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Ethical considerations and potential threats to validity for three methods commonly used to collect geographic information in studies among people who use drugs

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Abstract

Background—Analyses with geographic data can be used to identify “hot spots” and “health service deserts”, examine associations between proximity to services and their use, and link contextual factors with individual-level data to better understand how environmental factors influence behaviors. Technological advancements in methods for collecting this information can improve the accuracy of contextually-relevant information; however, they have outpaced the development of ethical standards and guidance, particularly for research involving populations engaging in illicit/stigmatized behaviors. Thematic analysis identified ethical considerations for collecting geographic data using different methods and the extent to which these concerns could influence study compliance and data validity.

Methods—In-depth interviews with 15 Baltimore residents (6 recruited via flyers and 9 via peer-referral) reporting recent drug use explored comfort with and ethics of three methods for collecting geographic information: (1) surveys collecting self-reported addresses/cross-streets, (2) surveys using web-based maps to find/confirm locations, and (3) geographical momentary assessments (GMA), which collect spatiotemporally referenced behavioral data.

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Results—Survey methods for collecting geographic data (i.e., addresses/cross-streets and web-based maps) were generally acceptable; however, participants raised confidentiality concerns regarding exact addresses for illicit/stigmatized behaviors. Concerns specific to GMA included burden of carrying/safeguarding phones and responding to survey prompts, confidentiality, discomfort with being tracked, and noncompliance with study procedures. Overall, many felt that confidentiality concerns could influence the accuracy of location information collected for sensitive behaviors and study compliance.

Conclusions—Concerns raised by participants could result in differential study participation and/or study compliance and questionable accuracy/validity of location data for sensitive behaviors.

Introduction

The socio-structural environment impacts risk behaviors for HIV transmission and use of preventative/treatment services.^{1–6} Aspects of the built and social environment (e.g., transportation, availability of health services, poverty, residential racial segregation, social capital) can shape disparities in HIV prevalence and incidence, retention in care, and other adverse consequences of substance use.^{7–15} Among people who use and inject drugs (PWUD; PWID), higher risk drug use behaviors and decreased health service use have been linked with laws/policies that influence the availability of HIV prevention services and products.^{1,5,9,16–27}

Analyses that incorporate geographic data are increasingly used in HIV and substance use research to: (1) identify “hot spots” of diseases, risk behaviors, and other health outcomes and “health service deserts” (i.e., areas with decreased availability of/access to health services); (2) understand the influence of proximity to services (i.e., clinics^{28,29}, drug treatment^{14,15,30}, syringe exchange services^{26,31–37}) and their use; and (3) link contextual factors with individual-level data.⁹ Given the importance of accurate geographic data for understanding environmental influences on individual-level risk behaviors and health service use, new methods are continually being developed to collect more valid and contextually-relevant data.

Methods for collecting geographic data include: (1) surveys that elicit self-reported addresses/cross-streets, (2) web-based surveys that use mapping application program interfaces (APIs) to allow participants to find/verify locations on interactive maps, and (3) geographical momentary assessments (GMA), which collect spatiotemporally referenced behavioral data via applications for GPS-enabled smartphones. Because people spend significant periods of time away from home and often engage in risk behaviors at other locations, a variety of approaches have evolved to more accurately assess the “risk environment”. For example, some researchers ask participants to provide addresses/cross-streets for a variety of different locations; however, this approach is prone to missing data, data entry errors, and responses must be geocoded. To address some of the limitations of this approach, some researchers now use web-based surveys with mapping APIs that allow participants to interact directly with a map to identify/confirm locations. One advantage of this method is that it automatically geocodes location information which results in fewer

data entry errors; however, typically only one location is recorded for each behavior (e.g., where a behavior occurs *most often*). This approach is limited as it results in static assessments of “risk environments” and the accuracy of the data collected depends on participant recall and willingness to report locations of illegal/stigmatized behaviors. GMA permits the simultaneous collection of location data (via a GPS device) and behavioral data (through ecological momentary assessments, or repeated samples of participants’ behaviors/experiences in real-time). GMA participants carry GPS-enabled devices (e.g., smartphones) and behavioral data is collected through random and event-based surveys completed using a smartphone application. Participants must complete random surveys several times each day and “event-based” entries are initiated by participants when engaging in specific behaviors. The result is a time-stamped map of daily movements and behaviors. GMA is thought to collect more valid data which can be used in analyses that account for exposures to multiple risk environments and for varied amounts of time.^{38–40}

