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Biometric Registration to an HIV Research Study may Deter Participation

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Abstract

Biometric registration may improve services associated with HIV research. A cross-sectional, observational survey was used to evaluate biometric fingerprint scanning for identification (ID) verification in the setting of an HIV prevention study. Survey outcomes were dichotomized (discouraged or not discouraged) by biometric scanning and statistical analyses were used to determine if participation decreased by greater than 10% overall and after stratifying by demographic variables and risk behaviors. 206 participants were recruited from a community-based HIV and sexual health research screening program. Participants completed a quantitative survey to assess their perceptions of biometric scanning for ID verification. The majority of participants (n=160; 77.7%) indicated no deterrence from testing due to biometric scanning, a significant number (n=45; 23.3%, P<.001) reported at least partial deterrence. Research using biometric scanning for ID verification may significantly limit access to HIV prevention services and may risk reducing meaningful participation among marginalized populations.

Resumen

El registro biométrico puede mejorar la prestación de asistencia sanitaria y proporcionar una identificación conveniente del paciente en la investigación de VIH. El objetivo fue encuestar a los participantes del estudio que buscaban pruebas de VIH para identificar la presencia o ausencia de barreras para el escaneo biométrico de huellas digitales para la verificación de identificación (ID) como parte del registro para futuras visitas al mismo estudio. Se recogieron datos de observación transversales de los participantes en una sola visita. Los participantes se dividieron en dos grupos:

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Ethics

The UCSD Human Research Protections Program approved the study protocol and consent with methods carried out in accordance with the UCSD Institutional Review Board's approved guidelines and regulations. All participants provided voluntary, written informed consent before study enrollment.

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“desalentados” o “no desanimados” por el escaneo biométrico. Se emplearon análisis estadísticos para determinar si la biometría disminuyó la participación en más del 10% y si la proporción de participantes desanimados difería entre las características de comportamiento de riesgo demográfico y sexual. 206 participantes fueron reclutados de un programa de detección de VIH y de infecciones de transmisión sexual (ITS) comunitario sin costo. Antes de la prueba, se encuestó a los participantes para evaluar sus percepciones de los participantes sobre el uso del software de escaneo biométrico para la verificación de identificación. Mientras que la mayoría de los participantes ($n = 160$; 77.7%) no indicó disuasión de la prueba debido al escaneo de huellas digitales, un número significativo (23.3%, $P < .001$) informó al menos una disuasión parcial del escaneo biométrico. La investigación del VIH que utiliza el escaneo biométrico para la verificación de identidad puede limitar significativamente el acceso a los servicios de prevención del VIH, un resultado particularmente perjudicial ya que priorizamos el acceso a las pruebas.

Keywords

HIV screening; Biometrics; Barriers; Men who have sex with men; Risk Factors

Introduction

The Ending the HIV Epidemic initiative includes increased access to HIV testing, and as these programs are implemented, it is critically important to eliminate structural barriers to HIV testing and prevention services, especially among marginalized communities that are disproportionately affected by HIV/AIDS [1]. These goals of care apply to HIV testing in all settings, including HIV research.

The barriers to accessing HIV screening services are particularly relevant among marginalized populations, as research studies often serve as their primary gateway to accessing all lines of HIV-related research including access to care and clinical trials [2, 3]. Currently, Black and Latinx research participants are underrepresented in HIV research despite being disproportionately affected by HIV [4, 5]. Overall, people of color living with HIV are less likely to be referred and recruited to HIV research studies [6], are less likely to participate in HIV research, and are more likely to report negative social stigma as structural barriers to their participation [5]. People of color in the United States also test for HIV more infrequently, at later stages of disease [7, 8], and when foreign born, sometimes report barriers related to citizenship documentation status [9–11]. With this in mind, reducing barriers to testing is critically important particularly among Latinx and African-American gay and bisexual men between 25 and 34 years old, populations that have demonstrated a 68% and 65% increase, respectively, in HIV incidence between 2010 and 2016 [12].

When considering potential barriers, it is important to note that participant identification is typically required in order to participate in HIV research. For example, patient identity must be verified upon subsequent study visits according to AIDS Clinical Trials Group policy [13]. While the types of patient identification methods vary, it is common for initial participant registration to include asking participants to provide their name, birthdate, or other identifying information that some participants may be reluctant to share [13]. It is

important that investigators and clinicians alike explore ways to conduct research in partnership with marginalized groups – including the provision of alternatives forms of patient verification – so that these groups are not systematically deterred from participation in HIV research [14].

