

APPLYING POPULATION ESTIMATION METHODS IN RURAL AMERICA

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This toolkit was supported by a grant from the Bloomberg American Health Initiative at the Johns Hopkins Bloomberg School of Public Health to Dr. Sean T. Allen. This research has been facilitated by the infrastructure and resources provided by the Johns Hopkins University Center for AIDS Research, an NIH funded program (P30AI094189), which is supported by the following NIH Co-Funding and Participating Institutes and Centers: NIAID, NCI, NICHD, NHLBI, NIDA, NIMH, NIA, FIC, NIGMS, NIDDK, and OAR. Dr. Allen is also supported by the National Institutes of Health (K01DA046234). Kristin E. Schneider is supported by the National Institute on Drug Abuse (5T32DA007292-25). The funders had no role in developing the toolkit and it does not necessarily reflect views or opinions of the funders. We are grateful for the collaboration of the Cabell-Huntington (WV) Health Department, without whom the research discussed in the toolkit would not have been possible. We are especially grateful to Thommy Hill, Tyler Deering, Kathleen Napier, Jeff Keatley, Michelle Perdue, Chad Helig and Charles “CK” Babcock for their support throughout the study. We are also grateful for the hard work of the West Virginia COUNTS! research team: Megan Keith, Anne Maynard, Aspen McCorkle, Terrance Purnell, Ronaldo Ramirez, Kayla Rodriguez, Lauren Shappell, Brad Silberzahn, Dominic Thomas, Kevin Williams and Hayat Yusuf. We gratefully acknowledge the West Virginia Department of Health and Human Resources. We also wish to acknowledge Josh Sharfstein, Michelle Spencer, Dori Henry and Akola Francis for their support throughout each phase of this project. Most importantly, we are grateful to our study participants.

INTRODUCTION TO THE TOOLKIT

The United States is in the midst of an unprecedented opioid epidemic. In order to implement effective population-level response strategies to this epidemic, health departments and community-based organizations must understand both the size and characteristics of the local population affected. Local data regarding the opioid epidemic are sparse and don't fully characterize the population of those most affected, such as people who inject drugs (PWID). Without these data, it is difficult to know which epidemic response strategies are meeting the most pressing community needs and whether services are delivered at the appropriate scale. For these reasons, we developed this toolkit for population size estimation with specific emphasis on applying population estimation methods among PWID in rural communities.

This toolkit seeks to:

- Provide background information on the opioid epidemic in the United States.
- Describe how to define a population of interest for population size estimation.
- Introduce population estimation strategies.
- Fully detail the capture-recapture strategy for population size estimation.
- Review data collection strategies for population size estimation.
- Discuss how to design data collection instruments for population estimation studies.
- Present issues surrounding the implementation of population estimation studies.
- Discuss lessons learned from implementing a population estimation study in rural Appalachia.

Background

THE NATIONAL OPIOID EPIDEMIC

The consequences of the opioid epidemic can be found in every community in the United States. In 2016, there were an estimated 11.8 million people aged 12 or older with past-year opioid misuse, including an estimated 948,000 individuals with past-year heroin use.¹

Opioid Overdoses

Overdose is one of the most devastating consequences of the opioid epidemic. Provisional data suggest that more than 72,000 overdose fatalities occurred in 2017.² Among these deaths, an estimated 49,068 — more than 68% — involved opioids. Despite ongoing efforts to reduce overdose fatalities, the number of deaths continues to increase. According to the Centers for Disease Control and Prevention (CDC), in 2017, the number of overdose deaths involving opioids was 5 times higher than in 1999. The rise in overdose fatalities is in part attributed to illicitly manufactured fentanyl.³ Fentanyl is a synthetic opioid that is 50 to 100 times more potent than morphine and is often mixed into street drugs.⁴⁻⁶ People who use drugs are often unaware that their drugs contain fentanyl, escalating the potential for overdose.

HIV, Viral Hepatitis and Opioids

The opioid epidemic also threatens to reverse the progress we have made in preventing the incidence of blood-borne infections, particularly those attributable to injection drug use (IDU) such as HIV and viral hepatitis. The opioid, HIV and viral hepatitis epidemics are closely linked as sharing syringes

and other injection equipment carries a significant risk of infection. According to the CDC, only an estimated 1%-3% of the US population injects drugs; however, PWID account for 6% of incident HIV diagnoses in the U.S.⁷ An outbreak in rural Scott County, Indiana, exemplified injection drug use-associated risks for infectious disease outbreaks among PWID when, between November 2014 and October 2015, 181 people were diagnosed with HIV. Among those infected, 92% were also co-infected with the Hepatitis C virus (HCV).⁸ Following the Scott County HIV/HCV outbreak, research was conducted to identify areas in the U.S. that were vulnerable to similar HIV/HCV outbreaks. The study identified 220 counties in 26 states that were vulnerable to comparable outbreaks (Fig 1). These counties were concentrated in Appalachia and predominantly rural.⁹

Figure 1. Map of Top 220 Counties Vulnerable to HIV/HCV Outbreaks⁹





Rural Communities and Opioids

Research has shown that there are numerous differences in drug use and associated risk behaviors between urban and rural areas. For example, adolescents in rural communities are more likely than those in urban areas to abuse prescription opioid analgesics.¹⁰ Studies have also described rural-urban differences in routes of administration and onset for use of nonmedical prescription opioids.^{11,12} There are also differences between urban and rural areas in terms of access to evidence-based drug treatment options, such as medication-assisted treatment.¹³⁻¹⁶ Rural residents may also have limited transportation options and be unable to access treatment providers.

