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Journal

BMJ Open, 13(12)

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Publication Date

2023-12-14

DOI

10.1136/bmjopen-2023-079900

Peer reviewed

BMJ Open

Exploring mobility data for enhancing HIV care engagement in Black/African American and Hispanic/Latinx individuals: a longitudinal observational study protocol

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ABSTRACT

Introduction Increasing engagement in HIV care among people living with HIV, especially those from Black/African American and Hispanic/Latinx communities, is an urgent need. Mobility data that measure individuals' movements over time in combination with sociostructural data (eg, crime, census) can potentially identify barriers and facilitators to HIV care engagement and can enhance public health surveillance and inform interventions.

Methods and analysis The proposed work is a longitudinal observational cohort study aiming to enrol 400 Black/African American and Hispanic/Latinx individuals living with HIV in areas of the USA with high prevalence rates of HIV. Each participant will be asked to share at least 14 consecutive days of mobility data per month through the study app for 1 year and complete surveys at five time points (baseline, 3, 6, 9 and 12 months). The study app will collect Global Positioning System (GPS) data. These GPS data will be merged with other data sets containing information related to HIV care facilities, other healthcare, business and service locations, and sociostructural data. Machine learning and deep learning models will be used for data analysis to identify contextual predictors of HIV care engagement. The study includes interviews with stakeholders to evaluate the implementation and ethical concerns of using mobility data to increase engagement in HIV care. We seek to study the relationship between mobility patterns and HIV care engagement.

Ethics and dissemination Ethical approval has been obtained from the Institutional Review Board of the University of California, Irvine (#20205923). Collected data will be deidentified and securely stored. Dissemination of findings will be done through presentations, posters and research papers while collaborating with other research teams.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The study aims to include a large sample of Black/African American and Hispanic/Latinx (N=400) individuals ages 18 years and over, living with HIV, and with poor engagement in care residing within an Ending the HIV Epidemic county.
⇒ Quantitative and qualitative data and approaches (ie, machine learning models and qualitative interviews/analysis) will be used to explore barriers and facilitators of engagement in HIV care.
⇒ We focus on Black/African American and Hispanic/Latinx communities, which may limit the generalisability of the findings.
⇒ Ethical and privacy concerns surrounding individuals sharing their location might be a challenge in data collection.

INTRODUCTION

In 2021, approximately 1.2 million people in the USA were living with HIV infection.[1] Black and Hispanic/Latinx men who have sex with men are particularly vulnerable to HIV as their risks of acquiring HIV are estimated to be four to eight times higher than their white counterparts,

respectively.[2] HIV prevalence was also found to be higher among Black or Hispanic populations in the USA, according to a study that constructed a mathematical model projecting HIV-related epidemiological outcomes including prevalence ratio, incidence rate ratio and HIV-specific mortality rate ratio.[3] Their engagement with HIV care is also lower according to previous literature. Black and Hispanic groups are more likely to test late for HIV infection, and schedule and attend fewer HIV clinic visits than their White counterparts.[4–6] Hence, there is a critical need to increase engagement in HIV care among people with HIV (PWH), especially those from Black/African American and Hispanic/Latinx communities.

Barriers to HIV care

Previous studies have revealed immediate barriers to HIV care, treatment adherence and retention of care. Fear and emotional burden associated with a serious disease,

perceived stigma against HIV and unawareness of improvements in HIV treatment and its affordability were some of these barriers.[7 8] Distance to care facilities and health providers are additional barriers to both HIV care and prevention services.[7 9]

Mobility data as a solution

Utilising mobility data (ie, aggregate measurement of one's movement over time using a mobile device), a relatively new form of data, may help to address these barriers by improving our understanding of engagement with HIV care and treatment among PWH and provide insights to improve such engagement. According to the literature, distance and location-based data, including mobility data, have proven to be relevant to public health interventions. Such data have been used in several context such as disease surveillance, health support systems, health promotion and disease prevention.[10–13] More recently, mobility data have emerged as a valuable tool for predicting COVID-19 outbreaks at both local and global scales in the USA and other countries.[14–17] In addition, mobility data have been useful for characterising, forecasting and controlling the spatial and temporal spread of other infectious diseases such as Ebola by providing case projections, helping focus resources and interventions and assessing the success of interventions.[18–20] In particular, longitudinal mobility data may be used to improve care for PWH as the data are generated near real time[11 21–24] and are correlated with HIV care barriers (eg, distance from clinics).[25 26] For instance, a study conducted in rural Uganda illustrated that GPS-measured distances to HIV clinics were associated with missed HIV clinic visits. This suggests that such distance and location-based data may want to be prioritised over self-reported measures to optimally risk-stratify patients in their access to care in rural, resource-limited settings.[25]