One alternative method of patient verification that has been considered in recent years is biometric identification. Biometric identification measurements such as fingerprint scanners and iris scanners have been proposed as convenient and low-cost strategies to improve research participant identification and healthcare delivery and have been demonstrated to improve outcomes in other healthcare settings [15, 16]. Biometric identification methods also offer patients some potential benefits including 1) better ability to gain access to their health information, 2) restricting unwanted access from others (e.g. fingerprint scanners could allow participants to securely login to a patient portal whereas a username/password can be hacked or intercepted), 3) reduced incidence of medical errors such as being given the wrong medication, and 4) shorter check-in times [17]. Biometric technologies may also be a promising tool to help researchers overcome some of the inherent challenges to conducting research with groups that may be reluctant to disclose risk behaviors due to stigma. For example, a recent study of female sex workers living with HIV in South Africa found that they were receptive to digital technologies for HIV care that included biometric identification methods [18]. However, while biometric identification appears to have some benefits for participants, it may also have some drawbacks for some groups including justice-involved people that may associate fingerprint scanners with the criminal justice system or people who use drugs who may fear legal consequences for disclosure of use [19]. Thus, before these biometric technologies are implemented in the field, it is important that investigators examine whether they are likely to enhance or deter access to HIV research so that we do not further exclude marginalized groups from research in the future.

Fingerprint scans represent one of many simple, unique biometric identifiers [20]. They are inexpensive and non-invasive to use and nationally, they are used to verify personal identification (ID) for access to gyms, mobile banking apps, and even school lunch programs [21]. Yet despite their widespread use, commercial benefits, and safety, fingerprint scanning systems have yet to be widely implemented in HIV research, possibly due to privacy and confidentiality concerns [19–21], stigma, or fear from participants that responses could be linked to the criminal justice system [19]. While the use of biometric identification for research is universally intended to be a secure process, concerns have been raised that one could “reverseengineer” the encrypted key that converts the fingerprint data into a series of numbers to identify the participating individuals [19, 22, 23]. A recent pilot study to improve engagement in HIV care for HIV-infected Malawi pregnant women found that the majority of participants felt the biometric fingerprint scanning was easy to use, required no additional assistance, and met their expectations, suggesting biometric registration may be a feasible and acceptable way to monitor HIV visits [24]. The Joint United Nations Program on HIV/AIDS has proposed a global need for longitudinal individualized client records to improve the equity and efficiency of HIV services [25]. Furthermore, as biometrics technologies become more available and accessible (e.g. many cell phones have fingerprint scanning capabilities), some HIV research sites that require ID may consider implementing biometrics

to improve engagement in HIV care over time and for ease of patient verification at future study visits.

Our study aimed to explore whether a biometric ID verification could be added to an HIV research study without deterring participants.

Methods

Study Population and Procedures

Participants of two community-based, research programs providing no-cost screening for HIV, were recruited between April and May 2019. The Primary Infection Resource Consortium (PIRC) supports two testing programs to identify persons with acute and early HIV infection; the “Early Test” and “Total Test.” Early test participants (age ≥ 13 years) were offered HIV screening, while “Total Test” participants (age ≥ 18 years) were offered screening for HIV and bacterial sexually transmitted infections (STIs). All testing was provided at no cost without need to provide documentation of citizenship.

All participants were asked to complete a short 3-question survey to assess their perceptions of biometric scanning for ID verification prior to undergoing screening for HIV or STIs. No incentives were offered for completion of this biometrics ID survey. This survey was added to the risk-assessment study questions offered as part of the no-cost screening for HIV and STIs.

The biometric survey consisted of three questions to assess participants’ perceptions related to the use of biometric scanning software for ID verification in order to link sequential HIV testing records (each performed under a unique study identifier) across multiple visits (to report results back to participants and research staff). Prior to answering the 3-question survey, participants were also provided a short 150-word description of biometric scanning and fingerprinting to address misconceptions and privacy concerns regarding fingerprint scanning. It stated, “we will not store an image of your fingerprint. Instead, it will be converted and stored in our database. For instance, software can convert the fingerprint to a string of numbers and letters. This is not the same fingerprinting used for legal or licensing purposes.”

The survey included three questions (see Appendix A1): 1) how important was it to have an automated software system to track participant information across multiple testing encounters; 2) which type of biometric identification would participants be willing to use; 3) to what degree might the participant be discouraged if fingerprint scanning was used. If participants answered that they were not interested in person-specific identifiers in Question 2, they were classified as “Discouraged” and were not asked the third survey question. Further, if the participant indicated in their response to Question 3 that they would be at least slightly discouraged from testing due to fingerprinting, they were also categorized as “Discouraged”. Everyone else was categorized as “Not discouraged”. Responses were compared between groups by demographic and sexual risk characteristics.