Opioid Response Strategies

Communities throughout the U.S. have implemented a variety of initiatives to combat the opioid epidemic. Collectively, these efforts have shown that there is no silver bullet to the opioid epidemic.¹⁷ Addressing the epidemic requires multiple interventions, evidence-based policies and innovative collaborations among stakeholder groups (e.g., law enforcement, first responders, public health officials, policymakers). It also requires understanding the public health benefits that can be achieved through effective treatments for opioid addiction. For example, according to the National Institute on Drug Abuse, the use of medication assisted treatment has been associated with decreases in opioid use, opioid-related overdose fatalities, criminal activity and infectious disease transmission. In addition, here are three low-threshold evidence-based strategies that are targeted toward PWID:

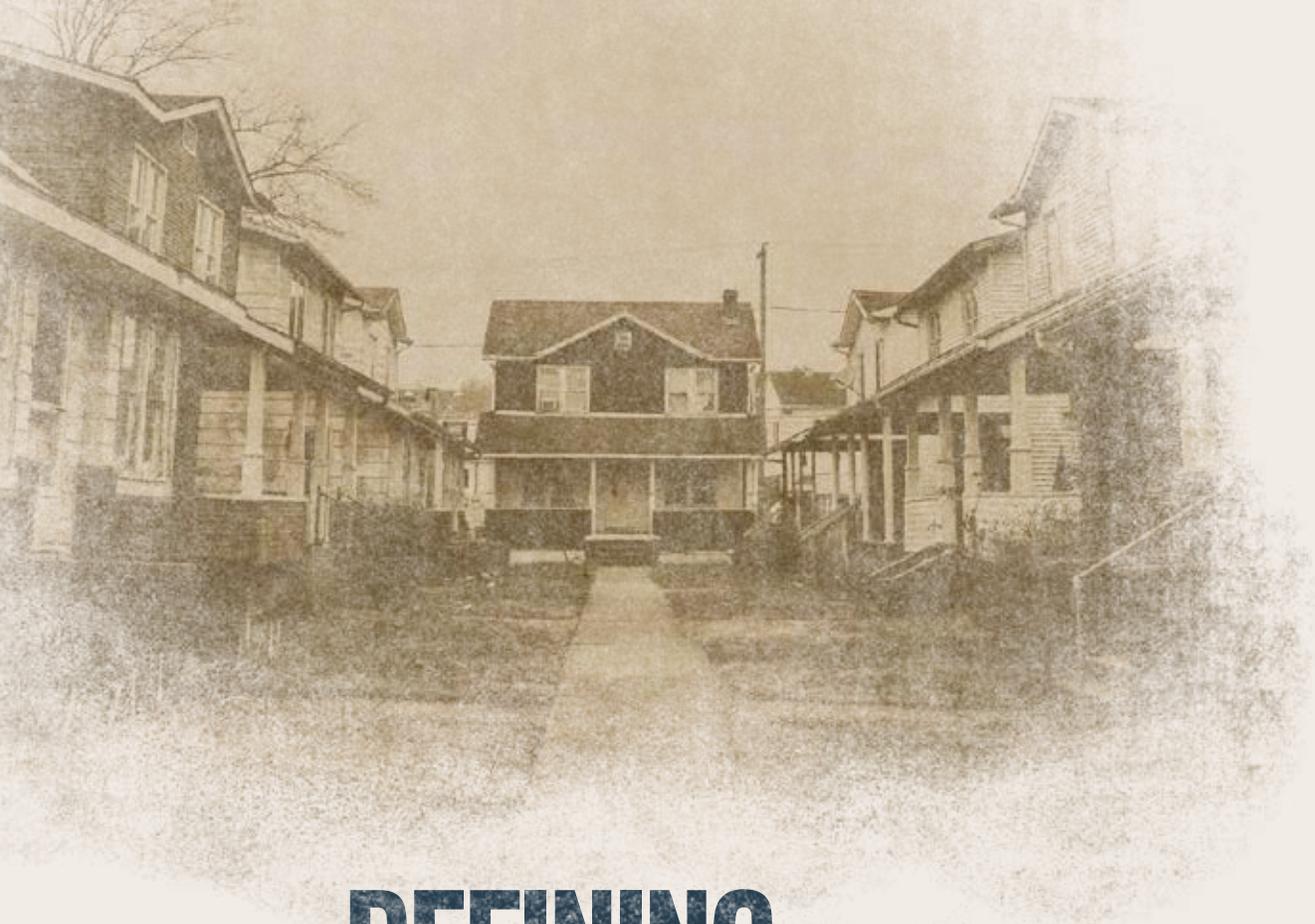
Implementing Syringe Services Programs: Syringe Services Programs (SSPs), also known as needle and syringe exchange programs, may provide numerous services to PWID, including: access to sterile injection equipment, referrals to drug treatment programs, wound care, and provision of overdose prevention resources.¹⁸ SSP utilization is also associated with reductions in high-risk injection practices, such as syringe sharing.¹⁹ These reductions in high-risk injection behaviors are of particular importance given the increasing number of PWID and escalating community-level risks for HIV/HCV outbreaks.^{20,21} Research has shown that SSPs reduce

the transmission of HIV among PWID and are cost-effective.²²⁻²⁷ For example, a 2016 study in Washington, D.C., found that SSP implementation resulted in a net savings of more than \$44 million USD via the aversion of 120 new HIV infections among PWID in a two-year period.²⁷ SSP operations can take many forms (e.g., operating from a single fixed site or providing services from a mobile van). However, communities should follow established best practices²⁸ when implementing SSPs, including:

- Ensure low-threshold access to SSP services, for example by maximizing the times and locations where people may acquire sterile injection equipment.
- Minimize administrative burdens associated with utilizing SSP services.
- Promote syringe access by not imposing restrictions on the number of syringes a person may receive.
- Provide SSP services anonymously.²⁸

