

# A Preliminary Estimate of the Number of People who Inject Drugs in Cherokee Nation using Capture-Recapture Methods

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## Research article

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# Abstract

**Background:** Injection drug use is an important public health issue in the United States, and estimates indicate that American Indian and Alaska Native people are disproportionately affected. Injection drug use is also the leading cause of Hepatitis C virus (HCV) infection in the United States, attributable to over half of all cases, and contributes to 44% of human immunodeficiency virus (HIV) acquisition in American Indian and Alaska Native females. Existing estimates of American Indian and Alaska Native people who inject drugs are limited. We aimed to estimate the number of people who inject drugs in Cherokee Nation.

**Methods:** A two-sample, capture-recapture approach was used. The first data source was an abstraction of Cherokee Nation Health Services electronic medical records from February 2017 through December 2018. The second data source was an abstraction from Cherokee Nation's HCV Elimination Program Database from August 2015 through December 2018. Individuals were included in the abstractions if they were asked if they had injected drugs in the past six months during their health visit. The indirect prevalence estimate of people who inject drugs was calculated in accordance with the *UNAIDS/WHO Guidelines on Estimating the Size of Populations Most at Risk to HIV*.

**Results:** In total, 198 individuals across both data sources reported that they had injected drugs within the past six months. This included 123 unique individuals from the first source, 69 individuals from the second source, and six individuals who were included in both sources. Capture-recapture calculations indicated an estimate of 1,613 people who inject drugs (95% CI: 404, 2,821).

**Conclusions:** This study was the first attempt at estimating the number of people who inject drugs in Cherokee Nation, and one of the few existing studies to estimate the number of American Indian/Alaska Native people who inject drugs in the United States. Gaining knowledge about the prevalence of people who inject drugs in Cherokee Nation will inform strategies to support addiction care and treatment among people who inject drugs living in Indian Country.

## Background

Increasingly, injection drug use has become recognized as an important public health issue in the United States, and estimates indicate that American Indian and Alaska Native (AI/AN) people are disproportionately affected. In 2018, the Substance Abuse and Mental Health Services Administration (SAMHSA) estimated that 1.8% of individuals in the United States aged 18 and older had used needles for injecting a drug that was not prescribed, including heroin, cocaine, and methamphetamine, in their lifetime, and that use of injection drugs was higher among AI/AN people (1). During this time, SAMHSA reported that approximately 6.5% of the AI/AN population aged 18 and older, compared with 4.7% of the non-Hispanic white population, reported opioid use within the last year; and approximately 4.7% of the AI/AN population aged 18 and older, compared with 0.7% of the non-Hispanic white population, reported methamphetamine use in the past year (1).

Injection drug use (IDU) contributes to increased spread of bloodborne infections, including hepatitis C (HCV) and human immunodeficiency virus (HIV), which disproportionately affect AI/AN people (2, 3). In addition, IDU is a major risk factor for endocarditis (4–6) and the leading cause of HCV infection in the United States, attributable to over half of all cases (7, 8). From 2012–2018, acute HCV cases have increased each year, with the largest increase seen among AI/AN people (9). HIV diagnoses among AI/AN people increased 39% from 2010 to 2017 and contributed to 44% of HIV acquisition in AI/AN females in 2018 (10).

Although addressing IDU among AI/AN people is key to overall HCV and HIV reduction efforts, research regarding estimates of people who inject drugs (PWID) among AI/AN people is limited. One cross-sectional study conducted by Eitle et al. in 2015 estimated that 3.1% of AI/AN young adults injected drugs; however, the study population only included individuals aged 18 to 26 years (11). In 2002, Mitchell et al. found that between 0.5–2.1% of AI people from two groups in the Southwest United States had injected heroin within their lifetime, but did not assess current use or injection drug use beyond heroin (12). In 2016, Simoni et al. found that 6% of AI women had ever injected drugs, although this study was conducted in an urban setting through a mail-based survey (13). Finally, in 2016, SAMHSA reported that approximately 1% of participants over 18 years had experienced lifetime use of needles to inject heroin (14).