However, technological innovations in data collection have outpaced the development of ethical standards and guidance⁴¹ and it is unknown whether the scientific benefits of GMA outweigh potential participant harms among populations engaged in illicit/stigmatized behaviors. Consequently, there is a need to empirically evaluate the balance between privacy/confidentiality concerns associated with each method and the accuracy/validity of the geographic information obtained through each. Several studies have evaluated the feasibility and acceptability of GMA among substance using populations (i.e., participation and phone-return rates),^{40,42} a few studies have noted concerns regarding privacy, confidentiality, data security, and the intrusiveness of GPS tracking among populations not engaging in illegal behaviors,^{43–45} and the few papers that have examined potential ethical concerns associated with data collection methods among populations engaged in illegal behaviors have been from the researchers’ perspective (i.e., physical harm and psychological stress associated with safeguarding phones, confidentiality/privacy breaches,^{39,46} unauthorized data access⁴⁷). Thus, there is a need to empirically examine participants’ privacy/confidentiality concerns among populations engaged in illegal/stigmatizing behaviors and the influence of these concerns on data validity and this paper fills this gap. Findings from our paper can be used by future researchers to develop research protocols that mitigate participant concerns and that collect information in a way that maximizes both the quality of the geographic information and the validity of the behavioral data.

Methods

Between November 2014 and April 2015, we recruited a total of 15 Baltimore residents (n=6 via flyers posted in a research office currently conducting studies among persons who use drugs, most of whom are HIV positive and n=9 via peer-referral by those already enrolled in our study). Study eligibility included self-reported heroin, crack, or cocaine use (past 6 months). As the purpose of this study was to assess ethical considerations for the collection of geographic information in HIV and substance use research from the participants’ perspective, we aimed to recruit a sample which was diverse with respect to HIV and experience participating in research studies, as both of these aspects were hypothesized to influence participants’ perspectives. Following phone screening, eligible participants were scheduled for an in-person interview appointment within two weeks.

Participants provided written informed consent and were compensated for their time (\$40). All study procedures were reviewed and approved by the Institutional Review Board [Institution blinded].

A semi-structured interview guide was developed with input from a community advisory board comprised of three Baltimore community members with an intimate familiarity with the local drug use scene and the problems affecting people living with HIV. The interview guide focused on the following data collection methods: 1) eliciting addresses/cross-streets, 2) web-based maps, and 3) GMA (Figure 1). The framework that guided the conceptualization of this study and informed the selection of domains and development of a semi-structured interview guide containing open-ended questions was the International Ethical Guidelines for Biomedical Research Involving Human Subjects.⁴⁸ After describing each method, open-ended questions explored issues relating to beneficence, confidentiality, and privacy for each data collection method, independently. Of note, all participants were asked for their perspective regardless of whether they had prior experience as a participant in that type of research. Participants lacking prior experience with a method were asked to describe how they *would feel* or how they thought *most people in the community would feel*. For each data collection method, participants were asked whether they thought any of the concerns mentioned would influence anticipated study compliance or the accuracy of responses provided. After the interviewer described a certificate of confidentiality, participants were asked how this additional protection could influence their concerns.

Interviews were recorded, transcribed, and coded deductively using the domains from the interview guide and inductively to include other emergent themes.⁴⁹ Two independent coders hand-coded the transcripts, reviewed each other's code applications, resolved discrepancies, and then updated the codebook and re-coded as necessary. For each category, themes were analyzed in terms of the similarities and differences in participants' perspectives for each of the different geographic data collection methods.⁵⁰ Representative quotes were selected to illustrate key themes.

Results

Most participants were male (73%), Black (87%), HIV positive (67%), did not own a cell phone with a data plan (53%), and had previously been arrested for a drug-related offense (87%)(Table 1). Sixty percent previously participated in a study where location information was collected via cross-streets, 53% where web-based maps were used, and one person was previously in a GMA study. In the past 6 months, crack was the most commonly reported drug used (93%), followed by heroin (67%); two individuals reported recently entering drug treatment.

Interviewer-administered surveys (cross-streets/addresses and web-based maps)

Confidentiality concerns associated with providing location information—

Most participants reported “no concerns” with providing location information to an interviewer using surveys that collected cross-streets/addresses or that used web-based maps. This may be related to prior research experience or comfort with their lifestyles, as exemplified below:

“I’ve been doing these studies for years, so I have no problem letting the community know what I did.”(PID 103)

“Whatever it is that I do on a daily basis, or how I live my life, I’m okay with it. And I’m not worried about someone else finding out that I use drugs or I’m HIV positive or I’m gay. I just don’t care.”(PID 018)

Others expressed concern regarding providing information for locations where they engaged in sensitive behaviors (e.g., purchasing/consuming illicit drugs) but explained that providing cross-streets rather than exact addresses would make them more comfortable: “I wouldn’t want to give them my exact address, but the cross-streets...I would feel comfortable with that.”(PID 001) Many participants also remarked that they would feel even more comfortable providing this information in studies with a certificate of confidentiality. According to one participant, having a certificate of confidentiality would “put the [participant] at ease, and give [him/her] more willingness to share information and be truthful” (PID 008). Overall, there were very few major concerns regarding confidentiality with the first two methods, and comfort increased when methods were thoroughly described during the informed consent process and the researchers had obtained a certificate of confidentiality.