Increasing Access to Naloxone: Naloxone is a non-addictive medication that rapidly reverses opioid overdose.²⁹ There are three formulations of naloxone that are approved by the Food and Drug Administration: an injectable formulation, a prefilled auto-injection device and a nasal spray.³⁰ Notably, in the era of fentanyl, multiple doses of naloxone may be required to reverse overdose.³¹ Increasing access to naloxone has been shown to reduce overdose fatalities.³² Importantly, naloxone can be provided at many different locations in community settings, such as health departments, pharmacies and SSPs.³³

Fentanyl Testing Strips: To prevent fentanyl-related overdose fatalities, people who use drugs can screen their drugs for the presence of fentanyl via fentanyl testing strips. A 2018 study found that fentanyl testing strips had high sensitivity and specificity for fentanyl detection. This study also showed that people who use drugs viewed fentanyl detection as a viable strategy to prevent overdose. Furthermore, 70% of study participants reported that if they knew fentanyl was in their drugs they would modify their behavior (e.g., not use the drugs, use the drugs slowly or use drugs only in the presence of persons with naloxone).³⁴



DEFINING YOUR TARGET POPULATION

The opioid epidemic has created an environment where multiple needs must be met simultaneously. Access to sterile injection equipment, drug checking technologies, naloxone, hepatitis vaccinations and treatment, HIV prevention resources, and drug treatment are needed for individuals who misuse opioids. To ensure that these resources are provided at the appropriate scale, communities must first understand the size and characteristics of the affected population. Conducting a population estimation study is one strategy that may be employed to inform strategic resource allocation and tailored program planning. The remainder of the toolkit outlines the process of planning and conducting a population estimation study.

The “Who” of your target population

The first step to any population size estimation effort is to define the specific population to be measured. A population is made up of individuals with similar characteristics. It is vital to precisely define the characteristics of your population of interest. To start, identify any of the pertinent characteristics or behaviors that define the community. Increasing specificity can enhance your results’ utility. For example, simply targeting “people who use drugs” may not offer a great deal of utility as this would include people who may have used drugs once in their lifetime as well as those who are currently using. People may also have varying definitions of what constitutes “drugs.” This is an important consideration given the evolving legality of marijuana.

In implementing a population estimation study, one must also consider the degree to which the target population is hidden. “Hidden” populations are comprised of people who are connected through social ties, shared behaviors or historical circumstances and who cannot be easily reached for research purposes or targeted by public health initiatives given the illicit and/or stigmatized nature of their behaviors. Hidden populations may also choose to remain hidden due to lack of trust stemming from adverse experiences in the past at the individual or group-membership levels (e.g. Native Americans or persons that identify as lesbian, gay, bisexual, transgender, or queer [LGBTQ]). Hidden populations may also be difficult to engage in studies due to geographic isolation, such as those who reside in rural areas.³⁵ There are many reasons why PWID may be considered a hidden population. Stigmatization of drug use, reluctance to disclose illegal behaviors, mistrust of people and institutions, and fear of legal consequences may act as barriers for PWID to engage in a population estimation study. Ideas for overcoming these barriers are discussed in the “Data Collection Strategies” section of this toolkit.

The “When” of your target population

After defining the population characteristics, next operationalize the time period of interest of a given behavior for the target population. Defining the time period has important implications for the findings of your study. For example, a target population could be people who have ever injected any drug (including those who do not currently inject) or people who have injected drugs in

the past six months. The overall goal of the population estimation study should inform what time interval is selected. A study that aims to calculate the number of people with recent histories of injection drug use, for instance, may focus exclusively on those who have injected in the past 6 months. On the other hand, a study that aims to better understand potential experiences of people with any history of injection drug use may focus on “people who have ever injected drugs.”

The “Where” of your target population

Next, specify your geographical area of interest. This step is essential to population estimation studies as it defines the sampling approach. For example, is the area of interest an entire county or a given community? Does the study focus exclusively on residents of a given geographical area? Or, does it include non-residents who work in or visit the area? For opioid epidemic research, it may be prudent to focus on PWID who engage in any activities (including both drug use and recreation), regardless of residence, in a defined geographic area, as they likely interact with other PWID who reside in the target area. Alternatively, if residency restrictions are in place for service provision (e.g., restricting SSP utilization to county residents), limiting data collection to a defined geographic area and its residents may be prudent. The issue of geographical boundaries for population estimation studies, especially those among PWID, should be thoroughly discussed prior to beginning a study. It has broad impacts on the final population estimate as well as its applicability to strategic resource allocation and jurisdiction-level policies.

Worked Example: Defining your target population

To define your target population, it may be useful to first gather key stakeholders. Define the population of interest as a group and in the broadest terms possible. It can be beneficial for the group to discuss how to refine the operationalization to maximize its utility. For example, your interests may be in quantifying the number of people who may benefit from accessing sterile injection equipment at an SSP. As shown in Figure 2, you may start with a broad definition, “people who have used drugs of any form,” and, after multiple refinements, be left with a clearly defined target population, “people who have injected drugs in the last 6 months and who reside in your county.”

Figure 2.

