reach and provide resources surrounding HIV prevention to marginalized populations who are most in need of intervention.

Aside from the question of novel locations to initially engage marginalized groups in HIV prevention services, there is a need to explore alternative ways of promoting and understanding uptake and adherence of services. Smartphones and other wearable sensors are potential sources of passive and active data collection that could provide contextual prompts that personalize and drive HIV prevention interventions (Arigo et al., 2019; Kang & Exworthy, 2022; Robards et al., 2018). In other words, such data collected from devices provides digital phenotyping – individualized, real-time assessment of a person (Prakash et al., 2021).

Smartphones can continuously and passively collect data for digital phenotyping and be a platform to implement empiric health behavior change coaching. With increasing ubiquity of smartphones among the general population and in emergency department patients, these devices could be a key for novel HIV prevention (Post et al., 2015; Ranney et al., 2012; Ranney & Suffoletto, 2014). For example, a recent HIV prevention intervention in South Africa collected continuous GPS location geo-coordinate data from participant smartphones. Based on GPS data, real-time interventions for care engagement were

delivered to the person's smartphone when near a clinic (Clouse et al., 2023). Smartphones not only collect data but can also deliver mobile health (mHealth) interventions. mHealth is advantageous such that it can address the complexities of HIV risk in marginalized groups by automating a personalized experience that can address an individual's unique holistic risk profile (including co-occurring psychosocial issues) without requiring presentation to traditional locations of medical care. The latter mitigating historical barriers to HIV prevention for marginalized groups including lack of access/ability to pay and an overburdened healthcare system.

Extending beyond passive data collection and digital phenotyping via smartphones, wearable sensor networks can also collect continuous data for novel HIV prevention. For example, digital pills (ingestible sensors) to monitor real-time medication adherence could be applied to HIV prevention (Goodman et al., 2022). Not only could this provide objective monitoring of PrEP use but would also allow for insight into the unique context of an individual's non-adherence pattern (e.g., environment, level of psychological distress, substance use). Additionally, wearable chest bands assessing continuous cardiac and respiratory signals have preliminary evidence supporting their ability to predict real-time substance use craving and drug-seeking behavior (Gullapalli et al., 2019). Highly applicable to HIV prevention given the robust drug use/HIV risk comorbidity (Shiau et al., 2017), this type of passive data collection could be utilized to signal for real-time intervention. Thus, similar to smartphones, networked groups of wearable and ingestible sensors could be utilized to select salient interventions related to situations an individual experiences in real time (Carreiro et al., 2018).

Despite the potential benefit of using smartphones and wearable sensors to address the ongoing HIV epidemic in key risk groups, there is paucity exploring if such digital phenotyping methods are an option among marginalized populations with HIV risk. Two major factors could undermine utilization of such innovative approaches. First, due to historical and current discrimination in healthcare and health research, marginalized groups report high levels of medical mistrust, especially surrounding adoption of new modes of medical care delivery and technologies to address HIV (Robards et al., 2018). Second, due to sequelae of marginalization, individuals may lack access to the technological resources needed to engage with smartphone-based methods and wearable body sensors - also known as the digital divide (Vassilakopoulou & Hustad, 2021). Therefore, prior to developing or testing methods for passive and active data collection via smartphones and wearable sensors

for HIV prevention, there is need to inform if this is implementable in the key HIV risk groups that need our focus. The goal of this study is to address this gap by exploring the feasibility and acceptability of utilizing digital phenotyping among those at risk for HIV acquisition presenting to the emergency department. Specifically, this study aimed to assess feasibility via assessment of smartphone usage and acceptability via assessment of attitudes toward passive data collection and toward technology.

2. Methods

2.1. Participants and procedures

From March to May 2023, N = 85 patients with an indication of HIV risk presenting to the emergency department completed a quantitative self-report cross-sectional psychosocial assessment. Participants were recruited from two urban academic emergency departments (one a quaternary care center and one a community emergency department) within the same hospital system in Boston, MA. Individuals were screened in the emergency department through the electronic medical record and were eligible if: a) they were 18 years of age or older, b) English speaking, c) did not have a documented HIV diagnosis or positive HIV test, and d) had a sexually transmitted infection (STI) test completed in the past 6-months. The STI test criteria was utilized as an indication of HIV risk given STI tests are performed post-risk exposure or screening for individuals engaging in risk behavior. Once confirmed eligible, patients were then approached about the study, completed informed consent, enrolled, and completed the study survey on a tablet using computer assisted self-interviewing (CASI) software. Participants were compensated for their time and effort. Study procedures were approved by the hospital institutional review board.

