

# Privacy, Confidentiality, and Safety Considerations for Conducting Geographic Momentary Assessment Studies Among Persons Who Use Drugs and Men Who Have Sex with Men

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**Abstract** Geographic momentary assessments (GMA) collect real-time behavioral data in one's natural environment using a smartphone and could potentially increase the ecological validity of behavioral data. Several studies have evaluated the feasibility and acceptability of GMA among persons who use drugs (PWUD) and men who have sex with men (MSM), but fewer have discussed privacy, confidentiality, and safety concerns, particularly when illegal or stigmatized behavioral data were collected. This study explores perceptions regarding privacy, confidentiality, and safety of GMA research among PWUD and MSM recruited in three different settings (rural Appalachia, a mid-sized city in the South, and a mid-Atlantic city). Between November 2014 and April 2017, we recruited 35 PWUD from rural Appalachian Kentucky ( $N = 20$ ) and Baltimore, Maryland ( $N =$

15) and 20 MSM from Lexington, Kentucky to complete semi-structured qualitative interviews. Through thematic analyses, we identified and compared privacy, confidentiality, and safety concerns by demographic characteristics, risk behaviors, and setting. Privacy, confidentiality, and safety concerns varied by setting, age, smartphone ownership, use of illegal drugs, and history of drug-related arrests. Among those who used drugs, participants reported concerns with being tracked and burden associated with carrying and safeguarding study phones and responding to survey prompts. Privacy and confidentiality concerns were noted in each setting, but tracking concerns were greatest among Baltimore participants and led many to feel that they (or others) would be unwilling to participate or comply with study procedures. While locations considered to be sensitive varied by setting, participants in all settings said they would take measures to prevent sensitive information from being collected (i.e., intentionally disable devices, leave phones at home, alter response times). Privacy, confidentiality, and safety concerns may limit the accuracy of risk location information, study compliance, and participation. As concerns were often greatest among those engaging in illegal behaviors and with the highest risk behaviors, selection bias and non-response bias could negatively influence the representativeness and validity of study findings.

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## Introduction

Geographic data are increasingly used in HIV prevention and substance use research to better understand how one's social environment influences risk behaviors and health service use [1–6]. Current methods for collecting this data range from interviewer-administered surveys, which are static and affected by recall, to geographical momentary assessments (GMA), which combine ecological momentary assessments (EMA) with time-stamped Global Positioning System (GPS) data to collect information on participants' behaviors both when and where they occur. With GMA, participants consent to have their location tracked over the course of the study and to complete random and event-based (i.e., initiated by participants when engaging in specific behaviors) surveys on a smartphone application. The result is a time-stamped map of their daily movements and behaviors. Analyses typically link the spatial data collected through GMA and other spatial data collection approaches with other data sources that characterize features of the physical and social environment. In the context of GMA and other data spatial data collection approaches which additionally collect information about the amount of time spent in different locations, analyses that weight neighborhood-level data by the time spent in each location are possible [7, 8]. GMA data are unique in that the data have both spatial and temporal references and can be used to assess temporal associations between neighborhood exposures and behaviors or outcomes.

From an analytic perspective, GMA has the potential to collect more accurate and contextually relevant data because real-time location (i.e., GPS) and behavioral data (i.e., EMA) can be collected simultaneously in one's natural environment. Further, unlike interviewer-administered surveys which often collect information about where events (i.e., risk behaviors) occur most often, GMA collects information about multiple different risk locations and the amount of time spent in each. Consequently, GMA is thought to collect more ecologically valid data which can be used in analyses that account for exposures to multiple risk environments and for varied amounts of time [9–11].

To date, GMA has been used in epidemiologic studies to provide a more comprehensive understanding of the environmental context of risk/health-seeking behaviors among HIV-at-risk populations, including persons who use drugs (PWUD) and men who have sex with men (MSM). Several studies have evaluated the

feasibility/acceptability of conducting GMA studies among PWUD [11, 12] and MSM [13, 14]; however, those enrolled in these studies involve only participants who previously agreed to participate in the GMA study and not those who may have opted out. A few studies have discussed privacy and confidentiality concerns from the viewpoint of participants living with HIV [15, 16] or engaging in illegal behaviors [15, 17, 18], but none address potential concerns among young MSM. Further, because geographic coordinates provide less anonymity in rural settings which are less densely populated than urban areas, privacy and confidentiality concerns may vary by setting. Related work examining privacy and confidentiality concerns associated with providing the locations of risk behaviors via interviewer-administered surveys suggested a greater reluctance in rural vs. urban settings to provide the locations of others' homes [19]. Concerns with being tracked or providing real-time data on risk behaviors may similarly be influenced by setting.