Accuracy of reported location information—Participants explained that the sensitivity of the behaviors measured could affect the accuracy of the location information provided. As described by PID 001:

“That would be kind of a sticky situation...If there’s an option of skipping [the question], they would probably skip it, but nine times out of ten, they’re not going to give the right answer...From personal experience, I’m not going to tell nobody where I buy no drugs at, or use drugs for fear of if I tell somebody where I buy [drugs] from...somebody going to send the police there, and that’s the code between drug sellers [and] drug users, you know, you don’t tell. You don’t say nothing.”

Several participants noted that compared with providing cross-streets, using a web-based map to find/verify locations could improve the accuracy of the information provided. As described by PID 028: “You’ve got the landmarks. It’s going to help...you could see a particular landmark right there, or a certain point you’re looking for, like the market, or a little corner store...it [would be] easy.”

GMA-related concerns

Although only one person had previously enrolled in a GMA study, all participants were provided information about GMA studies and participant expectations before they were queried about the things they would consider when deciding whether or not to participate in a GMA study. The potential harms/benefits of participating in GMA studies were distinct from those mentioned above for survey methods and included: (1) burden associated with carrying/safeguarding study phones and responding to survey prompts, (2) confidentiality concerns, (3) concerns with being tracked, and (4) lack of compliance with study procedures.

Concerns regarding carrying and safeguarding GMA study phones—

Although many participants stated that they would feel comfortable carrying study phones, some indicated that carrying, safeguarding, and keeping track of phones would be a burden. PID 018, who previously participated in a GMA study, explained:

“If someone has a gun or something like that, a weapon, I would freely give it up...people are crazy. They will try to hurt you, even for this [phone]. They’ll snatch it out of your hand.”

Some without GMA experience worried about keeping the phone out of others’ reach, “always having to keep a watch on it, that it’s safe, you know, not setting it down, not putting it...where it’s reachable.” (PID 011) Others described concerns about bringing it with them when they were using drugs or around other PWUD: “If I’m with somebody getting high on some heroin [or] smoking crack [I’d worry] because they got the ‘thieveness’ in them where they want to steal something and sell it just to get some more [drugs].”(PID 026)

Burden of responding to survey prompts in GMA studies—One participant without GMA experience viewed responding to prompts to take surveys on the phone as “no more burden than a person texting me” (PID 013). Two others without GMA experience indicated that completing surveys on the phone could be less burdensome than going to a study office. However, most participants without GMA experience indicated that receiving survey prompts would be “annoying” or could make them feel uncomfortable. As described by PID 014, “I don’t think I’d be very comfortable having the phone with me and then having to answer questions like where I’m at.”

Concerns regarding the confidentiality of location and behavioral data collected on GMA phones—Participants explained that they trusted researchers to protect their information: “the police can’t make you give it to them, [so] there’s no risk in it for me”(PID 019); however, several without GMA experience did not trust technology because “technology has a tendency to fail, and when it fails, other people wind up with your information”(PID 011). Similar to the first two methods, some were concerned that the police might gain access to information about “where I go and when I’m using [drugs] and the places I go to because the things I do are illegal”(PID 022).

Others without GMA experience mentioned potential harm to them or their family as a result of being seen with the phone. As described by PID 022: “[Drug dealers] could see it as just a regular phone, but [being] on the phone while I’m trying to deal with them, you know, it just wouldn’t look right...it would trigger [that] something [is] going on with me and [could] bring me harm [or] bring harm to my family.” Some also speculated that being seen with study phones could also signal to family/friends that a participant was using drugs:

“Somebody who’s not aware that you’re using drugs...[that] could be devastating...[my family] knew of [my drug use] at one time, [and] I became less than a person...but, I won all that back. For them to find out that I was even using drugs once or twice or periodically, they’d start treating me in a bad way [and] I would hate that. It would be most hurtful.”(PID 011)

However, others without GMA experience felt that phones would go largely unnoticed due to the ubiquitous nature of mobile technology: “Everybody has a phone these days...I know people with two and three phones on them...so for you to pull out a phone wouldn’t be something strange.”(PID 008)