Therefore, mobility data might prove to be a novel data source that may address limitations of current data on barriers to care such as delays and gaps in collecting survey data. While there exist some studies that have investigated the contextual barriers to HIV care using mobility data, most of them focused on non-US countries (eg, Nepal, India, Sub-Saharan countries, etc).[26–31] Moreover, the effectiveness of using mobility data to better understand contextual barriers to HIV care engagement can be further augmented when used jointly with sociostructural data (eg, crime, census, walkability data) as they have proved to be useful supplements for understanding and predicting various social phenomena such as crime and socioeconomic disparities.[32 33] The development of artificial intelligence (AI)-based models (eg, machine and deep learning models) based on these multifaceted datasets would enable researchers to better pinpoint mobile devices of the desired demographic, increase the accuracy of prediction of HIV care engagement and identify potential geographical hotspots falling out of HIV care.

Challenges in using mobility data

The implementation of mobility data is not without challenges. These include privacy, confidentiality and security concerns as well as more technical and regulatory issues. The use of mobility data, due to its sensitive and personal nature, may benefit from a framework that safeguards privacy and security encroachments.[34–36] Previous literature often discussed the fear of participants regarding the risk of misuse of mobility data in health research.[36] In addition, privacy legislation and restrictions to mobility data vary with location. Therefore, the data-gathering process should abide by location-specific laws such as the California Consumer Privacy Act, the European Union's General Data Protection Regulation and the Geospatial Information Regulation Bill among others.[36–39] Furthermore, challenges exist due to persistent inequities regarding access to emerging technologies. The use of specific models, devices or networks may be a prerequisite for acquiring high-quality mobility data, which are not always equally available for users across all demographics and socioeconomic statuses.[40] On a more technical level, applications that involve mobility data will be built by experts in various disciplines, and, thus, internal communication has to constantly take place to prevent the application from being lopsided towards only one aspect (eg, functioning well but not meeting the needs or demands of the end users).[40]

Study objectives

Hence, this study seeks to investigate the implementation and collection of longitudinal mobility data of PWH in conjunction with sociostructural data (eg, crime, census, walkability data), to develop AI models to better understand contextual factors for low engagement, predict HIV care engagement and improve the effectiveness of current interventions or develop new interventions that will lead to higher engagement with and retention in HIV care. More specifically, the primary aim is to investigate whether GPS mobility data can predict HIV care engagement within the population, as well as other secondary analyses using GPS mobility and neighbourhood data to predict HIV care engagement.