Statistical Analyses

We applied a one-sample proportion test to determine whether the true proportion of participants who would be discouraged by fingerprinting exceeds 10%. Secondly, we explored the potential barrier to HIV testing that would be introduced by use of fingerprint scanning for ID validation after stratifying by race/ethnicity, income and age, separately. We also considered the effects of different sexual risk measures (e.g. unprotected anal intercourse, drug use, testing history, and test result at study enrollment), independently, on willingness to use fingerprint scanners. For each variable with two levels, we applied Fisher's exact test and tabulated the odds ratios to make comparisons for each binary outcome and categorical predictors, without correcting for multiple comparisons at the usual 5% alpha level (2-tailed). For variables that had three or more variables, we conducted a chi-squared test at the usual 5% alpha level (2-tailed).

Results

Between April 1, 2019 and May 31, 2019, 206 adults completed the biometrics survey (Table 1) prior to HIV screening. The majority of the sample was male ($n = 195$; 94.7%), most of whom were men who have sex with men (MSM; $n = 189$; 91.7%). Participants were mostly aged between 26 and 35 ($n = 98$; 47.6%), and otherwise had an age distribution (range: 19–72) comparable to the testing population at large. Racially and ethnically, White ($n = 77$; 37.4%) and Hispanic ($n = 79$; 38.3%) participants made up the largest groups. Ten participants (4.9%) reported having tested positive for an STI in the 3 months prior to study, and of the 190 participants screened for STIs, 30 (15.8%) tested positive at study enrollment. No participants were excluded from the analysis.

In response to the first question in the survey, 93.2% of participants said that implementing some form of participant-management software would be important to them (Appendix A1). Furthermore, in their responses to Question 2, participants overwhelmingly preferred fingerprint scanning (38.3%; $n = 80$) to palm scanning (2.9%; $n = 6$), though 38.8% ($n = 80$) indicated no preference between the two, and 13.6% ($n = 28$) indicated a preference for an alternative identification method. The remaining 6.3% ($n = 13$) were not interested in person-specific identification. Question 3 responses indicated that the majority of participants ($n = 161$; 78.2%) would not be discouraged at all from testing due to fingerprint scanning; the remaining 32 participants (15.5%) said they would be at least slightly discouraged (Appendix A1). The 13 participants (6.8%) who indicated in Question 2 of the biometrics survey that they were not interested in person-specific identifiers were not asked Question 3 and were also assumed to be generally discouraged. One participant indicated that they preferred fingerprint scanning in response to Question 2, but did not provide a response to Question 3. Since the vast majority of participants who selected fingerprint scanning for Question 2 indicated that they were not at all discouraged ($n = 75/78$; 96.2%), this participant was also not considered to be discouraged.

Overall, the proportion of participants who expressed they would be at least slightly discouraged by fingerprinting was 21.8%, which significantly exceeds 10% ($P < 0.001$). In general, non-white participants were less likely to be deterred from testing than White participants, but this difference was not significant (Odds ratio: 1.659, $P = 0.161$ Table 2).

Income and poverty status (defined by a monthly income of less than \$1,000) [26], age (data not shown), and sexual risk behaviors were not significant predictors of perceived barriers to testing in the presence of biometric ID verification. The vast majority (98.5%) of the sample reported having healthcare coverage, so this factor was not included in the analysis. There was a non-significant trend for persons with a new STI diagnosis at study visit (after the survey was completed) to be less discouraged by fingerprinting than those who tested negative for an STI (Odds ratio: 2.986, $P = 0.095$, Table 2). In general, those exhibiting higher sexual risk were less likely to be discouraged by fingerprinting.

Discussion

Our study revealed that biometric registration should be implemented with caution, as a significant number of subjects (23.3%) were at least partially discouraged by the use of a simple biometric scan to register (verify their identity) for access in HIV testing sites. Biometric ID may make clinically-relevant data more transparent and accessible to participants by allowing them the potential to view their personal research data (e.g. track their viral loads over time or view their STI test results). These fingerprint scanning approaches would also eliminate the need for creation of a password that can be compromised or forgotten. However, the use of biometric technologies in research require a great deal of trust between participant and administrator, despite their benefits [27]. As we strive to improve inclusivity and diversity in HIV research, we need to minimize all barriers to research participation, particularly among justice-involved groups and other historically marginalized populations that have been underrepresented in HIV research [28].