Concerns associated with being tracked—The most striking difference between GMA and the survey methods was the tracking aspect. Most expressed concern about being monitored “twenty-four-seven,” which some likened to being tracked while on parole: “Just the thought of being tracked for a long time...When you’re using drugs, you’re doing wrong for a long time, you don’t want nobody to know every move you make, somebody watching your every move.”(PID 001) Others feared being seen as a “snitch” by friends/acquaintances who were “dirty,” and one participant simply stated, “I think this is a total invasion of privacy.”(PID 011) Although PID 023 was not worried about himself being tracked, he worried those around him might be concerned: “I would tell them that I’m being tracked... [it’s] up to them if they still want to be around me...if they don’t want to be around me, they know to leave...Or I’ve got to get away from them...But I would think that they will be concerned about that.” Still, a few participants were not at all concerned about being tracked: “I ain’t got no problem with it tracking me because I know I don’t do nothing wrong.”(PID 028)

In contrast, two participants without prior GMA experience expressed an interest in participating in future GMA studies. According to PID 021, “I could provide some precise information...you can hit me anytime and say, ‘Hey, what’s going on?...instead of comin’ into someplace one time...this is real-time.” PID 023, who had recently enrolled in a drug treatment program, explained: “I would be very interested...I’d be more aware of what I’m doing and knowing that I have something--I guess you’d call it monitoring me...Maybe that’s what I need...I feel that it might help me.”

Lack of compliance with GMA study procedures—Many without GMA experience thought it would be difficult to respond to self-initiated or random prompts to complete surveys while high/getting high, as explained by PID 001: “If they in the middle of using drugs, they not going to stop doing what they doing. I know I wouldn’t...that drug is going to come first.” PID 008 elaborated:

“A lot of these drugs make you very paranoid. And even if that [phone is] on vibrate, you already know who’s calling, and you already know what they want you to do, answer some questions. If I’m getting high, I don’t have the time for that... Sometimes it takes you hours to get yourself back together before you can even handle something, and I think people in the shooting gallery, somewhere like that, if the phone rang or vibrated, I don’t think they would stop and answer it. Because you’re more occupied in getting high.”

If in the middle of preparing/using drugs, several without GMA experience indicated that they would wait for a more convenient time to take the survey: “I would probably read it and not answer right then or just wait until after I copped, and then look at the phone, to be honest.” Others said they would turn the phone off, disable it, or leave it at home to prevent sensitive information from being collected:

“[If] I have the phone on me and I’m indulging, I would probably turn the phone off or take the battery out...sometimes you get a little paranoid when you think ‘somebody’s going to get me.’ I just wouldn’t be comfortable. I would definitely dismantle it before I got high.”(PID 014)

“It’s just as easy to leave it at home...if the individual has to be honest about what he’s going to do, whether he’s going to continue to carry it on a daily basis or whatever...if I didn’t want nobody to know I was buying drugs today, then I just wouldn’t take the [phone] with me.”(PID 008)

Discussion

Using the International Ethical Guidelines for Biomedical Research Involving Human Subjects as a guide, in-depth interviews with PWUD identified participant concerns related to (1) comfort with providing location information, (2) privacy (i.e., concerns specific to being tracked or providing exact addresses), (3) confidentiality (i.e., concerns about who might get access to the information provided during the interview), and (4) anticipated harms related to study participation (i.e. repercussions resulting from friends, family members, dealers, or police learning of their study participation). The specific concerns varied according to the particular method used to collect geographic information on substance use. With interviewer-administered survey methods (i.e., cross-streets/addresses and web-based maps), participants’ concerns were primarily related to confidentiality of exact locations for sensitive behaviors. Providing cross-streets rather than exact addresses was an acceptable alternative for most; however, some felt that participants might provide misleading locations to protect the confidentiality of specific locations rather than skipping questions. For this reason, non-sensitive locations are more likely to be collected without bias. To avoid misleading conclusions about the “risk environment” derived from data collected using these methods, future studies engaging the target population are needed to identify more acceptable ways to accurately ascertain location information for sensitive behaviors.

Concerns specific to GMA included the burden associated with carrying/safeguarding study phones and completing surveys, confidentiality concerns, and discomfort with being tracked. Most prior research with substance using populations has focused on GMA acceptability and feasibility and none has focused on ethical considerations for collecting this information among PWUD from the participants’ perspective. In the few existing studies among persons not using illicit drugs (i.e., HIV positive mothers⁴³ and in studies examining the role of human movement in dengue transmission⁵¹), similar ethical concerns were noted; however, these studies did not assess concerns related to the locations of illicit behaviors or evaluate the potential impact of participants’ concerns on anticipated compliance with study procedures or the accuracy of the location information provided. Furthermore, by including individuals who had not previously participated in a GMA study, we were able to ascertain perspectives from those who may have refused to participate and whose perspectives would not have been included in previous research. Concerns regarding GMA resulted in many participants feeling that they (or others) would be unwilling to participate or comply with study procedures (i.e., carry the device at all times, respond to survey prompts, initiate

event-specific entries). Others indicated that they would take measures to prevent sensitive information from being collected such as intentionally disabling devices or leaving it at home. Differential participation and study compliance could result in both selection bias and information bias. More research is needed to better understand how those who would be likely to participate in a GMA study differ from those who would not (and similarly how those who would and would not comply with study procedures may differ), as the generalizability of study findings may also be limited.

