Collecting Data During the COVID-19 Pandemic: Lessons From an In-Person Survey of People Who Use Opioids

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Abstract

Objectives: In response to the COVID-19 pandemic, much in-person data collection has been suspended or become tele-remote. However, tele-remote methods often exclude marginalized groups, including people who use drugs, many of whom lack the technology to participate. To inform future surveillance and research during the pandemic and other public health disasters, we report methods and lessons learned from an in-person survey of people who use opioids conducted by the New York City Department of Health and Mental Hygiene (DOHMH) during the COVID-19 pandemic.

Materials and Methods: This public health surveillance was a component of the Centers for Disease Control and Prevention Overdose Data to Action initiative and aimed to inform overdose prevention efforts. Survey domains inquired about participants’ drug use patterns, risk behaviors, overdose history, and service use.

Results: From June 16 through September 9, 2020, DOHMH staff members conducted 329 surveys with participants from 4 syringe service programs (n = 148, 44.9%) and via street intercept (n = 81, 55.1%). To survey participants safely and effectively, it was important to build rapport upfront so that requests to maintain distance were not perceived as stigmatizing. DOHMH staff members offered all participants, regardless of survey eligibility, Narcan and hygiene products, including face masks and soap.

Practice Implications: Surveys administered outdoors during the COVID-19 pandemic should be limited to 30 minutes. Although conducting in-person surveys poses unique challenges, this method should be considered so marginalized populations are included in data collection and public health responses.

Keywords

opioid use, COVID-19, surveillance methods, hard-to-reach populations
Given the burden of overdose and COVID-19 on PWUD, delaying in-person public health surveillance efforts and using tele-remote methods to collect data from an already hard-to-reach population could fail to reach those most affected.\textsuperscript{11}

To inform future studies with PWUD and other hard-to-reach populations, we describe methods used by the New York City Department of Health and Mental Hygiene (DOHMH) to conduct an in-person survey of PWUD during the COVID-19 pandemic. We share this methodology to guide research and surveillance efforts conducted during subsequent waves of the COVID-19 pandemic and during other public health disasters. For context, we first outline our surveillance strategy developed before COVID-19. We then describe how we adapted the survey in response to the COVID-19 pandemic, including the safety procedures we implemented and lessons learned.

**Context of the Survey Pre–COVID-19**

This project was funded by the Centers for Disease Control and Prevention (CDC) Overdose Data to Action federal initiative. Overdose Data to Action is part of the US Department of Health and Human Services’ 5-point strategy to combat the opioid epidemic.\textsuperscript{12} Support for 2 annual cross-sectional surveys with people who use opioids (PWUO) was awarded to enhance public health surveillance efforts related to the overdose epidemic. The aim of the survey was to understand current drug use patterns, risk behaviors, risk reduction strategies, overdose history, and service use of PWUO.

Before the COVID-19 pandemic, our recruitment strategy was to engage PWUO at New York City emergency departments, syringe service programs (SSPs), and through street intercept (approaching people on the street in areas where PWUO congregate). Recruitment was scheduled to start in March 2020 at emergency departments and move to SSPs and street intercept during the warmer months. Based on an initial pilot, surveys were expected to take approximately 45 minutes to administer; participants received $25 gift cards for their time.

Data collection was scheduled to begin at a Bronx emergency department the same week that New York City Mayor Bill DeBlasio declared a state of emergency and, on March 22, a stay-at-home order was implemented across the city.\textsuperscript{13} All DOHMH community-facing work was suspended, including the Overdose Data to Action survey. As the number of COVID-19 cases increased, it became clear the survey should be adapted to focus on how PWUO were experiencing the COVID-19 pandemic to inform a response during this public health crisis.

**Adapting the Survey to COVID-19**

The revised survey aimed to understand PWUO drug use patterns, risk behaviors, risk reduction strategies, overdose history, and service use in the context of the COVID-19 pandemic. We restructured survey domains to explore participants’ experiences before and during the COVID-19 pandemic, with pre–COVID-19 defined as the 90 days before March 1 and the pandemic period from March 1, the approximate date COVID-19 was first identified in New York City, until the date of interview. The primary difference between the original survey and the adapted survey was the addition of the March 1/COVID-19 reference point of interest.