START

People who have used drugs of any form



1ST REFINEMENT

People who have injected drugs



2ND REFINEMENT

People who have injected drugs in the last 6 months



3RD REFINEMENT

People who have injected drugs in the last 6 months and who reside in your county

POPULATION ESTIMATION STRATEGIES



There are multiple population estimation methodologies that could be used in opioid epidemic research. The following text is adapted from population estimation guidelines developed by the UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance.³⁶

The *census method* is a direct method for population estimation in which every individual in the group of interest is counted. Depending on the number of people in the target population and their relative geographic distribution, the census method may be costly to implement. Next, the *enumeration method* involves developing a complete list of all the locations where the target population can be found and then sampling people from some of those locations. The numbers counted in the sampled locations can then be used to estimate the numbers that would have likely been identified in the non-sampled locations. Importantly, the UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance states that census and enumeration methods tend to produce underestimates of the actual population size among hard-to-reach populations. The *multiplier method* is another strategy that may be used and requires the use of two independent data sources, typically one source from a program or service provider and one collected by a research team. In this method, data are collected from the target population to ascertain whether they accessed services at the program or service provider that was used

as the first data source. The population estimate is then calculated by dividing the number of people who received the service by the proportion who reported receiving the service. Importantly, to conduct the multiplier method, the data sources must be independent, able to define the target population in the same way, have the same time period, and cover the same geographic regions. The data sources must also be representative of the target population.³⁶ Finally, the *capture-recapture method* for population estimation involves two independent phases of data collection in which members of the target population are surveyed.³⁷ This method has been widely used in public health research among hidden populations and is described in detail in the following pages.

THE CAPTURE-RECAPTURE METHOD FOR POPULATION ESTIMATION

The capture-recapture (CRC) method is an effective strategy used to estimate the size of hidden populations. It was first used in 1662 to estimate the population of London and was adapted to estimate the size of animal populations in the 1900s.³⁶

The CRC method has also been used widely in the realm of public health. For example, it has been used to estimate the population sizes of female sex workers, PWID and refugees.³⁸⁻⁴² The CRC method works by counting all members of the target population in a given area (called the “capture phase”) and then returning to locations frequented by the target population to count the target population again (called the “recapture phase”) (Fig 3). During the recapture phase, counted persons should be identified as either individuals who were not counted during the capture phase or as recounted individuals (those who were also counted in the capture phase). The population size can then be estimated by

multiplying the number of individuals counted in the capture phase by the number of individuals counted in the recapture phase. That number is then divided by the number of individuals who were counted in both phases (Fig 4).

It is also recommended that calculations be conducted to create a 95% confidence interval around your population estimate. The 95% confidence interval provides a high and low population estimate that you can be 95% certain contains your true population estimate. Figure 4 provides the formula for calculating a 95% confidence interval.

Figure 3. The Capture-Recapture Method

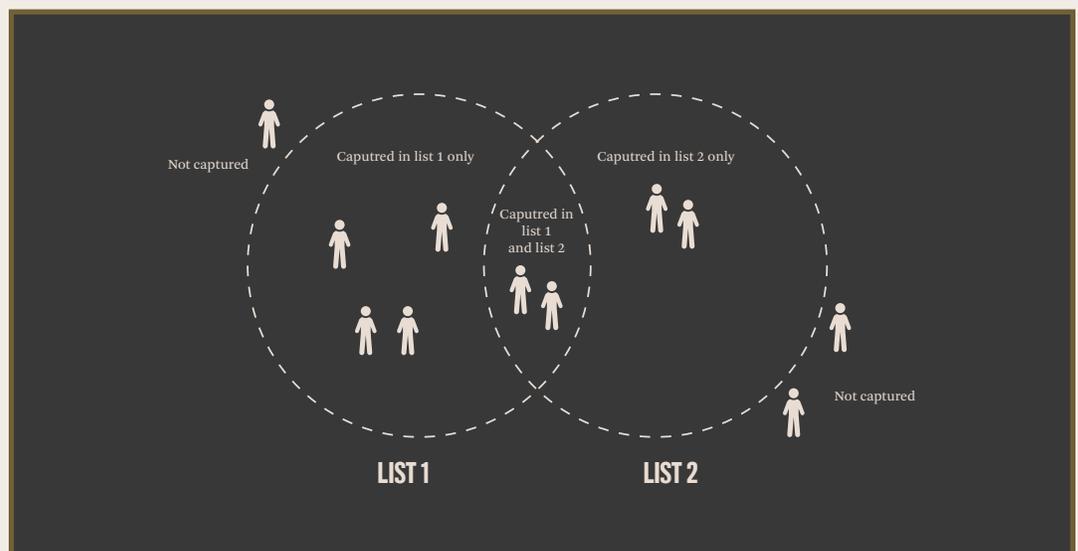


Figure 4. Capture-Recapture Estimation Formula

USING THE FOLLOWING ESTIMATION FORMULA

C1=Capture Phase Count
 C2=Recapture Phase Count
 M=Recaptures (those counted during the first and second phase)

Population Estimate = $\frac{C1 \times C2}{M}$

95% Confidence Interval = $N \pm 1.96 \sqrt{\text{Var}(N)}$, where $\text{Var}(N)$ is calculated as follows:

$\text{Var}(N) = \frac{((C1 \times C2)(C1 - M)(C2 - M))}{(M)^3}$

The following example (Fig. 5) demonstrates how a population estimate and associated 95% confidence interval could be calculated for a city that aimed to estimate the number of people who have dogs for pets. During the capture phase, 1,000 surveys were conducted in areas frequented by people who have pets (e.g., public parks). Of those surveyed, 750 unique individuals indicated owning a dog. During the recapture phase, another 1,000 surveys were conducted in other venues where people who have pets congregate. Of those surveyed in the recapture phase, 700 indicated owning a dog. Among those surveyed in the recapture phase who were dog owners, 200 had also completed the survey during the capture phase. Using the formulas described above, we can estimate the number of dog owners in the city as follows:

Figure 5. Population Estimation Example

C1= 750
 C2=700
 M=200

Population Owning Dogs = $\frac{(750 \times 700)}{200} = 2,625$

95% Confidence Interval = $N \pm 1.96 \sqrt{\text{Var}(N)}$, where $\text{Var}(N)$ is calculated as follows:

$\text{Var}(N) = \frac{((C1 \times C2)(C1 - M)(C2 - M))}{(M)^3} = \frac{((750 \times 700)(750-200)(700-200))}{(200)^3} = 18,047$

95% Upper CI = $2,625 + 1.96 \sqrt{18047} = 2,888$

95% Lower CI = $2,625 - 1.96 \sqrt{18047} = 2,362$

Our final population estimate of people who own dogs in the city is 2,625 (95% Confidence Interval: 2,362 to 2,888)

The CRC method can also be applied by using independent data sources in which people can be matched across datasets, such as registries or other public health records.³⁶ However, indirect CRC methods can be challenging to implement given sparse data sources that contain detailed information about stigmatized behaviors, such as injection drug use.