Finally, a related but distinct concern raised by many participants pertained to difficulty complying with all GMA study procedures while high/getting high. Few participants indicated they would be willing to complete random surveys while high/getting high, and even fewer would be willing to initiate event-based entries. As a result, event-based entries may be less reliable than random entries. Importantly, participants are required to complete random surveys within minutes of the initial prompt; those not completed within this time period are recorded as missing data. Given the lack of willingness to complete surveys while high/getting high, it is likely that many would not be able to complete random surveys within the required time frame. In fact, one participant indicated that it could take hours after getting high before she would be able to complete a survey. While both random and event-based surveys are likely to be biased by study non-compliance, self-initiated data may be subject to more severe biases than those generated by prompts that are not specifically tied to risk behaviors or sensitive locations.

Of note, most of our sample had extensive prior experience participating in research, including studies collecting location information. Their opinions and concerns may thus differ from those with less research experience. Given this limitation and the relatively small sample size, it will be important to explore whether similar issues are raised in other diverse samples with more participants. Given the emerging HIV epidemic among rural opioid users in the United States, it will be important to examine participant perspectives in these settings where substance use (e.g., illicit street drugs vs. prescription drugs), policing practices, and availability of harm reduction services differ. Similarly, although synthetic drug use was not reported by those enrolled in our study, it would be important to conduct similar assessments in populations where synthetic drug use is more common to see whether the context of drug use and the types of drugs used influence participants' concerns. Research is also needed to better understand perspectives on GMA among different HIV risk groups, including younger populations who may have more experience using mobile technology or among men who have sex with men.

Research on the "risk environment" and the geography of risk behaviors has contributed immensely to HIV prevention but requires accurate context-specific geographic data. Recent technological developments for collecting this data have the potential to improve the accuracy of the information collected and can permit more advanced analyses that account for spatio-temporal variations in risk/protective factors. However, methodological advancements have outpaced the development of ethical standards and guidance for conducting research involving populations engaged in illicit/stigmatized behaviors. Engaging the target population in additional formative research is necessary to devise methods to collect this information in a way that is sensitive to the concerns of those

involved. Together with researchers, members of these populations can develop strategies to enhance participation, reduce participant discomfort, and improve compliance with study procedures.

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References

1. Chakrapani V, Newman PA, Shunmugam M, Dubrow R. Social-structural contexts of needle and syringe sharing behaviours of HIV-positive injecting drug users in Manipur, India: a mixed methods investigation. *Harm Reduct J.* 2011; 8(1):9. [PubMed: 21569478]
2. Grund JPC, Stern LS, Kaplan CD, Adriaans NFP, Drucker E. Drug-Use Contexts and Hiv-Consequences - the Effect of Drug Policy on Patterns of Everyday Drug-Use in Rotterdam and the Bronx. *Brit J Addict.* 1992; 87(3):381–392. [PubMed: 1559037]
3. Hien NT, Giang LT, Binh PN, Wolffers I. The social context of HIV risk behaviour by drug injectors in Ho Chi Minh City, Vietnam. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv.* 2000; 12(4):483–495.
4. Rhodes T. Risk environments and drug harms: A social science for harm reduction approach. *International Journal of Drug Policy.* 2009; 20(3):193–201. [PubMed: 19147339]
5. Rhodes T, Mikhailova L, Sarang A, et al. Situational factors influencing drug injecting, risk reduction and syringe exchange in Togliatti City, Russian Federation: a qualitative study of micro risk environment. *Soc Sci Med.* 2003; 57(1):39–54. [PubMed: 12753815]
6. Singer M, Jia Z, Schensul JJ, Weeks M, Page JB. AIDS and the i.v. drug user: the local context in prevention efforts. *Med Anthropol.* 1992; 14(2–4):285–306. [PubMed: 1297901]
7. Poundstone KE, Strathdee SA, Celentano DD. The social epidemiology of human immunodeficiency virus/acquired immunodeficiency syndrome. *Epidemiologic reviews.* 2004; 26(1):22–35. [PubMed: 15234945]
8. Acevedo-Garcia D. Residential segregation and the epidemiology of infectious diseases. *Social Science & Medicine.* 2000; 51(8):1143–1161. [PubMed: 11037206]
9. Rhodes T, Singer M, Bourgois P, Friedman SR, Strathdee SA. The social structural production of HIV risk among injecting drug users. *Social science & medicine.* 2005; 61(5):1026–1044. [PubMed: 15955404]
10. White K, Borrell LN. Racial/ethnic residential segregation: Framing the context of health risk and health disparities. *Health & Place.*
11. Landrine H, Corral I. Separate and unequal: residential segregation and black health disparities. *Ethnicity & disease.* 2009; 19(2):179. [PubMed: 19537230]
12. Johns MM, Bauermeister JA, Zimmerman MA. Individual and neighborhood correlates of HIV testing among African American youth transitioning from adolescence into young adulthood. *AIDS education and prevention: official publication of the International Society for AIDS Education.* 2010; 22(6):509. [PubMed: 21204627]
13. Taylor SL, Leibowitz A, Simon PA, Grusky O. ZIP code correlates of HIV-testing: a multilevel analysis in Los Angeles. *AIDS and Behavior.* 2006; 10(5):579–586. [PubMed: 16552623]
14. Guerrero EG, Pan KB, Curtis A, Lizano EL. Availability of substance abuse treatment services in Spanish: A GIS analysis of Latino communities in Los Angeles County, California. *Substance abuse treatment, prevention, and policy.* 2011; 6(1):1–8.
15. Guerrero EG, Kao D, Perron BE. Travel distance to outpatient substance use disorder treatment facilities for Spanish-speaking clients. *International Journal of Drug Policy.* 2013; 24(1):38–45. [PubMed: 22705358]