This research will identify and compare privacy, confidentiality, and safety concerns associated with GMA in two HIV-at-risk populations (i.e., MSM and PWUD) and across three different settings. It will also examine the extent to which participants' concerns could influence study compliance, participation rates, and validity of participants' responses in each risk group and across research settings.

## Methods

Three different study locations were selected for their diversity on HIV prevalence, HIV-related risk behaviors, race/ethnicity, age, and population density: PWUD in a small rural Appalachian town, MSM in a mid-sized city in the south, and PWUD in a major urban center in the Mid-Atlantic region. Methods for recruiting PWUD participants have been described in detail, elsewhere [15, 19, 20]. The urban sample of PWUD consisted of 15 Baltimore city residents who reported using heroin, crack, or cocaine in the past 6 months. They were recruited between November 2014 and April 2015 specifically for enrollment in the current study using a combination of peer-referral and study flyers at a local HIV clinic and a community-based research center. The rural sample of PWUD was recruited from an ongoing prospective cohort study in rural Appalachian Kentucky which aimed to explore HIV and Hepatitis C risk behaviors.

Participants were recruited for the parent study using respondent-driven sampling [20] and provided written informed consent to be contacted about other future research opportunities. Twenty persons who reported drug use in the past 6 months were purposively sampled (i.e., for diversity on age, gender, arrest history, injection status, and type(s) of drug(s) used) from this the ongoing cohort study [20] between November 2015 and March 2016 to participate in the current study. Between August 2016 and April 2017, 20 MSM were recruited from an ongoing study in Lexington, Kentucky to participate in this additional study. Eligibility for the larger MSM study included being 18–34 years of age, biologically male, and reporting anal sex with another man in the past 6 months. MSM participants for the larger study were recruited through peer-referral and flyers distributed in LGBTQ venues (i.e., gay night clubs, novelty stores, community organizations, and men-seeking-men online forums) and the local HIV outreach organization and HIV treatment clinic that serves the county and surrounding area.

After providing informed consent, individuals participated in an in-depth semi-structured interview which focused on three different spatial data collection methods (in the following order): (1) eliciting addresses/cross-streets, (2) web-based maps, and (3) GMA. After describing each method, open-ended questions explored concerns informed by the International Ethical Guidelines for Biomedical Research Involving Human Subjects [21].

Specific to GMA, interviewers first described a hypothetical GMA study where participants would be asked to carry a smartphone with them for several weeks, respond to random prompts to complete a survey several times a day, and initiate event-based surveys. Interviewers then explained that the study could collect location data (1) at the time when participants complete survey responses and/or (2) at regular time intervals over the course of the study (i.e., data points collected every 15 s or 7 ft, whichever comes first). Participants were also shown several screenshots of example GMA survey questions and a figure from a published GMA study to depict how this data is typically presented in published studies. Interviewers also explained that the maps presented in papers contain data for all participants, together, rather than for an individual participant. Of note, only one of the 55 study participants had previously participated in a GMA study.

Participants were first asked (a) about their comfort carrying a smartphone with GPS capabilities for a period of time as part of a study, (b) for their preference with respect to using a study app which could be downloaded to their personal phone versus a study-provided phone, and (c) to compare and contrast concerns when locations were only collected when surveys were submitted versus at regular intervals over the course of the study. Study participants were also asked to compare their comfort with (a) random versus self-initiated/event-based surveys and (b) GMA versus other spatial data collection approaches which are more frequently used in interviews conducted at a study office. Participants were then asked whether they thought any of the concerns mentioned would influence anticipated study compliance or the accuracy of responses provided.