2.2 Measures and variables

2.2.1 Marginalization. For demographics related to marginalization, age, gender, sexual orientation, race, and ethnicity were collected. Economic status was assessed via a subscale from an adapted version of the Scale of Economic Hardship (Farero et al., 2022). Specifically, the financial strain subscale consisted of 2 items on a 5-point frequency Likert scale ranging from never (0) to quite often (4). Items were: “How often do you think that you will experience bad times such as poor housing or not having enough food?” and “How often do you expect that you will have to do without the basic things you need?”. For analysis, a dummy variable was created for economic strain

(participants reporting “sometimes” or more frequent on either item). Frequency of past year drug use, another indicator of a marginalized identity, was assessed via the validated Single-Item Screening Question (SISQ) for drug use (McNeely et al., 2015). For analysis, frequency was collapsed into a dummy variable for any drug use in the past year.

2.2.2 Feasibility and acceptability. Indicators of feasibility and acceptability of digital phenotyping were assessed with various measures:

Feasibility: smartphone usage. Smartphone usage was assessed via a 5-item measure developed for an ongoing study regarding using wearable sensors for HIV prevention. Items related to issues that would have implications in developing techniques for digital phenotyping leveraging smartphones or wearable sensors including ownership, charging behaviors, and specific device carrying behaviors (e.g., Where do you typically carry your phone?).

Acceptability: attitudes toward passive data collection. The latter half of the above-described scale (4 additional items) assessed data privacy concerns and behaviors (e.g., How willing are you to share your smartphone data with apps/third parties?).

Acceptability: attitudes toward technology. The positive and negative attitudes subscales of the validated Media and Technology Usage and Attitudes Scale (Rosen et al., 2013) were used. The positive attitudes toward technology subscale consisted of 6 items (e.g., Technology will provide solutions to many of our problems), and the negative attitudes subscale had 3 items (e.g., New technology makes life more complicated). Each statement was rated on a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5). A mean score was calculated per subscale with higher scores indicating greater positive or negative attitudes toward technology.

2.3. Data analysis

All analysis were completed in SAS version 9.04.01M7. To characterize sample and assess body sensor/digital technology acceptability and feasibility, descriptive statistics (i.e., measures of central tendency and variance) were completed for all study variables.

3. Results

3.1. Participant characteristics

During the study period, we recruited N=85 participants who met eligibility criteria. The sample

had an overall mean age of 36 (SD=12) ranging from 20 to 63 years old (Table 1). The sample represented various aspects of marginalization and key HIV risk groups. Nearly the entire sample was cisgender; specifically, 69% were cisgender women, 28% cisgender men, and 1% reporting a non-binary gender. Almost a quarter of the sample were a sexual minority (19%) and majority were BIPOC (60%). Almost a third of the sample reported economic strain (31%), and nearly half the sample reported past year illicit drug use (47%).

Table 1. Participant Characteristics, N=85

	<i>M</i> or <i>n</i>	(<i>SD</i> or %)
Age (in years)	36.1	(12.2)
Gender		
<i>Cisgender woman</i>	59	(69.4%)
<i>Cisgender man</i>	24	(28.2%)
<i>Non-binary/genderqueer</i>	1	(1.2%)
Sexual Orientation		
<i>Gay</i>	3	(3.5%)
<i>Lesbian</i>	1	(1.2%)
<i>Bisexual</i>	7	(8.2%)
<i>Queer</i>	1	(1.2%)
<i>Asexual</i>	2	(2.4%)
<i>Androsexual</i>	1	(1.2%)
<i>Demisexual</i>	1	(1.2%)
<i>Heterosexual</i>	68	(80.0%)
Sexual Minority	16	(18.8%)
Race		
<i>Black</i>	34	(40.0%)
<i>Asian</i>	3	(3.5%)
<i>White</i>	36	(42.4%)
<i>Indigenous</i>	1	(1.2%)
<i>Multiracial</i>	5	(5.9%)
<i>Different race not listed</i>	5	(5.9%)
Hispanic/Latinx	15	(17.7%)
BIPOC	51	(60.0%)
Economic strain	26	(30.6%)
Past year illicit drug use	40	(47.1%)

Notes. BIPOC = Black, Indigenous, and People of Color; *dummy variable was created for participants reporting sometimes or more frequent on either item

3.2. Smartphone usage

Almost the entire sample owned a smartphone (98%) with Apple/iOS (77%) and Android (21%) operating systems (Table 2). Nearly the entire sample charged their phone at least once per day (95%), and within that, 45% charged their phone multiple times or continuously throughout the day. Of note, 31% reported they do not use their phone while they are charging it. The majority of the sample reported

carrying phone directly on person (78%), 20% indirectly on person (e.g., in a bag), and 1% not on person.