16. Maher L. Drugs, public health and policing in indigenous communities. *Drug Alcohol Rev.* 2004; 23(3):249–251. [PubMed: 15370003]
17. Volkman T, Lozada R, Anderson CM, Patterson TL, Vera A, Strathdee SA. Factors associated with drug-related harms related to policing in Tijuana, Mexico. *Harm Reduct J.* 2011; 8
18. Koester SK. Copping, Running, and Paraphernalia Laws - Contextual Variables and Needle Risk Behavior among Injection-Drug Users in Denver. *Hum Organ.* 1994; 53(3):286–295.
19. Bluthenthal RN, Kral AH, Lorvick J, Watters JK. Impact of law enforcement on syringe exchange programs: a look at Oakland and San Francisco. *Med Anthropol.* 1997; 18(1):61–83. [PubMed: 9458668]
20. Feldman HW, Biernacki P. The ethnography of needle sharing among intravenous drug users and implications for public policies and intervention strategies. *NIDA Res Monogr.* 1998; 80:28–39. [PubMed: 3136344]
21. Zule WA. Risk and Reciprocity - Hiv and the Injection-Drug User. *J Psychoactive Drugs.* 1992; 24(3):243–249. [PubMed: 1432402]
22. Booth RE, Watters JK, Chitwood DD. Hiv Risk-Related Sex Behaviors among Injection-Drug Users, Crack Smokers, and Injection-Drug Users Who Smoke Crack. *Am J Public Health.* 1993; 83(8):1144–1148. [PubMed: 8342724]
23. Koester SK. The context of risk: ethnographic contributions to the study of drug use and HIV. *NIDA Res Monogr.* 1994; 143:202–217. [PubMed: 8742600]
24. Bluthenthal RN, Watters JK. Multimethod research from targeted sampling to HIV risk environments. *NIDA Res Monogr.* 1995; 157:212–230. [PubMed: 8684438]
25. Werb D, Wood E, Small W, et al. Effects of police confiscation of illicit drugs and syringes among injection drug users in Vancouver. *International Journal of Drug Policy.* 2008; 19(4):332–338. [PubMed: 17900888]
26. Cooper HL, Des Jarlais DC, Ross Z, Tempalski B, Bossak B, Friedman SR. Spatial Access to Syringe Exchange Programs and Pharmacies Selling Over-the-Counter Syringes as Predictors of Drug Injectors' Use of Sterile Syringes. *Am J Public Health.* 2011; 101(6):1118–1125. [PubMed: 21088267]
27. Small W, Kerr T, Charette J, Schechter MT, Spittal PM. Impacts of intensified police activity on injection drug users: Evidence from an ethnographic investigation. *International Journal of Drug Policy.* 2006; 17(2):85–95.
28. Eberhart MG, Yehia BR, Hillier A, et al. Behind the cascade: analyzing spatial patterns along the HIV care continuum. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2013; 64:S42–S51. [PubMed: 24126447]
29. Waldrop-Valverde D, Guo Y, Ownby RL, Rodriguez A, Jones DL. Risk and protective factors for retention in HIV care. *AIDS and Behavior.* 2014; 18(8):1483–1491. [PubMed: 24085375]
30. Beardsley K, Wish ED, Fitzelle DB, O'Grady K, Arria AM. Distance traveled to outpatient drug treatment and client retention. *Journal of Substance Abuse Treatment.* 2003; 25(4):279–285. [PubMed: 14693257]
31. Rockwell R, Des Jarlais DC, Friedman SR, Perlis TE, Paone D. Geographic proximity, policy and utilization of syringe exchange programmes. *AIDS Care.* 1999; 11(4):437–442. [PubMed: 10533536]
32. Bruneau J, Daniel M, Kestens Y, Zang G, Genereux M. Associations between HIV-related injection behaviour and distance to and patterns of utilisation of syringe-supply programmes. *J Epidemiol Community Health.* 2008; 62(9):804–810. [PubMed: 18701731]
33. Schilling RF, Fontdevila J, Fernando D, El-Bassel N, Monterroso E. Proximity to needle exchange programs and HIV-related risk behavior among injection drug users in Harlem. *Eval Program Plann.* 2004; 27(1):25–33.
34. Leibowitz AA, Taylor SL. Distance to public test sites and HIV testing. *Medical care research and review.* 2007; 64(5):568–584. [PubMed: 17728197]
35. Heckman TG, Somlai A, Peters J, et al. Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS care.* 1998; 10(3):365–375. [PubMed: 9828979]