What is a “tag” or “token”?

When conducting a CRC study, it is important to be able to correctly identify members of the target population who participated in each phase of the study. In practice, this is typically achieved by giving participants incentives or other memorable items (e.g., t-shirts, bags) during each study phase as “tags” or “tokens.” For example, a 2015 study that estimated the number of PWID in Washington, D.C., gave participants a toiletry kit labeled with a project logo sticker.³⁸ Providing incentives with branding of the study name or logo is one strategy that may make it easier for participants to remember their participation in your study. Participants can then be asked if they previously received a “tag” or “token” as part of their participation in the study. While it is important that the tags/tokens be memorable, it is equally important that they be distinct from other items local studies or programs disseminate. For example, if a program distributes toiletry kits, you would not want to use a toiletry kit as a token since it may be confusing for participants to distinguish where they received the item and in what context.

Five Assumptions for CRC Population Estimation

To properly implement a CRC population estimation study, one must ensure that the study design meets the five assumptions described below.^{36,37} Prior to beginning your CRC study, we recommend comparing the study design with the five assumptions and recording how your design addresses these key assumptions. Depending on what resources are available to support a CRC study, it may be useful to collaborate with public health professionals who have prior experience conducting population estimation studies to ensure your study design does not inadvertently violate one of the assumptions.

Assumption 1: The population is closed.

For CRC population size estimates to be accurate, the population that could be captured should be the same population at both the capture and recapture phases.^{36,37} This assumption refers to the relative

stability of the population; in other words, the degree to which the population size is constant. However, as noted by Gold et al, “In general, there are no populations that remain completely unchanged during the research period.”⁴² To limit the potential influence of in- or out-migration, one should shorten the time period between the capture and recapture phases and when applicable, avoid sampling on anomalous days, such as those that attract substantially more or less of the target population. For PWID CRC studies, anomalous days could include periods of targeted enforcement campaigns by law enforcement, city festivals that attract people to a community or extreme weather conditions (e.g., tornadoes). During these times, it may be difficult to identify your target population and collect representative data.

Assumption 2: Individuals captured in both samples can be matched. For a CRC population estimate to produce reliable estimates, you must be able to correctly identify people who participated in each phase of data collection.^{36,37} For studies that use the direct contact approach, this could be achieved by using a memorable token (described above) and asking people if they previously completed the data collection instrument and received the token. For those studies that do not use direct contact with the target population (e.g., those that use registries), people must be able to be linked across datasets by individually identifiable characteristics. Given that some people may have the same or highly similar names, we recommend matching across multiple fields if this approach is used (e.g., match across datasets on first name, last name, date of birth, race, and gender). We suggest that you conduct stakeholder interviews prior to launching a study among PWID, to determine what type of matching persons are most comfortable with. Stigma and fear of data being used by law enforcement may drive people to prefer anonymous data collection;

in which case, using memorable tokens and questions about previous participation in the survey may be preferred.

Assumption 3: Every member of the target population has an equal chance of being caught in the sample. It is essential that all members of the target population have an equal chance of participating in a CRC population estimate.^{36,37} For this assumption to be tenable, invest considerable effort before launching data collection in understanding the geotemporal distribution of the target population’s activities. This is especially important for CRC population estimates that focus on PWID as there may be different segments of the population that can be found at distinct, and potentially non-overlapping, times and locations. For example, a PWID population likely includes those who are unemployed and marginally housed as well as those who are employed and stably housed. A CRC study among this population must ensure efforts are directed toward both groups because focusing only on one segment of the population would result in an undercount of the population.

Assumption 4: The two samples are independent. CRC population estimates should be implemented in such a way that participation in the first phase of data collection does not increase or decrease the likelihood that someone will also participate in the second phase.^{36,37} In practice, this can be achieved by clearly defining the locations for the capture and recapture phases. For example, in a 2015 study that aimed to estimate the PWID population in Washington, D.C., data collection during the capture phase occurred at syringe services programs, while the recapture phase occurred in community locations known for drug use and via secondary exchange networks among PWID.³⁸ In studies implemented with no direct contact, researchers should confirm the independence of the registries and account for temporal lags.

Assumption 5: The sample size for each phase is large enough to be meaningful.

CRC population estimates with small samples or very little overlap between the two phases may not produce useful results.³⁶ The CRC method allows researchers to generate a point estimate as well as a 95% confidence interval. If there is very little overlap between the two phases of data collection, the confidence interval will be very large. A CRC study that yields a population estimate with a confidence interval that spans many thousands of people may not be informative for community organizations or policymakers. Similarly, a study that terminates data collection prematurely or struggles to access the target population may not have data representative of the population. Notably, there are no strict rules regarding what should be considered a sufficient amount of data collection. That said, if a population is very small in number or very narrowly defined (e.g., PWID that have injected crystal methamphetamine in the last 24 hours and are HIV positive) at the onset of a CRC study, a large volume of data collection may be required to access a reasonable number of the target population. In these scenarios, it may be useful to set inclusion criteria broadly.

DATA COLLECTION STRATEGIES FOR POPULATION ESTIMATION

The next step in developing a population estimation study is determining your data collection approach. The following section will provide an overview of some key issues, including defining your inclusion criteria, deciding between confidential and anonymous data collection, and determining your sampling area.