In contrast to what we hypothesized, none of the three demographic characteristics or eight sexual risk measurements studied were significant in predicting deterrence from HIV and STI testing at the $\alpha = 0.05$ level. These findings suggest that fingerprint scanning or other forms of biometric identification do not disproportionately deter access to HIV resources to underserved and high-risk populations including Latinx, Black, and young MSM in the community we sampled. Black and Latinx MSM are underrepresented in HIV research [3–6] test less frequently in HIV screening programs [2, 7], and are most likely to receive late HIV diagnosis [7]. Related to issues of stigma and discrimination in healthcare, we had hypothesized that fingerprinting would be less acceptable among Black and Latinx MSM. These findings suggest that at least within our study population, the use of biometrics may not disproportionately deter these populations.

Our findings still demonstrated that biometric ID methods serve as a deterrent for some members of marginalized groups. Therefore, it is still important that biometric ID methods are implemented in a culturally-informed way for Black and Latinx participants so the use of fingerprint scans for ID verification to ensure that these tools do not further exclude vulnerable populations from research [26]. We did identify two unexpected trends from our results: (1) non-white participants tended to be less discouraged by fingerprinting ($p > 0.05$); and (2) participants who were diagnosed with an STI at enrollment tended to be less discouraged by fingerprinting ($p > 0.05$). These trends highlight how offering free HIV screening services may be protective to vulnerable populations by offering needed services

that are not otherwise accessible. For these people, fingerprint scans may help to streamline access to healthcare and, in turn, serve to reduce barriers to HIV services.

Of note, although we found that the proportion of those who are at least slightly discouraged by fingerprinting exceeds 10%, 77.7% of our sample was not discouraged at all by fingerprinting, suggesting fingerprint scans might still be a viable and easy method for identifying participants and linking an individual's records across multiple visits in HIV/STI clinic settings. If the reasons that some participants are discouraged are properly addressed, biometric registration methods have the potential to increase participant access to services and linkage-to-care, and allow testing center staff to better prevent misidentification, more fairly distribute testing incentives, and more efficiently track an individual's use of HIV/STI services.

One major limitation of our study was its small sample size, making it difficult to generalize conclusions to other populations. Social stigma and personal reservations about biometric registration may vary by region, commensurate with differences in its racial and ethnic makeup. Finally, the third survey question offered too limited a range of responses. That is, participants did not have the option to indicate that they would be encouraged to participate in testing due to fingerprinting – a plausible response given the potential benefits of biometric scanning. Larger studies are needed to validate these data in different geographic settings, and with a more comprehensive set of survey questions.

While our study suggests a majority of users view fingerprint scans as an acceptable form of personal identification, identification strategies that discourage more than 10% of people from participating in HIV research are contrary to our goals of increasing access to and diversity among HIV research participants. Moreover, if biometric scanning is ultimately implemented in research, it is also important that all participants are informed about the risks, benefits, and uncertainties associated with biometric technologies (e.g., information cannot be linked to criminal or immigration databases due to its lower resolution) to ensure that they reduce barriers to HIV healthcare resources, particularly among marginalized groups. Future studies should also investigate the benefits of using reliable biometric identifiers to promote increased linkage to care among low-income and racial minority populations in various demographic regions, as the perceived stigma surrounding biometrics may vary across the United States.

Conclusions

Asking study participants to provide a form of identification – often times their name and birthdate – is relatively standard within the field of HIV research as part of study registration. The request to verify one's identity – using both traditional methods or new biometric technologies – may be intimidating to some participants who associate their HIV/STI status, drug use, or sexual risk behaviors with stigma or worry about how the data may be used by other entities (i.e., law enforcement, immigration officials). While some existing literature suggests biometric fingerprinting systems are feasible and acceptable for HIV research [22], efforts should be made to ensure that biometric ID verification is done in a way that does not lower meaningful HIV study participation among marginalized populations.

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Appendix

Appendix 1.