In 2015, Cherokee Nation Health Services (CNHS) implemented an HCV Elimination Program to respond to the public health burden of HCV. In 2019, CNHS implemented the Ending the HIV Epidemic Program to respond to the HIV epidemic affecting rural communities in the Southern United States. Harm reduction is an essential component of these programs, and harm reduction interventions may be optimized by knowing the number of PWID who require care.

Estimating the number of PWID will guide interventions by creating a visible need for harm reduction programs. Without knowing the number of PWID who require care, it is difficult to develop HCV and HIV outreach and harm reduction efforts. This study adds to the limited body of knowledge surrounding PWID estimates in AI/AN communities in the United States to begin understanding the need for harm reduction services in AI/AN communities.

## **Methods**

### **Aim and Study Design**

The objective of this study was to generate a preliminary estimate of the number of PWID in Cherokee Nation using capture-recapture methods. To address this aim, a two-sample capture-recapture approach, including retrospective review of two sources of electronic medical record (EMR) data, was used. Capture-recapture methods can be used in epidemiological studies to calculate indirect prevalence estimates among marginalized populations, including PWID (15–20). Implementing capture-recapture methods to estimate the number of PWID includes identifying two or more sources of data on PWID, and comparing

overlapping individuals across the sources to estimate the total number of PWID in the population, using the formula outlined in **Fig. 1** (19).

## Setting

Cherokee Nation is the largest tribal nation in the United States, spanning 14 counties in Oklahoma and includes over 355,000 registered Cherokee citizens (21). CNHS, Cherokee Nation's network of health centers, is the largest tribally operated health system in the United States, receiving over 350,000 patient visits annually at the hospital alone (22). CNHS serves Cherokee Nation citizens and citizens of other federally recognized tribes (22). This study was approved by the Cherokee Nation Institutional Review Board on October 8th, 2018.

## Study Data Sources And Participants

The project team implemented capture-recapture, comparing data collected through CNHS EMRs and the HCV Elimination Program Database. Although all patients included in the HCV Elimination Program Database are also part of the CNHS EMR system, the databases themselves are distinct. All patients that CNHS serves are included in CNHS EMRs, whereas the HCV Elimination Program Database was developed to track HCV specific indicators collected through the Infectious Disease Department.

The CNHS EMR abstraction included all individuals who received health care through one of CNHS' eight rural health centers or hospital between February 2017 through December 2018 who were asked, "Have you injected drugs in the past six months?" during their health visit. The CNHS HCV Elimination Program Database abstraction included patients who reported injecting drugs in the last six months between August 2015 through December 2018. If a patient was asked the question more than once during the study time period, their most recent response was used for analysis. The inclusion dates for the data abstracted from each source represents the full period of time in which the question "Have you injected drugs in the past six months" was implemented in clinical procedures.

## Indicators

Patient-level clinical and demographic variables were abstracted from the data sources to obtain PWID estimates, including injection drug use in the past six months (yes/no), sex, and age.

## Analysis

The indirect prevalence estimate of and confidence interval for PWID in Cherokee Nation were calculated using the formulas presented in **Fig. 1**, in accordance with the methods presented by Hickman et al and the *UNAIDS/WHO Guidelines on Estimating the Size of Populations Most at Risk to HIV* (19, 23). Inputs

for the calculations included the number of CNHS patients from EMRs who responded affirmatively to the question asking whether they had injected drugs in the past six months, and the number of patients from the CNHS HCV Elimination Program Database who responded affirmatively to the same question, between August 2015 and December 2018. These datasets were linked using a unique patient identifier to assess overlap in unique patients across the datasets.

All data cleaning and descriptive quantitative analyses were performed using SPSS Version 19 statistical analysis software (24).