Table 2. Smartphone usage

	<i>n</i>	(%)
Owns a smartphone	83	(97.7%)
Type of smartphone owned		
<i>Apple/iOS</i>	65	(76.5%)
<i>Android</i>	18	(21.2%)
<i>Does not own smartphone</i>	2	(2.4%)
Charging frequency		
<i>Continuously throughout day</i>	9	(10.6%)
<i>Multiple times per day</i>	29	(34.1%)
<i>Once per day</i>	43	(50.6%)
<i>Once every two days</i>	3	(3.5%)
<i>Never</i>	1	(1.2%)
Use phone while charging?		
<i>Never</i>	4	(4.7%)
<i>Rarely</i>	22	(25.9%)
<i>Sometimes</i>	35	(41.2%)
<i>Almost always</i>	14	(16.5%)
<i>Always</i>	10	(11.8%)
Where typically carry phone		
<i>Directly on person</i>	66	(77.6%)
Pocket	50	(58.8%)
Belt holder	2	(2.4%)
In hand	14	(16.5%)
<i>Indirectly on person</i>	17	(20.0%)
Bag or pouch	17	(20.0%)
<i>Not on person</i>	1	(1.2%)
<i>Depends on what wearing</i>	1	(1.2%)

3.3 Attitudes toward passive data collection

Nearly half the sample were not willing to share smartphone data with third parties or applications (49%) (Table 3). More than 2/3 of the sample were worried about third parties or applications having access to their smartphone data, with 48% reporting they have taken actions to limit data collected on their devices. There was notable prevalence of wanting to keep various types of data private including accelerometer (28%), phone operation (47%), Bluetooth (29%), GPS (60%), gyroscope (24%), time and duration of phone calls (59%), power status/battery (17%), number/frequency/time of text messages (67%), application usage (52%), and Wi-Fi usage (26%).

3.4. Attitudes toward technology

Participants had an overall mean of 4.1 (SD = 0.6) on the positive attitudes toward technology subscale

and a mean of 3.3 (SD = 0.9) on the negative attitudes subscale.

Table 3. Attitudes toward passive data collection

	n	(%)
Not willing to share smartphone data with apps/third parties	42	(49.4%)
Worried about apps/third parties having access to smartphone data	65	(76.5%)
Types of data want to keep private		
<i>Accelerometer</i>	24	(28.2%)
<i>General operation of phone</i>	40	(47.1%)
<i>Bluetooth</i>	25	(29.4%)
<i>GPS</i>	51	(60.0%)
<i>Gyroscope</i>	20	(23.5%)
<i>Phone calls (time/duration)</i>	50	(58.8%)
<i>Power status (battery life)</i>	14	(16.5%)
<i>Text messages (number, frequency, and time)</i>	57	(67.1%)
<i>Application usage</i>	44	(51.8%)
<i>Wi-Fi usage</i>	22	(25.9%)
Take actions to limit data collected	41	(48.2%)

4. Discussion

The current study is among the first to explore the potential feasibility and acceptability of digital phenotyping among marginalized groups with ongoing HIV epidemics. The study also defines key individual operating characteristics that may govern the collection of smartphone data, a ubiquitous way to collect personalized, passive digital data from individuals. Such technologies may be an alternative HIV prevention approach needed to address the complexity of HIV risk among key populations (i.e., BIPOC individuals, transgender women, men who have sex with men, and persons using drugs). Preliminary findings support the feasibility of using smartphones for digital phenotyping (and potentially other devices/sensors) but indicated barriers to acceptability that should be addressed during adoption of technologies in HIV prevention.