36. Siedner MJ, Lankowski A, Tsai AC, et al. GPS-measured distance to clinic, but not self-reported transportation factors, are associated with missed HIV clinic visits in rural Uganda. *AIDS* (London, England). 2013; 27(9):1503.
37. Taylor BS, Reyes E, Levine EA, et al. Patterns of Geographic Mobility Predict Barriers to Engagement in HIV Care and Antiretroviral Treatment Adherence. *AIDS patient care and STDs*. 2014
38. Watkins KL, Regan SD, Nguyen N, et al. Advancing Cessation Research by Integrating EMA and Geospatial Methodologies: Associations Between Tobacco Retail Outlets and Real-time Smoking Urges During a Quit Attempt. *Nicotine & Tobacco Research*. 2013:ntt135.
39. Stahler GJ, Mennis J, Baron DA. Geospatial Technology and the “Exposome”: New Perspectives on Addiction. *American Journal of Public Health*. 2013; 103(8):1354–1356. [PubMed: 23763413]
40. Kirk GD, Linas BS, Westergaard RP, et al. The Exposure Assessment in Current Time Study: Implementation, Feasibility, and Acceptability of Real-Time Data Collection in a Community Cohort of Illicit Drug Users. *AIDS research and treatment*. 2013; 2013
41. Labrique AB, Kirk GD, Westergaard RP, Merritt MW. Ethical Issues in mHealth Research Involving Persons Living with HIV/AIDS and Substance Abuse. *AIDS research and treatment*. 2013; 2013
42. Phillips KA, Epstein DH, Mezghanni M, et al. Smartphone Delivery of Mobile HIV Risk Reduction Education. *AIDS research and treatment*. 2013; 2013
43. Ramanathan N, Swendeman D, Comulada WS, Estrin D, Rotheram-Borus MJ. Identifying preferences for mobile health applications for self-monitoring and self-management: Focus group findings from HIV-positive persons and young mothers. *International journal of medical informatics*. 2013; 82(4):e38–e46. [PubMed: 22704234]
44. Wiehe SE, Carroll AE, Liu GC, et al. Using GPS-enabled cell phones to track the travel patterns of adolescents. *International journal of health geographics*. 2008; 7(1):22. [PubMed: 18495025]
45. Mitchell JT, Schick RS, Hallyburton M, et al. Combined Ecological Momentary Assessment and Global Positioning System Tracking to Assess Smoking Behavior: A Proof of Concept Study. *Journal of Dual Diagnosis*. 2013 just-accepted.
46. Meurk C, Hall W, Carter A, Chenery H. Collecting real-time data from substance users raises unique legal and ethical issues: reply to Kuntsche & Labhart. *Addiction* (Abingdon, England). 2014; 109(10):1760.
47. Luxton DD, McCann RA, Bush NE, Mishkind MC, Reger GM. mHealth for mental health: Integrating smartphone technology in behavioral healthcare. *Professional Psychology: Research and Practice*. 2011; 42(6):505.
48. Sciences CfIOoM. International ethical guidelines for biomedical research involving human subjects. *Bulletin of medical ethics*. 2002; (182):17.
49. Ryan GW, Bernard HR. Techniques to identify themes. *Field methods*. 2003; 15(1):85–109.
50. Patton, MQ. *Qualitative Research & Evaluation Methods*. 3. Sage Publications, Inc; 2002.
51. Paz-Soldan VA, Stoddard ST, Vazquez-Prokopec G, et al. Assessing and maximizing the acceptability of global positioning system device use for studying the role of human movement in dengue virus transmission in Iquitos, Peru. *The American journal of tropical medicine and hygiene*. 2010; 82(4):723. [PubMed: 20348526]