## Results

In total, 198 individuals across both data sources reported that they had injected drugs within the past six months. This included 123 unique individuals from the CNHS EMR abstraction, 69 individuals from the HCV Elimination Program Database, and six individuals who were included in both sources.

The CNHS EMR abstraction included 906 total CNHS patients who were asked if they injected drugs in the past six months in CNHS EMRs. Of the 906 patients, 129 (14.2%) responded “yes”. Slightly more than half (54.7%) of individuals in this dataset were female, and the age range varied widely. Among those who reported injecting drugs in the past six months, a slightly higher proportion of participants were female (58.1%), and individuals tended to be a little younger (Table 1).

Table 1  
Characteristics of patients included in CNHS EMRs

Characteristics N = 906	n	%
<b>All patients who were asked if they had injected drugs in the past six months</b>		
Injected drugs, past six months		
Yes	129	14.2
No	777	85.8
Sex		
Female	496	54.7
Male	410	45.3
Age		
20–30	217	24.0
31–40	211	23.3
41–50	189	20.9
51–60	202	22.3
Older than 60 years	86	9.5
<b>Subset of those who reported injecting drugs in the past six months</b>		<b>129</b>
Sex		
Female	75	58.1
Male	54	41.9
Age		
20–30	47	36.4
31–40	34	26.4
41–50	25	19.4
51–60	17	13.2
Older than 60 years	6	4.7

The HCV Elimination Program Database included 947 total CNHS patients who were asked whether they had injected drugs in the past six months. Of the 947 patients, 75 (7.9%) responded “yes”. Approximately 60% of individuals in this dataset were male, and more than one-third (35.5%) were between 51 and

60 years old. Among those who reported injecting drugs in the past six months, a slightly lower proportion of participants were male (57.3%), and individuals tended to be younger, with nearly one-third (32.0%) of participants aged 31 to 40 years (Table 2).

Table 2  
Characteristics of patients included in the HCV Elimination Program Database

<b>Characteristics N = 947</b>	<b>n</b>	<b>%</b>
<b>All patients who were asked if they had injected drugs in the past six months</b>		
Injected drugs, past six months		
Yes	75	7.9
No	870	91.9
Sex		
Female	380	40.1
Male	567	59.9
Age		
20–30	101	10.7
31–40	174	18.4
41–50	219	23.1
51–60	336	35.5
Older than 60 years	117	12.4
<b>Subset of those who reported injecting drugs in the past six months</b>		<b>75</b>
Sex		
Female	32	42.7
Male	43	57.3
Age		
20–30	18	24.0
31–40	24	32.0
41–50	15	20.0
51–60	15	20.0
Older than 60 years	3	4.0

A higher proportion of PWID included in CNHS EMRs were 40 years old or younger and female, compared with PWID included in the HCV Elimination Program Database (**Figure 2**).

In implementing capture-recapture methods that compare patient health record data collected through CNHS EMRs and CNHS HCV Elimination Program data, results indicated an estimate of approximately 1,613 PWID (95% CI: 404, 2,821) (**Figure 3**).

## Discussion

Using a two-source capture-recapture approach, we generated a preliminary estimate of approximately 1,613 PWID served through CNHS, with a 95% confidence interval ranging from 404 to 2,821 PWID. This study was the first attempt at estimating the number of PWID in Cherokee Nation, and one of the few existing studies to estimate the number of AI/AN people who inject drugs in the United States.

The proportion of reported PWID was high. Among the 906 individuals who were asked if they had injected drugs in the past six months, as reported in the CNHS EMRs, 14.2% of individuals responded affirmatively. Among the 947 patients who were asked the same question through the HCV Elimination Program, 7.9% responded affirmatively. Each of these proportions were much higher than existing PWID estimates among AI/AN people in the literature. However, past studies have also focused on particular groups within AI/AN communities, and not the population of PWID as a whole (11–14).