The interviewer also explained the protections afforded by a NIH-issued Certificate of Confidentiality and then asked each participant whether knowing that the research was protected by a Certificate of Confidentiality would influence any of their concerns [15, 19]. In addition to explaining the protections in place by the Certificate of Confidentiality, the interviewer explained that for each of the three data collection methods discussed, researchers often take additional steps to protect the confidentiality of participants' locations, such as aggregating point level data up to the level of neighborhood, zip code, or census tract.

All study procedures and materials were reviewed and approved by the Institutional Review Boards at Boston University and the Pacific Institute for Research and Evaluation. Interviews were recorded and transcribed verbatim using unique identification numbers. The PI first reviewed all transcripts to develop a broad understanding of content. Transcripts were then coded using the domains from the interview guide and other emergent themes using MAXQDA software [22]. All a priori and emergent codes were organized in a codebook and reviewed by another research team member (see Table 1).

## Results

### Sample Characteristics

The samples differed significantly on most criteria examined (Table 2). For example, the Baltimore PWUD sample was the oldest (median age = 49) and the Lexington MSM sample was the youngest (median age =

**Table 1** Key domains identified through in-depth interviews with 20 MSM/TGW and 35 PWUD

Domain	Details
Privacy Concerns	<p>Concern about GPS tracking</p> <p>Preference for study app installed on personal device rather than a study-provided device due to greater confidence in the security of one's personal device</p> <p>Preference for study-provided phone due to fear that they would continue to be tracked after the study ended if the app was installed on their personal phone</p>
Confidentiality Concerns	<p>Worry that police and others may access the data</p> <p>Potential disclosure of drug use activities to others who do not already know</p>
Study Compliance	<p>Would disable GPS device or take other measures to prevent the phone from tracking them at certain locations or around some people</p> <p>Not responding to prompts when around others</p> <p>Not responding to prompts when high</p> <p>Concern about phone theft / selling the phones</p>
Accuracy of data collected	<p>GMA will collect better quality data than methods which collect only cross-streets/addresses for key locations or those that use a web-based map to collect similar data because it is harder to lie; this method is also less subject to recall bias</p> <p>Refusal to carry study phones to locations where individuals do not want their location tracked</p> <p>Non-response to survey prompts when in locations that participant does not want recorded</p>
Study burden	<p>Respondent burden is less with GMA because surveys can be completed anywhere</p>

28 years). While almost all Lexington MSM participants owned a smartphone with a data plan (95%), only 60% of rural PWUD participants and 35% of urban PWUD participants did. Drug use in the past month was reported by all Baltimore and rural Appalachian participants but only by 45% of Lexington MSM participants. Types of drugs used also differed by setting, with heroin and crack most common among those in Baltimore, prescription opiates most common among those in rural Appalachia, and marijuana most common among Lexington MSM participants. There were also differences with respect to prior drug-related arrests by setting (5% of those in Lexington, 45% of those in rural Appalachia, and 87% of those in Baltimore).

Differences in perceived GMA study burden, privacy and confidentiality concerns, and general interest in participating in future GMA studies were apparent across settings and by age, smartphone ownership, drug use, and history of drug-related arrests. Representative quotes are shown below to illustrate key themes.

### Study Burden

Most discussions with Lexington MSM participants (who were younger and more likely to own smartphones) regarding perceived study burdens

focused on whether data should be collected on one's personal device or a study-provided phone. Among Baltimore PWUD participants, where smartphone ownership was lowest, most indicated that they would be uncomfortable carrying a smartphone and that safeguarding the phone against theft would be stressful.

Among those comfortable taking part in a study using a smartphone, there were mixed opinions regarding whether the study should be downloaded as an app on one's personal device or a separate study phone should be provided. Those who preferred downloading a study app noted that it would be more convenient to use their own phone, it would be difficult to keep track of two phones, and being responsible for and carrying a second device (potentially with a different charger) would be a burden. Among Lexington MSM participants, just over half ( $n = 11$ ) preferred an app on their personal phone. A few MSM participants in Lexington and rural Appalachian PWUD participants indicated a preference for an app on their personal device so that they could control the privacy settings on the phone (i.e., what information the app was requesting and when tracking was turned on).