METHODS AND ANALYSIS
Study design

This is a longitudinal observational cohort study of PWH who are at risk of being out of HIV care. The aim is to enrol 400 Black African and Hispanic/Latinx PWH, ensuring a final count of 280 participants postattrition, maintaining a 95% CI with a 5% margin of error. Recruitment will occur over 2 years and each eligible participant will be asked to share their mobility data for 12 months. This study protocol specifically addresses a segment of a broader study planned to run from 24 September 2022, until 30 June 2027. The study will create an illustrative map of the participants' daily mobility patterns through consistent monitoring of their mobile device and use
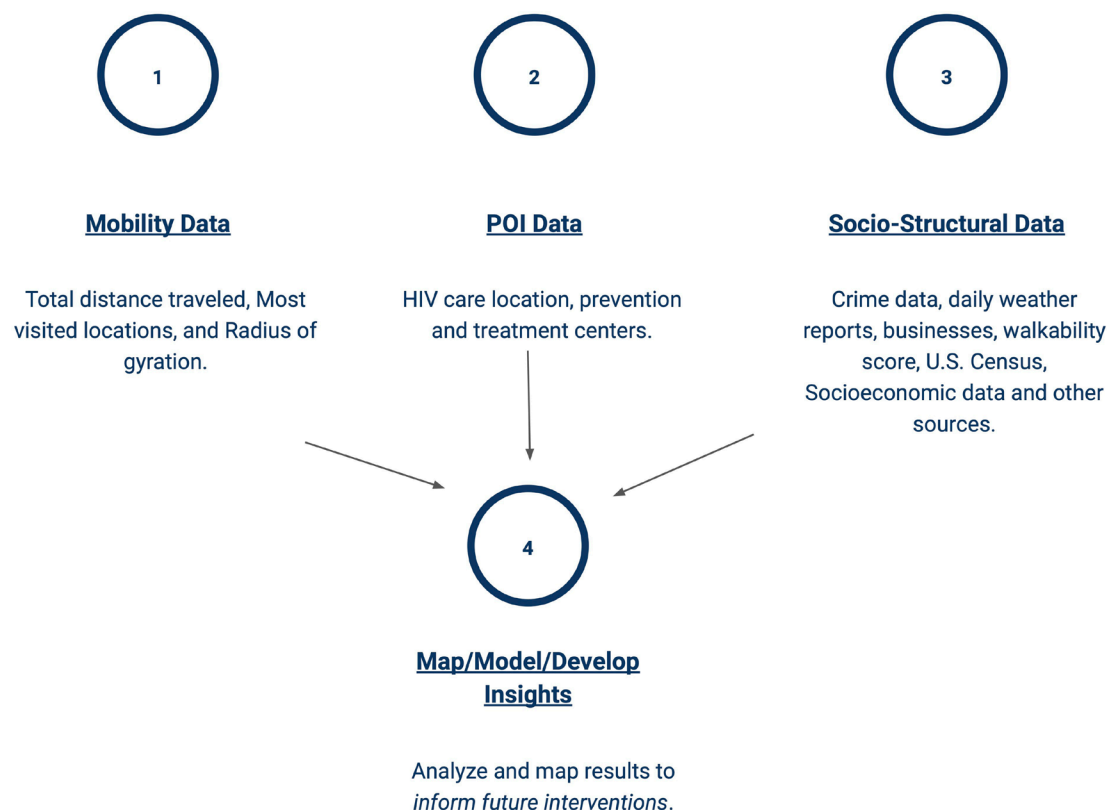
Figure 1 Project outline.

mobility data along with accompanying sociostructural data (eg, crime, census, walkability data) to predict their engagement in HIV care. Each participant will be asked to share at least 14 consecutive days of mobility data per month via the study app for a year. The study app will collect continuous GPS data with each participant being identified through their email and the unique mobile advertisement ID (MAID) of their device. In developing an illustrative map of participant mobility patterns, our study aims to identify geographical contexts that may interfere with individuals' ability to receive consistent HIV care. Patterns such as frequency of contact with clinical settings (eg, HIV care location, substance use prevention/treatment centres), time spent outside their home, miles travelled and risk environments will be evaluated to identify their engagement in HIV care. Community data on crime, substance use locations and socioeconomic data within neighbourhoods will also be analysed to learn contextual predictors. The study proposes the development of a comprehensive mapping tool that will draw associations between HIV care and mobility patterns. This will inform the development of a valid and reliable tool for assessing important contextual barriers to engagement in HIV care. Figure 1 illustrates a project outline of the primary objectives of this study: first, ongoing collection of mobility data along with other data streams, and second, map development to generate insights into mobility patterns using AI models.

Recruitment

Participants will be recruited via social media advertisements (eg, Facebook, Grindr and Craigslist). Online advertisements will be developed in conjunction with industry partners (eg, Cphere Digital Communications) that will assist in identifying devices owned by individuals who fit the demographics we seek to recruit. To recruit individuals who are not currently receiving HIV care, we will use two deidentified data sets that comply with the Health Insurance Portability and Accountability Act (HIPAA) regulations. The first data set will contain marketing advertising IDs and smartphone GPS mobility data. By analysing mobility histories, we can identify behaviours and risk factors based on frequented locations, such as hospitals and pharmacies. The second data set will contain aggregated US Census demographic information linked to likely home locations. We will match identified home locations to these demographics to further refine our targeting. By combining mobility patterns, pharmacy and healthcare utilisation, home Census demographics and marketing advertising IDs, we can build profiles to accurately target advertisements on social media platforms to our desired demographic. The use of these specific digital signals will allow us to reduce recruitment costs and validate social media as an effective recruitment tool for this population.