Biometrics Survey: Questions and Responses

Biometrics Survey		
Question	Response	N (%)
Question 1: Participant-management software will allow us to provide a summary of all your test results on a protected website. How important is this to you?	1. Not so important	14 (6.8)
	2. Slight important	35 (17.0)
	3. Very important	85 (41.3)
	4. Extremely important	72 (35.0)
Question 2: Participant-management software will allow us to link your records without asking you to use another password or present a barcode card every time you test with us. Which of the following systems would you be willing to use?	1. Fingerprint scanner	79 (38.3)
	2. Palm scanner	6 (2.9)
	3. I don't care, as long as it's not complicated.	80 (38.8)
	4. None of the above, I'd rather memorize another password.	28 (13.6)
	5. None of the above, I am not interested in a person-specific identifier (if checked - skip next question).	13 (6.3)
Question 3: If we decide to use a fingerprint scanner, would this discourage you from free HIV and STD testing with us?	1. Not discourage me at all	160 (77.7)
	2. Slightly discourage me	14 (6.8)
	3. Somewhat discourage me	8 (3.9)
	4. Very much discourage me	6 (2.9)
	5. Extremely discourage me	4 (1.9)

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Table 1.

Description of sample's demographic characteristics and sexual risk behaviors

Characteristic	n (%); N = 206*
Demographic Characteristics	
Race / Ethnicity	
Hispanic / Latino(a)	79 (38.3)
White	77 (37.4)
Asian	20 (9.7)
Black	15 (7.3)
Other / Multiracial	11 (5.3)
Unknown	4 (1.9)
Sex at Birth	
Male	198 (96.1)
Female	8 (3.9)
Gender	
Male	195 (94.7)
Female	8 (3.9)
Trans Female	2 (1.0)
Non-binary	1 (0.5)
Income	
<\$1k /V	28 (13.6)
>\$1k	178 (86.4)
Age	
18–25	31 (15.0)
26–35	98 (47.6)
36–50	48 (23.3)
50+	29 (14.1)
Sexual risk characteristics	
MSM	
Yes	189 (91.7)
No	17 (8.3)
3-month drug use, any^a	
Yes	25 (12.1)
No	181 (87.9) V
Unprotected anal intercourse^b	
Yes	134 (65.0)
No	72 (35.0)
Testing history - ever tested for HIV	
Yes	197 (95.6)

Characteristic	n (%); N = 206*
No	9 (4.4)
Self-reported STI, last 3 months^c	
Yes	10 (4.9)
No	196 (95.1)
Active STI test results; n = 190^d	
Positive	30 (15.8)
Negative	160 (84.2)

^aExcludes cannabis and alcohol.

^bUAI = receptive or insertive anal intercourse; 1 unknown, classified as “Yes ”

^cBacterial STIs: gonorrhea, chlamydia, or syphilis (defined as RPR 1:8)

^dBacterial STIs; Total test only; N = 190 (92.2)

* Total response less than N = 206 for some categories

Table 2.

Discouragement from testing, predicted by demographics and sexual risk behavior

Demographic Characteristic	Discouraged	Not discouraged	Total	Odds ratio ^a	P
Race / Ethnicity				1.6586	0.161
White, non-Hispanic	21 (47.7)	56 (35.4)	77 (38.1)		
Non-White	23 (52.3)	102 (64.6)	125 (61.9)		
Income^b				1.6075	0.32
<\$1k	8 (19.0)	20 (12.7)	28 (14.1)		
>\$1k	34 (81.0)	137 (87.3)	171 (85.9)		
Sexual Risk Characteristics	Discouraged	Not discouraged	Total	Odds ratio ^a	P
MSM				0.750	1
No	3 (6.7)	14 (8.7)	17 (8.3)		
Yes	42 (93.3)	147 (91.3)	189 (91.7)		
Unprotected anal intercourse (UAI)				1.1472	0.291
No	19 (42.2)	53 (33.1)	72 (35.1)		
Yes	26 (57.8)	107 (66.9)	133 (64.9)		
STI diagnosis at enrollment				2.986	0.095
No	40 (93.0)	120 (81.6)	160 (84.2)		
Yes	3 (7.0)	27 (18.4)	30 (15.8)		
3-month drug use^c				1.134	1
No	40 (88.9)	141 (87.6)	181 (87.9)		
Yes	5 (11.1)	20 (12.4)	25 (12.1)		
Sexual Risk Characteristics	Discouraged	Not discouraged	Total	X ² statistic ^d (df)	P
Number of male partners				3.912 (2)	0.141
0	11 (24.4)	22 (13.7)	33 (16.0)		
1-4	25 (55.6)	90 (55.9)	115 (55.8)		
>5	9 (20.0)	49 (30.4)	58 (28.2)		

^aFisher's exact test. Of note, the p-value for the Fisher Exact Test is calculated by permutation directly and not from a probability function to estimate a test statistic.

^bEstimated San Diego poverty threshold per month [26]

^cExcludes marijuana and alcohol.

^dChi-square test for independence.