Others preferred to use a study phone due to concerns that (1) the app would be able to access their personal data (i.e., photos, contact list, name/address, text

**Table 2** Sample Characteristics of rural Appalachian PWUD, Baltimore PWUD and Lexington MSM ( $N = 55$ )

	Rural Appalachian PWUD ( $N = 20$ )		Baltimore PWUD ( $N = 15$ )		Lexington MSM ( $N = 20$ )		<i>P</i> value
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Age (median, IQR)	39.5	34.5–42	49	43–52	28	26–30	0.0002 <sup>a</sup>
Gender							0.0036
Male	10	50	11	73	18	90	
Female	10	50	4	27	0	0	
Trans-woman	0	0	0	0	2	10	
Sexual orientation							n/a
Bisexual	n/a	n/a	n/a	n/a	4	20	
Heterosexual	n/a	n/a	n/a	n/a	1	5	
Gay/mostly gay	n/a	n/a	n/a	n/a	14	70	
Other	n/a	n/a	n/a	n/a	1	5	
Race							< 0.0001
White	20	100	2	13	16	80	
Black	0	0	13	87	4	20	
Hispanic	0	0	0	0	4	20	0.0004 <sup>b</sup>
Own a smartphone with a data plan	12	60	7	50 <sup>c</sup>	19	95	0.0081
Prior experience with GMA	0	0	1	7	0	0	0.4102
Drug use (past 30 days)	20	100	15	100	8	40	
Heroin	1	5	7	47	0	0	0.0001 <sup>b</sup>
Crack	1	5	11	73	0	0	< 0.0001 <sup>b</sup>
Cocaine	6	30	5	33	0	0	0.0010 <sup>b</sup>
Methamphetamine	5	25	0	0	0	0	0.0045 <sup>b</sup>
Other	20	100	4	27	8	45	n/a
Marijuana	8	40	2	13	6	67	0.2268
Prescription sedatives	7	35	n/a	n/a	2	22	n/a
Neurontin	5	25	n/a	n/a	n/a	n/a	n/a
≥ 1 prescription opiate	18	90	n/a	n/a	2	22	n/a
Injected drugs (past 30 days)	8	40	4	27	0	0	0.0030 <sup>b</sup>
Ever arrested for a drug-related offense	9	45	13	87	1	5	< 0.0001
Ever been told by a healthcare professional that he/she was HIV positive	0	0	10	67	8	40	< 0.0001

n/a not available

<sup>a</sup> There is a significant difference in age between Baltimore, Maryland and Lexington, Kentucky using PROC ANOVA and the Bonferroni correction for multiple comparisons in SAS version 9.4

<sup>b</sup> *P* value from Fischer's exact test

<sup>c</sup>  $N = 14$  in Baltimore, Maryland

messages, browsing history), (2) the app would continue to access their data after the study ended, (3) they would incur extra costs for data usage or run out of storage space on their personal device, and (4) the app might give their phone a virus. Some also explained that due to the Certificate of Confidentiality, they would rather use

a study phone because their personal phone was not protected by the Certificate and could be subpoenaed or more easily intercepted by a third party. Participants in both rural and urban Kentucky also mentioned a desire to keep the study separate from their personal life. The majority of rural Appalachian PWUD preferred

a separate phone, and due to privacy concerns, several said that they would not participate in a GMA study if using their own phone was a requirement.

### Privacy-Tracking Concerns

Concerns about being tracked were mentioned in all three settings but were most common among those who reported using drugs. Most did not like the idea of being tracked and viewed it as an “invasion of privacy.” Many others worried that they could get arrested if law enforcement agencies were able to access the data. Although more rare, one rural Appalachian PWUD and several Lexington MSM participants did not want to be tracked due to concerns about the government accessing this data. According to one Lexington MSM participant, “I’m antigovernment, so I wouldn’t want this tracking my every move”.

Almost all Baltimore PWUD and about half of rural PWUD sampled were bothered by the tracking aspect of GMA. In Baltimore, concerns about being tracked led many to feel 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 when high or getting high, and initiate event-specific entries). Those reporting drug use in all three settings indicated that if they participated in a GMA study, they would take measures to prevent sensitive information from being collected such as removing the battery or disabling the device, intentionally leaving the phone at home or not carrying it with them to certain locations, and altering their response times. MSM in Lexington who did not use drugs reported fewer privacy concerns.