Participants

Interested individuals will click on a link in the social media advertisement and proceed to fill out an online

form, expressing interest and providing initial eligibility details. Study staff will then conduct a full eligibility screening by phone, asking questions to confirm that inclusion/exclusion criteria are met. Only those meeting all criteria during the phone screening will be enrolled. Participants must satisfy all inclusion criteria: (1) 18+ years of age, (2) Black/African American and Hispanic/Latinx, (3) PWH, (4) residing within an Ending the HIV Epidemic county,[41] (5) reporting one or more risk factors associated with and predictive of poor engagement in HIV care in the past 12 months[42 43] and (6) willing to download the study app on their personal mobile device.

Measurement procedures

On confirming eligibility, participants will be invited to download and install the study app on their smartphones. This app passively collects geolocation data that will allow the research team to track mobility patterns.[44] Participants will create an account on the app using their email address, which will be used as means of communications for the study. Over the 12-month study period, participants will complete online surveys at regular intervals (baseline, 3, 6, 9 and 12 months) to provide information on technology use, HIV beliefs and social networks. Surveys, hosted on Qualtrics, will be distributed via email (currently available in English with a Spanish version in progress). These surveys address various topics related to HIV care engagement and risk factors,[42 43] covering many of the performance measures from HRSA,[45] including (1) visits: not attending an HIV care appointment in the past 12 months (including telehealth), (2) viral load: detection of the most recent viral load or reports of no viral load test in the past 12 months, (3) Antiretroviral therapy (ART) : reports of not being on ART or poorly adherent (<70% pills taken in the past 30 days). In addition to these, we inquire about general health, mental health (eg, GAD-7 and PHQ-8) and explore substance use and internet behaviour. Subsequently, we will conduct qualitative interviews with participants and stakeholders (eg, providers, health departments). Interviews will gather feedback on how these data types could enhance public health surveillance and HIV care. Interviewees will receive compensation for their time.

Compensations

To incentivise ongoing participation, we will provide compensation for survey completion on the following schedule: $30 USD for baseline, $40 USD for months 3, 6 and 9, and $50 USD for month 12. Additionally, participants will receive $10 USD each month for keeping the study app active on their phone for at least 14 consecutive days. The study team will monitor app activity and notify non-compliant participants.

Mobility App

The study app (Mobility App) is publicly available on Google Play[46] and App Store.[47] The app uses activity recognition sensors and GPS receivers to continuously track movement (ie, longitudinal GPS coordinates) with ~5 m accuracy while having minimal effect on the battery life and performance of participants' phones.[44] This allows for reliable and passive geodata collection over 14 consecutive days each month. The study app has been rigorously tested to ensure continuous geolocation tracking and collection of high-quality data, accounting for gaps in trajectories and computing the mean accuracy of the collected data points. Additionally, a qualitative study[48] was conducted to evaluate the ethical and privacy concerns of 30 individuals who installed the study app on their phones and used it for a 48-hour period as a feasibility sample of the longer goal plan (ie, 14 consecutive days each month over a 1-year period). The insights gained from the qualitative study have been incorporated into the latest version of the study app. Most participants stated that they did not notice major changes in their battery level and phone performance and the study app did not interfere with or impact their normal phone usage. They also shared that they forgot the study app was running on their phone in the background, after a few hours of enrolling in the study and sharing their location with the study app.[48] The study app also collects the MAID, which is a unique ID used by advertising agencies to identify the individual's device that can later be used to send targeted messages using ad platforms. If a participant shuts off, restarts their phone or closes the app, the research team will send them a reminder to their phone to notify them that they need to allow data collection again or they will lose their consecutive days of data sharing, which might make them ineligible for compensation for that month. After the completion of the year, users will be emailed letting them know the study is over and that they can delete the study app from their phones. Figure 2 provides screenshots from the latest version of the study app.

The study app will provide detailed information about the study, including the study information sheet. Contact information for the study team will also be readily available within the app, allowing participants to easily reach out with any questions or concerns. Additionally, the app will have a progress tracker that allows participants to monitor their consecutive days of location tracking. This tracker will show their progress towards the 14 consecutive days required each month to receive compensation. Features like the study information, contact resources and progress tracker aim to keep participants fully informed while supporting their sustained engagement.