There are multiple limitations to this study design, related to patient population, health systems, data sources, and methods. Research has demonstrated that social desirability biases lead individuals to underreport drug use, and, in particular, injection drug use (25). It is possible that underreporting of injection drug use led to a falsely low estimated number and proportion of PWID within CNHS. Alternatively, although injection drug use in the past six months is intended to be asked across all CNHS patients, most CNHS patients were not asked this question during their visits. Due to the small percentage of total CNHS patients who were asked the question, it is possible that clinicians were selectively asking this question. This may have introduced selection bias, leading to a falsely high estimated number and proportion of PWID within CNHS and violating the capture-recapture assumptions that all individuals included in the databases were correctly classified, truly had an equal, non-zero probability of being captured, and were representative of the true PWID population within CNHS.

Although the two sources used for the capture-recapture estimate were from different databases, the sources are inherently connected because both sources are abstractions from CNHS patient databases and, thus, are only representative of individuals who receive health services through CNHS. In addition, those who test positive for HCV from within a CNHS clinic are later included in the HCV Elimination Program Database, and PWID are more likely than the general population to become infected with HCV. Although PWID-related data are collected separately in these databases, the inherent connection violates the capture-recapture assumption that samples are independent from one another, which may have led to a falsely low PWID estimate. Although this is a key study limitation, it is also a frequently identified

limitation in capture-recapture studies, as reliance on related institutions or services to provide data sources is common (23).

In addition, this study violates the capture-recapture assumption of homogeneity of the data sources. Individuals are only captured in the HCV Elimination Program Database if they are enrolled in HCV care, whereas all individuals served through CNHS are captured through CNHS EMRs. However, these were the two available data sources that captured injection drug use in Cherokee Nation and violation of homogeneity is common when using healthcare data (26).

Finally, CNHS is not a closed population and the number of PWID served through CNHS is not stagnant. Individuals can register for health services, leave the healthcare system, start injecting drugs, and stop injecting drugs over time. We attempted to reduce the potential bias of this violation of capture-recapture methods by limiting the data abstraction time period for both data sources to one year. However, when we attempted this analysis, the sample size of PWID was too small to conduct the necessary calculations. Even when including all available data on PWID from CNHS EMRs and the HCV Elimination Program Database, the sample sizes of PWID from the two sources were very small.

Although there were limitations, this study adds to the increasing body of research surrounding PWID estimates among indigenous communities in the United States and provides the first attempt at generating a PWID estimate in Cherokee Nation. There is a need for continued assessment of PWID in Cherokee Nation, including utilizing data sources outside of the healthcare system and reducing the length of time for data abstraction as the sample size of PWID recorded across CNHS databases increases, to inform accuracy of estimates. There is also a need to assess the impact of social determinants of equity on injection drug use and infectious disease among AI/AN people.

## Conclusions

Gaining knowledge about the prevalence of PWID in Cherokee Nation and other indigenous communities across the United States should inform policy and programmatic investments in culturally responsive, strengths-based substance use treatment and harm reduction efforts among PWID in Cherokee Nation and other AI/AN communities. Understanding the prevalence of PWID in indigenous communities is also foundational to address social determinants of equity among AI/AN people who are disproportionately impacted by bloodborne infections, including HCV and HIV.

## Abbreviations

AI/AN

American Indian and Alaska Native

AI

American Indian

CNHS

Cherokee Nation Health Services  
HCV  
Hepatitis C virus  
IDU  
Injection drug use  
PWID  
People who inject drugs  
RNA  
Ribonucleic acid  
SAMHSA  
Substance Abuse and Mental Health Services Administration  
UNAIDS  
The Joint United Nations Programme on HIV/AIDS  
WHO  
World Health Organization

## **Declarations**

## **Ethics approval and consent to participate**

**This study was approved by the Cherokee Nation Institutional Review Board on October 8<sup>th</sup>, 2018.**

## **Consent for publication**

Not applicable

## **Availability of data and materials**

The datasets analyzed during the current study are not publicly available to ensure Cherokee Nation has full oversight of any projects using data from Cherokee Nation Health Services but may be made available with permission from Cherokee Nation IRB on reasonable request.