### Places Participants Were Unwilling to Carry the Phone or Enter Data

There were key differences in the types of locations where participants said they would be unwilling to carry the phone. Both rural PWUD and Lexington MSM participants were most concerned about bringing the phone to others’ homes “because that’s invading their privacy.” According to one participant, “I would be okay with sharing if it only affected me, but as soon as the other person came into play I would be more concerned with protecting them and the trust or the bond we have” (26 years old, MSM, Lexington). This participant went on to say that he would alter his response time to prevent someone else’s location from being “pin-

pointed,” “if I were to be in that situation and knowing that I have X amount of time to respond, I would probably wait to respond versus responding there in the moment because I would be concerned that others that I might be with would worry that they could get caught.”

In all three settings, those reporting drug use in the last month indicated that they would not bring the phone with them to buy drugs. Participants worried that by bringing the GMA phone with them to locations where they bought drugs, they would “be running the risk of being considered a rat” (39 years old, rural PWUD with a prior drug-related arrest), which could cause harm to them or others. Many participants did not want to be responsible for getting others in trouble, felt it was important to respect others’ privacy, and worried about the consequences if others learned that their location had been recorded. One rural Appalachian participant worried, “If they get busted, then I feel like it’s my fault” (36 years old, rural PWUD with no prior drug-related arrests). Others emphasized the importance of respecting “the privacy of others...it’s their personal business...that would be something they’d have to talk about, not me” (32 years old, rural PWUD with a prior drug-related arrest). Another 53-year-old rural PWUD participant with no prior drug-related arrests explained that he could get in trouble for bringing it with him to other peoples’ homes: “I wouldn’t want to be at somebody’s house and give away that location...If somebody were dealing illegal stuff and I was going there, I would be afraid to get them caught because—when I was a little younger back in the day, if you ratted on somebody...somebody would catch up with you and beat you up”. According to a 39-year-old Baltimore PWUD participant with no prior drug-related arrests, “[being] on the phone while I’m trying to deal with [a drug dealer]—it just wouldn’t look right... it would trigger [that] something [is] going on with me and bring me harm [or] bring harm to my family.” Many also worried about losing drug connections: “I would be more worried that I would lose the confidence from the people that I was getting drugs from or that I would lose them as somewhere that I could use drugs at and that they would be worried” (26 years old, Lexington MSM/PWUD). Others worried that their participation could cause paranoia among others. One rural participant noted, “It would probably set off some paranoia [among] everybody that I hang out with. Even the people that don’t do drugs would be concerned about that.” (40 years old, rural PWUD with no prior drug-related arrests).

Compared with PWUD in Baltimore and rural Appalachia, MSM participants in Lexington were more likely to feel that they would be unlikely to complete surveys at work and school or when around family and friends, because the study would not be prioritized.

### Confidentiality

#### *Disclosure of Drug Use*

Some in each setting did not think phones would be noticed by others. Others worried that using the study phone or completing surveys around friends, family, or co-workers (or sharing their phone with others) might disclose their drug use.

“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.” (52 years old, Baltimore PWUD with no prior drug-related arrests) [15]

“If somebody catches you... just picks your phone up and looks at that shit, you’re in trouble” (40 years old, rural PWUD with no prior drug-related arrests).

Reasons for not wanting to be tracked or provide information about illegal behaviors in surveys were primarily related to a fear that this information would be released to law enforcement agencies, social services, and employers. One rural Appalachian PWUD and several Lexington MSM participants also described concerns about the government and “big brother” getting access to study data.

#### *Disclosure of Drug Use Locations*

A few PWUD in Baltimore and Lexington noted no issues with the phone tracking them in places where they used drugs because (1) they moved around frequently and were unlikely to be in the same place twice, (2) their drug use was infrequent or in locations they were unlikely to return to, or (3) because they had

agreed to participate in the study and understood this as a requirement. Others, primarily those in Lexington and rural Appalachia, said that their willingness to comply with GMA study procedures and answer survey prompts about their drug use honestly would depend on their understanding of the technology and the legal protections in place by the Certificate of Confidentiality. According to a 36-year-old rural PWUD participant with no prior drug-related arrests, “My biggest thing is confidentiality and if it’s specifically for research, I know I would be completely honest with where I was.” Several participants reiterated the importance of having a Certificate of Confidentiality for this type of research: “I think the one main thing that they would have to be reassured is just because they’re carrying the cell phone for this study and they’re out buying a pill that they’re not going to go to jail for buying that pill or selling the pill” (40 years old, rural PWUD with a prior drug-related arrest). In Baltimore, participants viewed the informed consent process more like a business agreement, “I don’t take on something and don’t commit to it.” (44 years old, Baltimore PWUD with a prior drug-related arrest).