Patient and public involvement in user experience testing of the app

As part of a different study, participants with opioid use disorder (OUD) were involved in the initial feasibility and acceptability assessment of the study app during the development process. This involvement aimed to refine the app development. We include this information as we believe the stigma and chronic nature of OUD has some similarities with HIV. Insights obtained in the study[48]
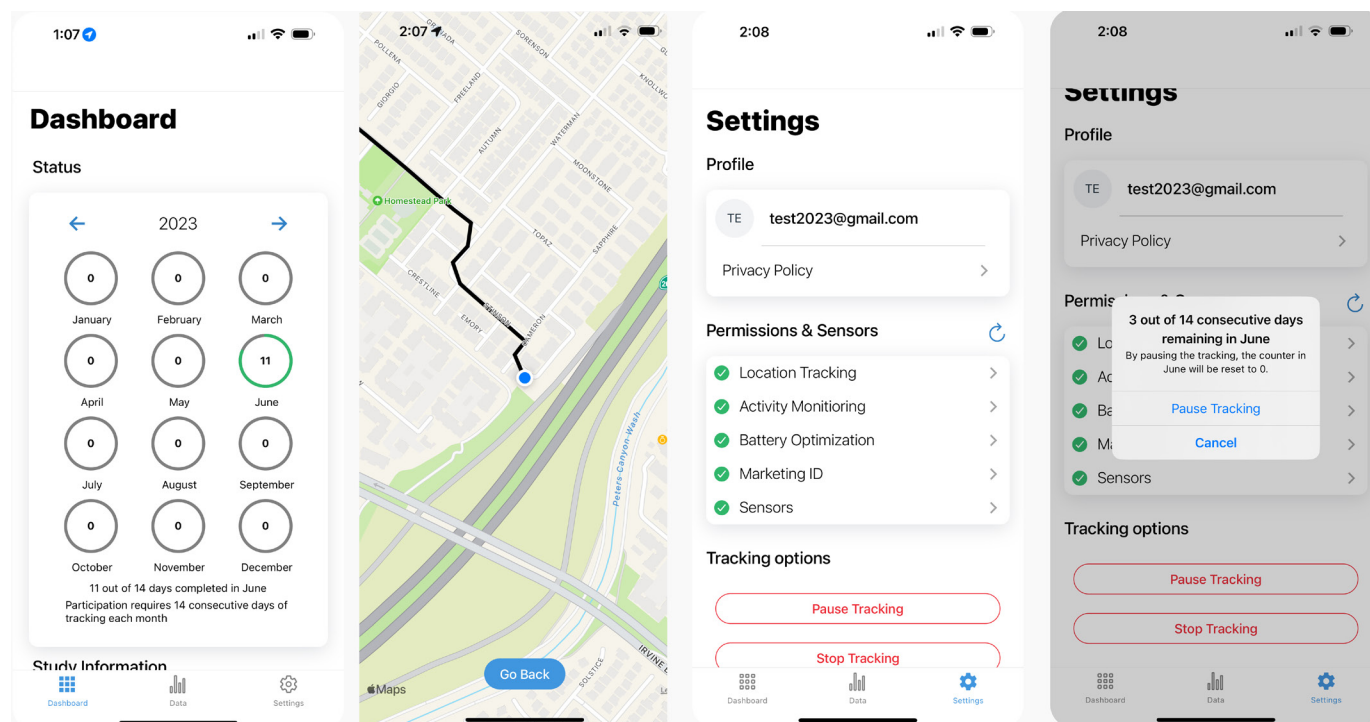
Figure 2 Mobility App screenshots (from left to right: dashboard stating the number of consecutive days per month that participants shared their location data; a snapshot of their mobility path; setting page to control different features; warning to stop/start location tracking).

from two interviews with participants at baseline and after 48 hours of using the app regarding functionality, privacy concerns, battery conservation, ability to directly manage location sharing within the app and the overall 48-hour experience have been integrated into the latest version of the study app. After experiencing the app for 48 hours, participants were also asked about their willingness to participate in a year-long study, aligning with this protocol. Notably, most participants (25 out of 30) expressed interest in this extended study. Research questions, carefully crafted by an experienced, multidisciplinary team, have been informed by their field expertise and insight gained from the interviews. Participants were not directly involved in the design, recruitment or conduct of the study. We believe that the incorporation of patients with OUD in the app design has helped to improve the likelihood that the app being used in this study will be found acceptable and align with ethical principles. Furthermore, the current study incorporates interviews with both participants and stakeholders, including HIV care providers, to assess the ethical implications and effective implementation of utilising mobility data to enhance engagement in HIV care.