Inclusion Criteria

Inclusion criteria refer to characteristics a person must have to be included in your study. If you've clearly defined your population, you can use those characteristics to guide your inclusion criteria. For example, age (e.g., 18 or older) and being able to speak English are often used as inclusion criteria. Special attention must be given to ensure your target population is fully captured by the inclusion criteria; overly broad criteria could lead to a waste of resources. That said, you may also broaden inclusion criteria to reduce stigmatization of illegal behaviors, such as setting inclusion criteria as having ever injected drugs rather than having injected drugs in the past day. Key informant interviews can help determine what criteria are most useful to capture the target population without causing people to avoid participation due to stigma.

Confidential vs. Anonymous Data Collection

Protecting participants' privacy is essential in research, especially when dealing with hidden populations engaging in illegal behaviors. There are multiple strategies that may be employed to protect participants, foremost of which is deciding whether data collection will be confidential or anonymous. Confidential data collection means that the study will collect identifiable information, such as names, addresses, dates of birth, phone numbers, etc.

Collecting identifiable information may deter people from participating in studies if they are asked to disclose sensitive or illegal behaviors. Anonymous data collection, on the other hand, does not involve recording any identifiable information. In studies involving substance use, the target population may prefer anonymous data collection. Importantly, you must also consider whether data collected anonymously could be indirectly identifiable. For example, a study in a rural community that collects demographic data could unintentionally lead to the exposure of a participant.

Determining Sampling Areas

Determining where to recruit the target population is a critical step for all population estimation studies. These locations can be identified via geospatial analyses of secondary data (e.g., locations of overdose fatalities) as well as via key informant interviews with members of the target population or service providers. Ideally, one should employ all of these strategies to identify where and when to engage the target population. Data triangulation could ensure that you efficiently use resources and comprehensively survey the target population. While it is ideal to survey as many members of the target population as possible, one should remember that is not always possible given resources and other considerations (e.g., geographic isolation, safety).

INSTRUMENT DESIGN: WHAT QUESTIONS TO ASK AND HOW TO ASK THEM

Carefully designing your data collection tool is one of the most important steps of any research effort. The following sections provide an overview of issues to consider.⁴³

Surveys

Surveys, or questionnaires, are written data collection tools that participants complete. All surveys should be written at a level that can be understood by your target population. If a population has low literacy, one may consider collecting data via Computer Assisted Personal Interviews (CAPI) in which study staff read questions to participants and record their answers on a tablet. Similarly, data could be collected via audio computer-assisted self-interview (ACASI) in which questions and answers are read to participants via headphones.

Paper-based vs. Digital Data Collection

Implementing a population estimation study also requires you to decide between using paper-based or digital data collection tools. Paper-based surveys require data entry. They may also make participants less likely to answer honestly about illicit behaviors if they believe that you will review their responses. In contrast, using electronic devices, such as tablets, for data collection does not require data entry but may intimidate participants uncomfortable with using the devices. Staff can help alleviate this issue by guiding participants through technical difficulties. Electronic devices for data collection can also have skip patterns, or rules for skipping questions based on previous responses, preprogrammed into the survey.

Selecting Questions

The questions you select for your data collection tool depend on the goals of your study. Different types of questions you may want to ask include ones about sociodemographic characteristics, knowledge and attitudes/opinions. Sociodemographic characteristics include race, gender, age, education, housing status

and employment status. Knowledge questions deal with objective information, and the questions are presumed to have a correct answer. Opinion questions refer to personal views or beliefs about a topic. Such questions often ask people to rate how much they agree or disagree with a statement. Attitude questions deal with bundles or groups of opinions about complex topics. Multiple questions are often needed to assess an attitude. Importantly, when designing a survey, you should give special attention to the overall length of the instrument. Long surveys can fatigue participants and cause them to randomly select answers or quit the survey prematurely.

Response Options

When designing a survey, one must first decide if the items will be open-ended (i.e., participants can respond however they choose) or close-ended (i.e., there are fixed response options). Open-ended questions can enable participants to talk about whatever comes to mind and provide more comprehensive answers. However, these answers can be difficult to process and analyze. People with low literacy may also struggle to provide detailed answers for open-ended items. Close-ended questions are dependent on the structure of the responses. Inadvertently omitting some categories can lead to incomplete data capture; therefore, researchers should thoroughly pilot test all instruments with members of the target population before implementation. Relatedly, providing too many options may overwhelm participants. It is also important to balance positive and negative response options. For example, if you include “strongly agree” and “somewhat agree” options, you should also have equivalent disagree options, “strongly disagree” and “somewhat disagree.” Examples of these types of questions are shown in Table 1.

Table 1.

QUESTION CONTENT TYPE	OPEN-ENDED EXAMPLE	CLOSE-ENDED EXAMPLE
Knowledge	What are the differences, if any, between HIV and AIDS?	Which of the following is true about HIV and AIDS? (1) HIV is the virus that causes AIDS. (2) Only men can get HIV. (3) There are no differences between HIV and AIDS.
Opinion	How do local police treat people who use drugs?	How do you think police treat people who use drugs? (1) Very fairly (2) Somewhat fairly (3) Somewhat unfairly (4) Very unfairly
Attitude	How would you describe the amount of time you spent talking to your doctor at your last appointment?	Please select how much you agree or disagree with the following statement: During my last appointment with my doctor, we had enough time to talk. (1) Strongly agree (2) Somewhat agree (3) Somewhat disagree (4) Strongly disagree

Choosing How to Ask the Questions

When writing a survey question, there are several pitfalls to avoid that may unintentionally bias your results. First, the wording of the question should avoid jargon and acronyms (e.g., PWID) as these may confuse the participants. The wording should also be as precise as possible to ensure participants are responding to the question that you intended to ask. The phrasing of a question can also introduce bias or confusion. Unbalanced questions, where both sides of the question are not adequately represented, can encourage participants to respond in a biased manner. Some questions may also be loaded, meaning they encourage persons to respond in a particular way. Questions that have more than one question embedded in them are problematic as well, because they can make it difficult to determine which part of the question a participant is answering. Examples of these types of problematic questions are shown in Table 2.