We added a COVID-19 specific domain inquiring about COVID-19 testing, infection, and participants’ ability to practice CDC prevention recommendations (eg, having regular access to a face mask) to the survey. COVID-19 questionnaires available online from the research community informed survey items.\textsuperscript{14} Public sharing of survey items before publication has been common across disciplines during the pandemic, allowing for the rapid development of studies and the later comparison of findings.\textsuperscript{15-17} We removed other items from the original survey, including assessments for depression and posttraumatic stress disorder, a measure of health care–related stigma, and questions about sexual experiences, fentanyl, and prescribed opioid analgesics, to decrease the administration time to approximately 30 minutes. Survey domains for the adapted survey were COVID-19 testing, prevention and infection, access to basic resources, drug use patterns, overdose experiences, health care access and use, mental health, and injection behavior. Once the survey was finalized, DOHMH staff members programmed the survey into REDCap Cloud, a secure web-based application used to collect and store data.\textsuperscript{18}

In early June 2020, an institutional review board amendment was approved that included the adapted survey and recruitment procedures for 2 potential recruitment scenarios. If stay-at-home orders remained in effect, tele-remote methods would be used, and all participants would be recruited through SSPs. PWUO continued to use SSPs because they were deemed essential during the stay-at-home period. In this scenario, SSP staff members would be provided with informational cards, including a unique identification number, to distribute to potential participants. Individuals would then call a number quoting the unique identification number to learn more about the survey and eligibility. Once eligibility had been established, DOHMH staff members would administer the survey via telephone. DOHMH would then provide SSP staff members with a list of identification numbers and stipends in the form of gift cards that could be claimed by survey participants. If stay-at-home orders were lifted, recruitment and data collection would be conducted in-person via street intercept and in the immediate vicinities of SSPs providing physically distanced services. This scenario would require minimal SSP staff member involvement so as not to burden an already stressed system. Interviews would be conducted face-to-face and stipends distributed directly to participants. Fortunately, surveys were not conducted tele-remotely through SSPs.
because stay-at-home orders were lifted on June 8, allowing the survey to be conducted in person. We piloted the adapted survey the same week the order was lifted. After incorporating minor changes, face-to-face data collection commenced in mid-June.

**Materials and Methods**

From June 16 through September 9, 2020, we conducted 329 surveys with participants recruited outside 4 SSPs with whom we partnered for the project (n = 148, 44.9%) and via street intercept (n = 181, 55.1%). We approached potential participants and asked if they were interested in taking a survey about their health and drug use during the COVID-19 pandemic. If they affirmed, we provided them with a ticket describing the survey and containing a unique identification number. Staff members handed out only a few tickets at a time to help control the flow of participants; if people approached survey staff members wanting to participate while an interview was already in process, staff members explained the survey was limited to those already in possession of a ticket. All potential participants we approached were engaged in a casual and conversational manner.

Participants provided us with the number on their ticket to be screened for eligibility. To be eligible, participants had to (1) be aged ≥18, (2) have used opioids (heroin and/or prescription opioids not as prescribed) ≥3 times in the past 30 days, and (3) have engaged with 1 of the following services in the past 12 months: an SSP, outpatient substance use disorder treatment, methadone treatment, homeless shelter, emergency department, hepatitis C program, COVID-19 isolation hotel, and/or buprenorphine treatment. We selected these 8 service touchpoints because they serve a high number of PWUO. COVID-19 isolation hotels were also included to capture the experience of PWUO who used these facilities as a result of the pandemic.

Data collection took place across the 5 New York City boroughs, but participants did not have to reside in New York City to participate; some were transient or traveled to New York City for health care services. DOHMH staff members administered the survey via computer-assisted personal interview devices, and participants received a $25 gift card for their time. Regardless of eligibility, we offered everyone we approached a bag of hygiene products and a Narcan (naloxone) kit.