## **Competing interests**

WE and JM were investigators for a grant that was given to Cherokee Nation Health Services for Hepatitis C Elimination by the Gilead Foundation. The Gilead Foundation did not participate in the design of the study, data collection activities, analysis, interpretation of data, or in writing this manuscript.

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## Authors' contributions

MF made substantial contributions to the design of the work and analyzed and interpreted data, including conducting calculations for PWID estimates. AW was a major contributor in the conception and design of the work, and writing the manuscript. WE was a major contributor in the conception and design of the work, acquisition of data, and writing the manuscript. JM was a major contributor in the conception, design, and oversight of the work, and writing the manuscript. All authors read and approved the final manuscript.

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## Figures

		Data source two (S2)		
		Yes	No	
Data source one (S1)	Yes	a(m)	b	N1
	No	c	? (x)	
		N2		N

Population estimate:  $N = (n1 \times n2)/m$

Number observed:  $n = a + b + c$

Number hidden:  $x = N - n$

95% Confidence interval:  $\pm 1.96 \sqrt{(n1 \times n2 \times b \times c / m^3)}$

a or m = matches or marks; number of people in both S1 and S2

b = number of people in S1 but not in S2

c = number of people in S2 but not in S1

x = hidden population; number of people not in S1 or S2

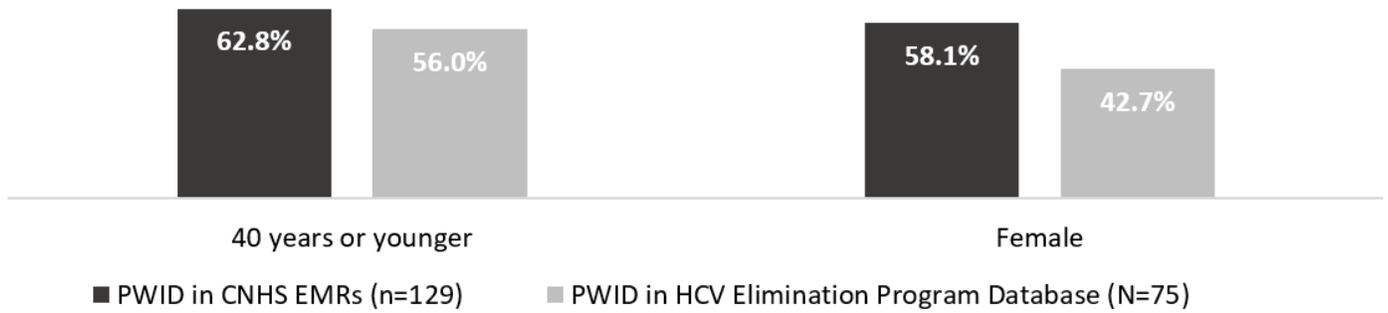
n1 = number of people in S1

n2 = number of people in S2

N = total population

**Figure 1**

Formula for attaining PWID prevalence estimates using capture-recapture method with two data sources



**Figure 2**

More PWID in EMRs were young and female compared with the HCV Elimination Program Database

		CNHS HCV Elimination Program Data		
		Yes	No	
CNHS EMR Data	Yes	6	123	129
	No	69	?	
		75		N

*Population estimate:  $(129 \times 75)/6 = 1,612.5$*   
*Number observed:  $6 + 123 + 69 = 198$*   
*Number hidden:  $1612.5 - 198 = 1,414.5$*   
*95% Confidence interval:  $\pm 1.96 \sqrt{(129 \times 75 \times 123 \times 69/6^3)} = \pm 1,208.46$*   
*PWID estimate = 1,612.5 (95% CI: 404.04, 2,820.96)*

**Figure 3**

Estimating PWID in CNHS using capture-recapture calculation with two data sources