Table 2.

PROBLEMATIC QUESTION TYPE	DEFINITION	EXAMPLE
Double Barreled	A question that has multiple questions embedded within it	Do you agree or disagree that drug use is a large problem in your community and that more drug treatment options should be available?
Loaded	A question that encourages participants to respond in a certain way	Do you agree or disagree that using drugs makes you unable to properly care for your children?
Unbalanced	Both sides of the question are not adequately represented	Do you agree that drug use is driven completely by an individual's inability to control themselves?

When writing questions, you should also avoid wordiness and complicated sentence structures. Brief, direct questions are often best. A general rule is that all the questions should be written at a fifth grade reading level or less so that they can be easily understood by participants. All questions should also have clear instructions, enabling the participant to know whether they should select one or multiple answers. It is also important to give participants recall periods, or periods of time to think about, when asking about past behaviors.

PRACTICE CONCERNS FOR POPULATION ESTIMATION

Once you have designed your data collection tool and identified your recruitment area the next step is to think about the practical elements of being in the field.

Safety

Before staff collect data, inform them of known potential safety concerns. Information about safety can be gleaned by conducting key informant interviews with members of the target population, people who reside in potential areas of data collection, and community stakeholders who regularly engage with the target population. Also, train staff on how to deal with unpleasant or unexpected situations in the field. One way to do this is by developing fictitious scenarios that staff act out, such as how to respond if someone is offended by a question on the survey. Finally, staff conducting opioid-related research should be prepared to administer naloxone, since they may encounter someone who has overdosed.

Participant Comfort

It can be beneficial to find ways to make participants comfortable while they complete surveys. In hot weather, for example, they might appreciate a bottle of water. A safe and secure space where people can take part in your study, such as on a study van, may also be useful.

Staff Training

It is critical to ensure staff are comfortable in their role and properly trained to administer the survey. Prior to data collection, all staff should familiarize themselves with the survey questions and administration methods so they understand what is being asked of participants and how to use the technology, if applicable. In addition, familiarizing staff with scenarios of situations they could encounter will increase participant and staff safety and improve data quality. Refreshers in the field can also be useful. More experienced staff members or team leaders should use real encounters with participants to reinforce the lessons and skills taught during pre-study training. Finally, study staff should complete human subjects research trainings, such as the CITI training program. Participants deserve respect and privacy during and after the study process, and such training can help prepare study staff.

Case Study

ESTIMATING THE NUMBER OF PWID IN RURAL WEST VIRGINIA

In June and July 2018, we implemented a study to quantify the size and characteristics of the population of PWID in Cabell County, West Virginia. The results of this study are detailed in a related publication.⁴⁴ Here we provide an expanded discussion of how we met the five assumptions of the CRC method during our study in rural Appalachia, as well as lessons learned.

ADDRESSING THE 5 ASSUMPTIONS OF CRC METHODS

To ensure the highest rigor in our CRC population estimate, we took multiple steps to address each of the five methodological assumptions.

Assumption 1: The population is closed. We scheduled the recapture phase just two weeks after the end of the capture phase. As noted in the UNAIDS guidelines, shortening the time period between the phases of CRC studies is an effective strategy to ensure this assumption is not violated.

Assumption 2: Individuals captured in both samples can be matched. To ensure people could be matched between the two study phases, we gave participants memorable tokens. During the capture phase, participants received a bright green bag filled with snacks. We found that people appreciated the bags — not only for their contents, but also because many of the target population were homeless and found them useful for storage. We chose bright green bags because they were memorable and similar to the school colors of a local university. The color allowed people to feel that they would blend in with the broader community and not be identified as PWID simply by possessing the bag. During the recapture phase, all participants received a \$10 grocery gift card. To match people between the capture and recapture periods, we included items on the survey that assessed whether people had previously completed the survey and received the bright green bag and/or the grocery gift card.

Assumption 3: Every member of the target population has an equal chance of being caught in the sample. During the capture phase, we addressed this assumption in two ways. First, all people who presented for harm reduction services (e.g., syringe exchange,

drug treatment referrals, naloxone) at the syringe services program were informed about the study and invited to participate. Second, all people who came to the health department who sought to participate in the study (e.g., individuals who heard about the study from previous participants) were allowed to participate if they met eligibility criteria. During the recapture phase, we ensured equal chance of participation by collecting data every day of the week and at varying times and locations. By implementing the recapture phase multiple days and at various times, we were able to ensure equal participation for all segments of the population, including those who work during the day, night and evenings or on weekends. We also had a large staff during the recapture phase that enabled us to saturate target areas with data collectors while maintaining safety.

Assumption 4: The two samples are independent. We ensured independence by collecting data at a syringe services program during the capture phase and in community locations where PWID congregate in the recapture phase. Notably, participants completed the survey during the recapture phase at a variety of venues, including public parks, transit locations, green spaces, neighborhoods known for drug-related activities, parking lots, apartments and businesses, gas stations, homeless encampments, on the stoops of abandoned properties, and sidewalks. By defining distinct venues for each phase, we achieved independence and were able to access different segments of the PWID population.