Even with the Certificate of Confidentiality, those who used drugs said that they would be less likely to complete surveys or answer surveys honestly when high or getting high because they would not want the location to be recorded. According to some, “If I’m getting high, I don’t have time for that” (52 years old, Baltimore PWUD with a prior drug-related arrest) and “the higher they are, the more they are going to lie” (53 years old, rural PWUD with no prior drug-related arrests). When asked if they would respond truthfully about where they were when they were using drugs, some indicated that they would not be honest or would be “apprehensive about being honest since it does have your exact location” (23 years old, Lexington MSM/PWUD with no prior drug-related arrests), particularly because drug use is illegal. Participants generally expressed fewer concerns with reporting legal behaviors such as smoking, drinking alcohol, and sexual behaviors.

#### *Interest Due to Convenience*

Despite the concerns mentioned above, some participants preferred GMA over other survey-based methods because of their interest in the technology, the convenience of not having to go to a study office to participate, and improved accuracy of the

data collected. According to a 32-year-old rural PWUD participant with no prior drug-related arrests, “the GPS is accurately recording where you’re using instead of you having to remember all that and tell the surveyor...it more accurately logs everything in for you, so you don’t have worry about people lying.” Others noted that with GMA, it is easier to forget about the level of detail you are providing: “ignorance is bliss—it’s easier for you to forget that you’re actually giving someone this information” (27 years old, Lexington MSM). Despite these concerns, several rural PWUD and Lexington MSM participants acknowledged that cell phone towers, credit cards, and their regular cell phone were already routinely tracking them.

Participants also noted the increased risk associated with GMA as compared to interviewer-based survey approaches. Due to the increased “risk” associated with GMA, several participants in rural Appalachia and Lexington suggested that the incentives for GMA participation should be higher. As one person explained, “that sounds like a lot of risk. That’s worth a lot more than coming in here and sitting in a safe little office” (40 years old, rural PWUD with no prior drug-related arrests).

## Discussion

In this study, we observed qualitative differences with respect to comfort with GMA and related privacy and confidentiality concerns by study setting, age, smartphone ownership, drug use, and prior involvement with the criminal justice system. General acceptability and comfort with GMA was highest among MSM in Lexington who were the youngest, most likely to own a smartphone, and least likely to report drug use and prior drug-related arrests; it was lowest among Baltimore PWUD where participants were the oldest, least likely to own a smartphone, and most likely to report recent drug use and prior drug-related arrests. The convenience of not having to come to a research site to participate in a study was a selling point for many of the younger MSM participants in Lexington. On the contrary, Baltimore PWUD were more likely to be disinterested in a study that

would require them to carry a smartphone and felt that it would make them a target for theft. MSM and persons who inject drugs (PWID) enrolled in other urban studies similarly noted safety concerns (including theft) associated with carrying the device [14, 17, 18, 23, 24]. The qualitative differences observed here may be attributed to the [1] older age of Baltimore PWUD, [2] fewer Baltimore PWUD reporting smartphone ownership, and [3] more Baltimore participants reporting use of street drugs (i.e., heroin, crack, cocaine) and prior drug-related arrests (also noted by others [18]).

As with MSM in Baltimore, MSM in Lexington had mixed opinions regarding whether the study should be administered on a study phone vs. an app installed on their personal device [13], with slightly more preferring an app. On the contrary, 95% of rural PWUD preferred a study-provided phone due to privacy concerns. Two Baltimore PWUD indicated a preference for a study phone, but only because they did not own a smartphone and would need one to be provided in order to participate. This qualitative difference is most likely due to engagement in illegal activities and PWUD not wanting to have those locations connected with other data on their personal device. It may also reflect differences in smartphone ownership among the groups sampled.