Highlights

- Qualitative study of ethical concerns for collecting location data via 3 methods
- Confidentiality of illicit behavior locations may influence location data accuracy
- Geographical momentary assessments (GMA) collect real-time behavior/ location data
- GMA concerns included study burden, confidentiality, and discomfort with tracking
- GMA concerns could lead to nonparticipation and noncompliance with study procedures

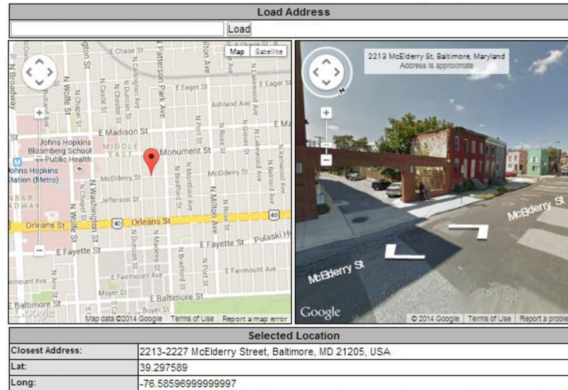
A	Interviewer-administered surveys that collect residential location (either an address or intersection)
	<p>In many studies, interviewers may ask participants to provide the address or cross-streets for where they live. In addition to providing this information, researchers may also ask participants to provide additional addresses or cross-streets, for example, for the location where he/she works, hangs out with friends, buys drugs, uses or injects drugs, goes for medical care, obtains syringes, or where he/she first heard about the study they are participating in.</p> <p>So, for example, a researcher might ask:</p> <p>Can you please tell me the address or intersection where you lived or slept most often in the past 6 months?</p> <p>_____ and _____, City State zipcode</p>
B	Interviewer-administered surveys that collect this information using an interactive map.
	<p>In some studies, researchers may use an interactive map to help locate the addresses and cross-streets that you provide. One advantage of using this approach is that you can use the map to interactively search for a location using landmarks (e.g., parks, stores, street</p>

Figure 1a

names, churches, restaurants, shops) if you are unsure of the exact address or cross streets. Another advantage is that you can look at the street view of the address or intersection you provided and make sure that it is correct.

Here is an example:

Can you please tell me the location where you lived or slept most often during the last six months? By location mean the address or cross streets. We can look at the map together to find the place.



C Using smartphones with GPS capabilities to gather spatiotemporally referenced behavioral data in one’s natural environment.

The next set of questions ask for your opinion about participating in a study where you would be asked to carry a smartphone with a GPS tracking device which continuously records your location information for several weeks. In addition to collecting information on your location, the phone would prompt you to fill out short surveys several times a day and ask you to input information about your drug or alcohol use on your own for several weeks.

Remember, the study I am describing is hypothetical and we are currently NOT

Figure 1b

conducting any studies that use this method. If you enrolled in a study like this, you would get a study phone to carry with you at all times. Each day the phone would beep at three different times to let you know that it is time to take a survey. After the phone beeps, you will have 15 minutes to complete the survey. If you do not respond in this amount of time, you will not get credit for taking the survey. Each day that you are in the study, the phone will beep at different times. The researchers will also ask you to tell the phone when you are using drugs or craving drugs each day. To tell the phone that you are craving drugs, you will press one button and to tell the phone that you are using drugs you will press another button. You can press these buttons at any time over the course of the study

Figure 1c

Figure 1.

Overview of three different location data collection methods, as presented in the interview guide

**The screenshot of the web-based mapping software displayed in Figure 1B was developed for use in K01DA033879 (PI: Rudolph).*

Table 1

Sample characteristics (N=15)

	N	%
Age (median, IQR)	49	43–52
Male	11	73
Race		
Black/African American (Non-Hispanic)	13	87
White (Non-Hispanic)	2	13
Heroin use (past 30 days)	7	47
Crack use (past 30 days)	11	73
Cocaine use (past 30 days)	5	33
Methamphetamine use (past 30 days)	0	0
Injection drug use (past 30 days)	4	27
History of a drug related arrest	13	87
HIV positive	10	67
Currently have a mobile data plan	7	47
Experience in a study where location information was collected	9	60
Experience with address/cross-street method	9	60
Experience with web-based map	8	53
Experience with GMA	1	7

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