Assumption 5: The sample size for each phase is large enough to be meaningful. Although there are no strict rules for what constitutes a meaningfully large sample size for CRC studies, one should invest considerable effort to survey as many members of the target

population as possible. To achieve a meaningful sample size, we had each phase of data collection last two weeks. We selected two weeks for a number of reasons, including the overall cost of staffing and the frequency with which PWID came to the syringe services program at our partnering health department. Another way we ensured adequate sample size was by monitoring the number of people who reported having previously completed the survey during each phase. By monitoring the number of people who reported completing the survey more than once in each study phase, paired with analyses of daily recruitment, we were able to approximate when we achieved saturation in the population and end data collection.

LESSONS LEARNED IN RURAL APPLICATION

There were many lessons learned throughout our implementation of a CRC population estimation study in rural Appalachia.⁴⁴ We have organized our takeaways into four domains:

1. Staffing
2. Locating the target population
3. Working with PWID
4. Data collection

1. Staffing: Our implementation of a CRC study was enhanced by having a large, well-trained, demographically diverse staff that reflected a range of lived and work experience. For example, our staff included people formally trained in research methods and people who resided in the county of interest and similar rural communities. Our staff also included people in recovery, which not only increased our credibility with the target population but also afforded additional insights into how and where we might engage rural PWID in the study. We also learned the usefulness of investing heavily in staff training before implementing the study. Our staff members role played potential study scenarios, completed Naloxone overdose training, and familiarized themselves with the survey and the ACASI data collection system.

2. Locating the target population: Our study yielded several key lessons related to locating the target population. First, using heat maps of overdose fatalities and locations of syringe disposal were incredibly useful in identifying specific locations at which to engage the target population in the community (during the recapture phase). That said, stakeholder interviews about where and when to engage the target population were equally useful, given the fluidity of where and when PWID congregate. Stakeholder interviews also provided valuable insights into safety issues in each venue. In terms of systematically covering target areas, we learned that providing staff with maps of relatively small, defined geographic areas was better than giving them specific walking directions based on street intersections. The latter was time-consuming and often yielded few participants if not many people were in the target area. We also learned

that when recruiting PWID in remote rural areas, it is useful to first conduct windshield tours of the proposed survey location to identify whether they are viable areas for recruitment. Although many remote areas may contain members of the target population, based on our experience, they may not have viable locations in which to engage the population such as public parks, sidewalks, businesses, restaurants and other venues where PWID congregate.

3. Working with PWID: In order to enhance our ability to engage with rural PWID, we branded our CRC study as “West Virginia COUNTS!” and had staff wear bright green T-shirts and hats with the study logo. We also carried similarly colored bags filled with snacks. Staff also wore identifying badges that were created by our partnering health department. Collectively, this branding was an effective strategy that allowed PWID to rapidly identify study staff. It also enhanced our ability to engage with PWID by word of mouth. People knew to look for researchers in bright green shirts/hats if they wanted to participate. Throughout our study implementation, we also learned that members of the target population appreciated our efforts to support their needs when appropriate. For example, we referred many individuals to our partners at the Cabell-Huntington Health Department to receive drug treatment referrals, HIV/HCV testing, overdose prevention resources (e.g., naloxone) and sterile injection equipment. Staff also carried limited amounts of snacks and drinks for persons they engaged; we elected to do this given the heat and humidity on days we collected data as well as a way to keep persons engaged throughout the survey. We also learned early in the study that a large portion of rural PWID were marginally housed and experienced severe food insecurity. Providing small snacks and drinks, when possible, was another way to establish rapport with rural PWID. Our provision of snacks and drinks was not predicated on study participation, however, as that could have led to bias.

4. Data collection: Throughout our application of CRC methods in rural Appalachia, we learned many lessons related to data collection. First, ACASI enabled participants to answer the survey honestly and anonymously. Participants reported to study staff that this method of data collection made them more comfortable than they would have been had they answered the survey items verbally with staff. An additional benefit of collecting data via ACASI is that analysis is significantly easier because data do not have to be entered by hand. We also learned that it was essential to build in multiple items at the end of the ACASI survey to inform participants they were finished. We found that people’s curiosity would lead them to continue advancing through the survey even after they were informed they’d finished. Third, including an item at the end of each survey for staff to enter any comments or notes improved data collection. For example, if a participant reported answering a specific question incorrectly, we were able to clean



the data via staff notes. Fourth, and perhaps most important for CRC studies, we learned that while we wanted to survey as many members of the target population as possible, it simply was not possible. Although we generally found people to have a high degree of willingness to engage with our study team, some individuals did not want to complete the survey or did not have time to do so. When implementing CRC studies, one should undertake efforts to establish rapport with the target population and work to collect data from as many individuals as possible, but also recognize the limitations of the method and not potentially jeopardize community relations or staff safety in favor of overly exhaustive approaches to collecting data.

ESTIMATING YOUR POPULATION

As noted earlier in this toolkit, there are multiple strategies communities may use to estimate the size of their population of people who inject drugs. We developed an [online calculator](#) to demonstrate how the CRC method may be used to estimate not only the size of a PWID population, but also its estimated need for services. To demonstrate how population-level needs may vary, the calculator allows the user to input assumptions about service needs, such as number of syringes needed per day and the percentage of the population interested in treating their opioid use disorder. The calculator is an additional tool communities may use to better understand the CRC method and population-level needs for essential evidence-based response strategies.

CONCLUSION

In summary, population estimation methodologies can be successfully applied in rural communities to quantify the size and characteristics of populations of PWID. Through our study,⁴⁴ we estimated that approximately 1,857 people who inject drugs reside in Cabell County. These data reflect an estimated 2.4% population prevalence of injection drug use in the past six months among

Cabell County residents aged 18 or older. Through these data, we were able to identify significant risk behaviors for HIV and overdose and ascertain population-level needs for services (e.g., drug treatment). As rural communities continue to combat the opioid crisis, implementing a PWID population estimation study may provide important information that can be used to guide policy discussions, strategic resource allocation and scaling up of existing opioid epidemic response initiatives.

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