**Safety Procedures**

For staff member and participant safety, we implemented COVID-19 safety procedures adhering to CDC and DOHMH recommendations. We collected data outdoors and always maintained a 6-foot distance from one another and from participants. We reminded participants of the necessity of wearing face masks and remaining physically distanced during the screening protocol and survey administration; if needed, we provided face masks to participants. Most participants were already familiar with these prevention practices and were willing and able to follow them. We obtained verbal consent so no paperwork needed to be signed or passed between staff members or participants, and staff members used their own computer-assisted personal interview devices to administer the survey. Two to 4 staff members participated in data collection each day with at least 2 staff members present at any time.

**Use of Telephones During Data Collection**

Lastly, although we approached and paid all potential participants in person, 1 staff member continued working remotely and conducted surveys with participants via telephone. We offered potential participants who were waiting to be interviewed the option of completing the survey by telephone and provided those who agreed with a number to call. The remote staff member screened them for eligibility and conducted the survey. Upon completion, the participant received an honorarium from an on-site staff member. We administered 38 (12%) surveys this way, and we conducted the remainder (n = 291) face-to-face.

**Results**

A total of 516 people were screened for eligibility, of whom 329 were eligible and participated. Almost one-third (29.5%) of participants were women, two-thirds (67.5%) were men, and the remaining (3.0%) participants indicated they were transgender, gender nonconforming, or “other.” Reported racial and ethnic identities included 32.2% Hispanic/Latinx, 27.1% White, 21.9% Black/African American, 16.1% multiracial, 0.6% Asian, and 2.1% another race. The average age of participants was 45.7 (SD = 10.5; range, 19-69), and 53.8% of participants were aged ≥45. A relatively equal distribution resided in Manhattan (26.4%), the Bronx (25.5%), and Brooklyn (21.3%); fewer participants were from Staten Island (8.8%) and Queens (8.5%); and the remainder (9.4%) resided outside of New York City or were transient. Two-thirds (67.0%) of participants were currently engaged with an SSP.

**Practice Implications**

Tele-remote research and surveillance methods have been promoted for the benefit of keeping staff members and participants safe during the COVID-19 pandemic. Although recommendations exist to guide transitions to tele-remote methods, information about conducting safe and effective in-person interviews during the pandemic is limited. Face-to-face recruitment and data collection are the optimal ways to engage participants who might not have access to technology, a home, or regular access to health care services. As vaccinations roll out and nonessential research resumes, we...
provide lessons learned from an in-person survey of PWUO during the COVID-19 pandemic, including recommendations for researchers considering similar work.

**Building Rapport While Wearing Personal Protective Equipment**

When possible, the data collection period should align with temperate weather so that interviews can be comfortably conducted outside, where COVID-19 transmission is reduced, and staff members and participants can adhere to CDC physical distancing guidelines. Staff members found that maintaining physical distance was sometimes challenging, because participants naturally gravitated toward interviewers administering the survey, prompting the need for reminders to maintain a 6-foot distance. It is important, therefore, to build rapport with participants upfront so requests to maintain distance are not perceived as stigmatizing.

Staff members were trained to use personal protective equipment and how to communicate proper use of personal protective equipment to participants. Most participants we encountered had a face mask and used it without having to be asked. However, we recommend that researchers carry extra face masks for people who do not have one or, more commonly, to replace a face mask that has been heavily used.

Social interactions between strangers have been less frequent as a result of the pandemic, and many people were initially wary of survey staff members. To build rapport, staff members should introduce themselves clearly and check in with participants to see how they are doing before diving into the survey protocol. Wearing a face mask also makes it difficult to communicate empathy and build trust through facial expression. In response, we took time to ensure potential participants were comfortable speaking with us before commencing the survey.