Data collection and integration

Mobility exposures: these data will be used to generate mobility metrics such as total distance travelled, most visited locations and radius of gyration, which measures the average distance a person travels from their most frequent location, such as home or work. Moreover, mobility data will be merged with point of interest (POI)

data, a list of specific locations that represents a place such as a landmark or business,[49] to create a timeline of the locations/POIs visited by the participants. The POI data will be compiled from databases of businesses, landmarks and other venues. For this study, the POI data set will be static, meaning it will not change over the course of data collection. This will allow for consistent identification of location types visited by participants throughout the study period. For instance, to capture the impact of such exposures on engagement in care and to determine whether participants visited or were near HIV care locations, we will merge the user's trajectory with geocoordinates of HIV-related facilities, such as substance use prevention/treatment service locations, locations of violent crimes, daily weather reports, business, walkability, US Census and other data sources that can be linked to participants' GPS path. These data can be aggregated at the participant level to calculate the frequency and time of the day when the participant visits these locations. The mobility data will also be merged with Census data to calculate the socioeconomic attributes associated with the locations visited by the participant. Daily mobility trajectories, mobility metrics and socioeconomic attributes will be measured to study the statistical relationship between these variables and HIV care engagement.

HIV care engagement: predicting HIV care engagement is the primary aim of this study; thus, measuring this dependent variable is crucial for conducting the analysis. While clinical validation is the preferred benchmark, considering the national distribution of participants,

verifying clinic attendance would not be feasible. Our definition of HIV care engagement entails consistent attendance at HIV care appointments and adherence to HIV medication, as reported by participants in the surveys. We will also use the survey responses as gold standard data to validate the GPS data. For example, greater consistency in HIV care is expected to correlate with a higher number of visits to healthcare facilities. We plan to measure HIV engagement using two methods: (1) surveys (baseline, 3, 6, 9 and 12 month), which are required as part of the study participation and 2) frequency of matching participant's location to an HIV care facility.

Analysis plan

The proposed study follows a mixed methods framework aimed at merging qualitative and qualitative data to assess HIV care engagement. Quantitative data are used for the primary analysis, with qualitative interview data used to help support the analysis and understand potential barriers to implementing the findings in real-world settings. We intend to collect mobility data from each participant for a minimum of 14 days per month over 1 year.[50] The study app collects latitude and longitude data and sends it to the database along with the MAID and email address. The collected data will be encrypted in transit and securely stored in HIPAA-compliant cloud-based databases (eg, AWS DynamoDB[51]). The data can be accessed securely by researchers using encrypted pipelines and is aggregated at the individual level.

Based on the combined data, we plan to undertake a variety of analytical methods. Initially, we will use descriptive statistics to study factors such as demographic variables, engagement in HIV care, and mobility metrics. Moreover, we will carry out inference-based analysis, where we will study the impact of mobility-related factors on access to HIV care and controlling for demographic variables to account for confounders.

We intend to use or develop a range of standard statistical and machine learning models like generalised linear regression, LASSO, and decision trees. These models will help us to use GPS data to predict engagement in HIV care. The chosen can help identify which demographic or mobility factors are most strongly associated with better engagement in HIV care. In addition, we will conduct spatial analysis, a method used to study the geographical distribution of HIV care engagement and mobility patterns.[52] Through machine learning clustering-based techniques, we will identify areas or clusters where individuals are more likely to fall out of HIV care. Spatial analysis involves mapping to visually comprehend the variations in HIV care engagement across different locations.

We also plan to utilise advanced deep learning models to perform similar predictions but with potentially higher accuracy. Deep learning is a form of AI that allows computers to learn from data and improve over time.[53] Specifically, we plan to generate models based on Long Short-Term Memory (LSTM) models, which are capable of understanding and remembering patterns over time.[54]

This is particularly useful for analysing sequences of data, like tracking the mobility and healthcare engagement of individuals over a period. Moreover, we will include other relevant health outcome measures such as mental health, both as covariates and as secondary outcomes. This will help us explore the relationship between mobility and health outcomes among the participants.