We demonstrated that the prevalence of smartphone ownership among emergency department patients with HIV risk is high and reflective of other emergency department populations (Ranney et al., 2012). Nearly the entire sample owned a smartphone indicating that regardless of marginalization,

individuals have access to a device that may be used for continuous passive data collection, as a data receiver for wearable sensors, or the means to deliver mHealth. Further, almost all participants kept their phone charged and carried it on person, suggesting that these devices are accessible and may be leveraged to assess individual and environmental contexts that impact health behaviors and deliver real-time interventions in response. In other words, results preliminary demonstrate feasibility of digital phenotyping with smartphones that may extend to other wearable sensors.

This study additionally demonstrates key boundary conditions and acceptability concerns that may relate to the development of digital phenotyping and mHealth that leverage smartphones or similar wearable sensors. Smartphone-based methods have been shown to be acceptable among emergency department patients for follow-up care (Ranney et al., 2012; Ranney & Suffoletto, 2014) and previous work has indicated willingness for individuals to share smartphone location data to detect acute health needs (Dulin & Gonzalez, 2017; Liss et al., 2018). However, more consideration is needed for those with overlapping marginalization and HIV risk. Participants indicated hesitancy in allowing access to smartphone data, although we did not ask participants for data access specifically related to health behavior change. Smartphone-linked data that participants were most hesitant to share included GPS and metadata surrounding text and phone calls. This suggests that other surrogates of health behavior may need to rely on more acceptable forms of smartphone data like accelerometry power and duty cycling or network connectivity. Further, although participants reported positive attitudes about technology, they also reported having negative attitudes about technology in tandem. Findings indicate a need to not solely focus on increasing positive attitudes toward technologies to ensure successful implementation of technology-assisted HIV prevention, but to directly address acceptability concerns.

Careful consideration of protecting privacy and security of more sensitive data may need to be explored if such intimate and personalized data is to be leveraged to understand patterns of health related and stigmatized behaviors. Digital phenotyping in key groups with HIV risk should therefore consider the historical and current discriminations experienced by marginalized populations in health research and digital criminalization (Jefferson, 2020; Robards et al., 2018). Ethical considerations should be priority when designing, testing, and implementing such technologies among groups at high risk for their data to be used against them. Breslin et al. (2019), outline

specific research ethics considerations for mobile sensing device use by marginalized populations that are important to attend to. Such considerations cover topics of data storage and access, discreteness of device, informed consent of all data collected, autonomy over data, and technology partner data policies. Further, inclusion of stakeholder groups that include patients who may use these technologies may improve the acceptability of smartphone phenotyping. In other words, digital technology interventions need to be informed, developed, and implemented *with* the communities they are meant for. The Hybrid Framework (Zhang et al., 2022) provides guidance on developing behavioral intervention technologies to promote healthcare utilization among socially marginalized populations. A key feature of the framework is the consideration of both individual-level factors (e.g., medical mistrust) and system-level factors (e.g., confidentiality) to address the multifaceted nature of implementing new technologies among groups historically discriminated against.

Although the current study provides novel insights into acceptability of smartphone data collection among individuals with HIV risk, there are key limitations. The study was restricted to English speakers and does not include all key HIV risk groups (e.g., transgender women); results thus may not fully represent the population of interest. Our study was also completed in a major metropolitan area; smartphone ownership and baseline use characteristics may vary based on geographic region. The study utilized a proxy for HIV risk, a documented recent STI test, and does not precisely represent one's HIV risk. Further, self-report data may be subject to social desirability bias, although study procedures aimed to mitigate this by using CASI and providing privacy. Measures did not specifically assess attitudes about different types of body sensors, but rather used smartphones as a proxy for all; future research should expand on current findings. Finally, we did not specifically ask about collecting smartphone data with respect to measuring health behavior change specifically.

Despite the limitations, this exploratory study provides important information. For the populations at highest risk for HIV and highest risk for not connecting to and not benefiting from extant prevention services, alternative methods for HIV prevention are needed. Thus, for individuals from key HIV risk groups presenting to the emergency department, utilization of smartphone or other wearable sensors for digital phenotyping and mHealth intervention delivery could provide innovative methods for HIV prevention. However, as demonstrated in the current study, although feasible, acceptability of such methods are questionable.

Continued engagement with end user communities, clear communication of intent of developed systems, and thoughtful data collection in marginalized populations may increase acceptability and utilization of such systems. Technology-assisted HIV risk assessment and intervention needs to be designed with the target community and address key ethical considerations.

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