**Benefits of Face-to-Face Interactions**

Some participants who were offered the option of completing the survey via telephone declined and chose to wait to complete the interview face-to-face with an on-site staff member, often expressing a mistrust in talking about their drug use with someone they could not see. In addition, many participants did not have their own telephone or did not want to use their limited telephone plan minutes. When participants did agree to complete the survey by telephone, building rapport and trust was more difficult than in-person interviews, and surveys took longer to administer because questions often had to be repeated because of street background noise.

Although the quality of the data collected between the 2 methods (ie, by telephone or in person) was similar in regard to missing or declined items (1.3% missing or declined for in-person interviews compared with 0.5% for interviews conducted by telephone), many participants chose not to participate by telephone, stating they would prefer to wait and participate with a person they could talk to face-to-face. Furthermore, participants who completed the interview by telephone indicated it took too long and was repetitive. Finally, in-person recruiting through SSPs but conducting the surveys tele-remotely (ie, our back-up plan) would have excluded many of our participants not only because of the lack of telephone access described previously but also because of the challenges of distributing stipends to people with little access to email or a stable postal address. The alternative option of relying on SSP staff members to distribute honorariums after the fact would have been an additional time burden on staff members who were already overstretched.

**Minimizing Participant Burden**

Although administering the survey and paying participants in person was ideal, it was still important to minimize the energy and time it required. Although conducting interviews outdoors helped ensure safety, it was physically exhausting for staff members and participants. Places to sit were scarce while conducting interviews, and both participants and staff members had difficulty accessing public bathrooms. Although SSPs remained open during and after stay-at-home orders because of their status as essential services, many worked out of mobile vans and drop-in spaces were closed. Survey questions and answers had to be repeated frequently because of street noise and the difficulties that wearing a face mask imposed on communication. Individual surveys were conducted at a distance from other people to maintain participants’ privacy, but this sometimes meant administering surveys in areas that were loud because of traffic or other street noise. Perhaps most important was limiting the time required for study participation to about 30 minutes, after which many participants became tired.

The honorarium for participating in the survey was important to participants, because many of them were experiencing extreme financial difficulty from the COVID-19 pandemic. In addition to receiving the honorarium, everyone who was engaged as part of the recruitment process was offered hygiene products and a naloxone (Narcan) kit. In response to requests from participants, staff members also started distributing water and hand sanitizer.

**Supporting Surveillance Staff Members and Collaborating With Community Partners**

Limiting the time staff members spent conducting interviews each day was also necessary to prevent staff member burnout. Although the team collectively had many years of experience administering in-person surveys, the added complications of doing this work during a pandemic took its toll. The time staff members spent recruiting and interviewing participants was limited to a maximum of 4 or 5 hours each day, and taxi
transportation was provided to and from interview sites. Avoiding public transportation helped staff members feel safer and reduced psychological exhaustion. Collaboration and consultation with local SSPs, community partners, and drug use researchers throughout New York City was crucial to this project’s success and enabled the identification of new locations where PWUO were congregating. Many of the usual locations (eg, train stations, outside storefronts) were no longer places where the public, and especially PWUO, could congregate because of stigma and/or restrictions to the use of public spaces. Identifying new locations helped staff members reach people not connected to SSPs or treatment programs. It is important to note how critical SSPs and other harm reduction services were to this project. Despite great challenges, SSPs have filled gaps in services for PWUO while other social service facilities temporarily closed. In addition, much of the conducted research specific to PWUO has been made possible through collaborations with SSPs, demonstrating a great generosity in the face of already challenging circumstances.

This article describes the methods and lessons learned during an annual survey of PWUO conducted in the early months of the COVID-19 pandemic. Our role as health department officials and our project’s status as public health surveillance enabled us to conduct this work despite the pandemic. Disasters, including pandemics, require rapid data collection to understand the needs of marginalized communities, and researchers need to establish sufficient and safe methods for data collection during these events. Marginalized communities had greater housing, economic, and food insecurity compared with the general population during the COVID-19 pandemic. It is our hope that these recommendations and lessons learned can help inform future surveillance and research efforts, not just during the COVID-19 pandemic but also during public health disasters more generally.

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