We intend to further examine the variations across space and time. Our initial step will involve the calculation of both descriptive and bivariate mobility statistics, such as the percentage of time spent in different kinds of places. Subsequently, we will use both standard and multilevel regression techniques to manage recurrent measures over time for each participant as well as variables that vary over time and space. This also involves considering spatial autocorrelation, which can introduce bias into effect estimations and SD. If we detect spatial autocorrelation, we will deploy spatial regression models, specifically when linking exposures with spatial correlation. We will factor in space and time by distinguishing between travel duration and time spent at a particular location to calculate the exposure based on the time spent at a given location. Our longitudinal models will initially incorporate subject-level random effects for recurring measurements of subjects. For binary outcomes, such as HIV care engagement/dropout, we will use mixed-effect logistic regression. For count data, such as the number of visits to HIV care facilities, we will use mixed-effect Poisson regression and/or negative binomial regression. The mediation effect between the total distance travelled by the participants and HIV care engagement will be explored using estimates that consider the hierarchical structure of the data.

The results of this longitudinal study are expected to inform the development of interventions. These interventions will use new forms of data (mobility data) aimed at increasing care among PWH who are at risk of dropping out of care. Mobility data can offer insights into behavioural patterns and access to resources, potentially highlighting barriers to consistent care such as geographical distance from clinics or lack of transportation. With these insights, more targeted interventions can be developed to ensure consistency in care.

Qualitative interviews

We plan to conduct semistructured online interviews with HIV care providers, health department staff and PWH from Washington D.C. (an East-coast community with a predominantly African American population) and Orange County, California (a West-coast community with a primarily Latinx demographic). The aim is to gain a deeper perspective on barriers and facilitators to implementing the proposed approach for scaling-up timely detection of HIV care disengagement and integrating it into their future epidemiologic and programmatic efforts. We will ensure diversity in terms of age, race/ethnicity and geographic location by strategically targeting specific demographics in online recruitment. This process will

enable us to apply the approach of creating personalised advertising campaigns, drawn from the practices in digital advertising and other health domain efforts, tailored to specific demographic characteristics such as age, gender, location, to the field of HIV. It also aims to investigate ethical concerns related to using data and machine learning algorithms in analysing the exposure of HIV patients and its impact on their HIV care engagement.

Our analysis will use the qualitative data collected through interviews with participants and stakeholders. The analysis will focus on understanding the implementation and potential ethical issues of using this outreach approach and data collection method to increase engagement in care among Black/African American and Hispanic/Latinx living with HIV. Analysis of qualitative data will include both a real-time review of incoming data and formal coding of the data set. Interview field notes and observations will be collected and examined to identify the core themes emerging from the interviews. The study team will prepare transcripts of completed interviews and code them for content analysis using modified grounded theory. These findings will be reviewed with study investigators during weekly meetings.

ETHICS AND DISSEMINATION

This work follows a protocol reviewed and accepted by the Institutional Review Board of the University of California, Irvine (approval number #20205923) before the start of the study.

We do not anticipate any harm as a direct consequence of participating in our study. On completion of the initial survey, we will be passively collecting mobility data and participants will not be asked to modify their behaviour. Participants will be individuals who are at least 18 years of age and will freely consent to take part in the study during our recruiting process. We can expect some possible discomforts associated with a potential breach of confidentiality. To mitigate this, participants will be fully informed about the objectives of the study, the data collection process and how we plan to maintain their data privacy. All participants will voluntarily agree to enrol in the study, and they will be made aware of their ability to rescind their participation at any point.

A third-party digital marketing company will provide us with participants' MAID when reached out by our advertising-triggered survey. The digital marketing company will not have access to our survey data and/or participants' information. Participants who choose to install the study app will grant access to their mobility data during the installation process and throughout their enrolment in the study. All location data and mobility patterns, as well as survey data regarding our participants' location, demographics, health-related conditions, behaviours and socioeconomic status, will be de-identified and securely stored in cloud-based platforms (eg, AWS DynamoDB).

Previous research has shown how economic incentives can significantly alter survey recruitment[55] and responses.[56] However, we do not ask participants to modify their behaviour. Therefore, we do not expect that providing compensation will affect our data collection process. Nevertheless, it remains an ethical concern regarding whether participants, who accept enrolment, may factor the economic incentive in their decision.

Finally, our data dissemination will only include deidentified data sets when collaborating with our partner research teams (University of South Carolina, George Washington University, Florida State University and Tulane University). We expect to contribute to the literature via posters, presentations and research papers based on the findings of this study.

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