Similar to findings from an EMA study among PWID, rural PWUD in our sample stressed the importance of detailing the procedures in place to protect study data and keep it private in the consent form [17]. As with PWID in San Diego [17] and San Francisco [18], PWUD in this study also worried that the phone might cause inadvertent disclosure to family or friends who see the phone or the messages that pop up on their phone and that it could lead others in their network to believe they were a snitch or working with the police as an informant. Our finding that participants would not respond to prompts or initiate entries when high or getting high is also consistent with what others have reported among PWUD [25, 26].

While concern about being tracked was highlighted by participants in each setting, it was much more prominent among Baltimore PWUD and led many to conclude that they would not be



willing to participate in GMA studies. In Baltimore, some likened this aspect of GMA to wearing an ankle bracelet while on parole [15]. Participants in all three settings indicated that concerns about being tracked in specific locations would lead them to take measures to prevent these locations from being recorded if they did participate in a GMA study. In Baltimore, participants were most concerned with tracking the locations where drugs were used and purchased; in rural Appalachia and Lexington, participants were most concerned about the GPS recording the locations of others' homes and the locations where drugs were purchased (often also others' homes), because they did not want to be responsible for others getting in trouble. Due to these concerns, many participants indicated that they would [1] not bring the phone with them to sensitive locations, [2] alter their response times so that others' homes or locations where drugs were used would not be pin-pointed, or [3] disable the device or GPS tracking. Similar to findings reported in other studies [16, 18], participants in rural Appalachia and Lexington [1] wanted control over when they were being tracked by the GPS, [2] felt the app should be password-protected, and [3] expressed concerns about law enforcement and the government getting unauthorized access to the data collected through the study. Our findings are also consistent with feasibility and proof of concept studies which reported that some participants declined to participate or did not wear the GPS due to privacy concerns [24, 27].

In Baltimore, very few participants indicated they would be willing to complete random surveys while high or getting high, and even fewer were willing to initiate event-based entries. Although fewer individuals used drugs in Lexington, the same viewpoints were expressed by those who used drugs. On the contrary, only one participant in rural Appalachia expressed a similar concern about being able to respond to survey prompts while high. This difference may in part reflect the differences in the type(s) of drug used in each setting. In Baltimore, the majority (93%) used crack, followed by heroin (67%). In rural

Appalachia, the majority (95%) used prescription opioids to get high.

There was also a greater interest in participating in future GMA studies among PWUD participants in rural Appalachia and MSM participants in Lexington. This difference may in part be due to differences in the ages and smartphone ownership among study participants in each sample (50% of Baltimore, 60% of rural Appalachian, and 95% of Lexington participants) owned a smartphone with a data plan. This point is further reinforced by the fact that more participants in Baltimore felt that having a smartphone would make them a target for theft and stated that carrying a study phone would make them uncomfortable.

As most of the prior research on GMA feasibility and acceptability among PWUD and MSM has been conducted among participants who have recently completed a GMA study, this study is unique in that only one participant had previously participated in this type of research. This is an advantage, as we were able to capture the attitudes of those who had not already consented to be enrolled in this type of research. However, most of the participants enrolled in the current study had previously participated in research conducted at a study office with an interviewer, including the interview for the current study. Consequently, this group may naturally be more comfortable with face-to-face interviews conducted at a study office.

Collectively, the concerns expressed by participants are consistent with the findings from other research examining potential ethical concerns associated with GMA and EMA; however, our findings also highlight differences in participants perspectives based on drug use (and types of drugs used), history of drug-related arrests, setting, age, and smartphone ownership. Based on our findings, ethical concerns related to privacy, confidentiality, and safety may limit the validity of the risk location information collected and may induce selection bias in GMA studies, as those with the greatest concerns were often the least willing to participate.

Based on previous research comparing perspectives on spatial data collection approaches among PWUD, some urban participants preferred using the web-based map approach to GMA because they felt that it would permit more anonymity in their responses and most were very opposed to being

tracked [15]. Among PWUD in a rural setting, providing any level of spatial data was considered to be too identifying given the low population density [19]. Current and prior findings from this project suggest a need to engage the target population in formative research to select an appropriate and acceptable data collection approach that is sensitive to the specific concerns of the study population.

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**Abbreviations** EMA, ecological momentary assessment; GMA, geographical momentary assessments; GPS, Global Positioning System; MSM, men who have sex with men; PWUD, persons who use drugs; TGW, transgender women

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