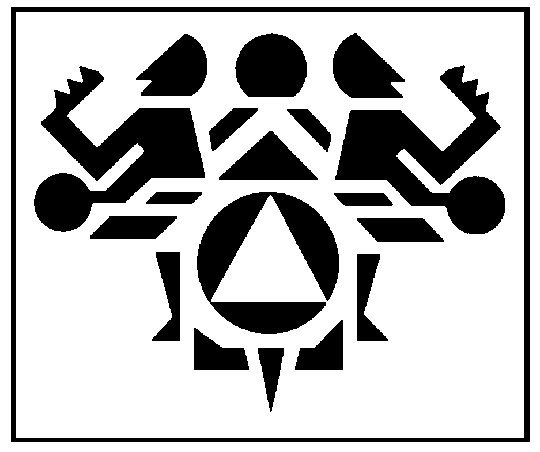
PROJECT RED TALON

Interview Project with People Who Inject Drugs, Community and Health Care Staff to Explore Community-Driven Education, Prevention and Healthcare Systems Improvement

September 30, 2015



Northwest Portland Area Indian Health Board

**2121 SW Broadway, Suite 300**

**Portland, OR 97201**

**Ph (503) 228-4185**

**Fx (503) 228-8182**

## Project Overview

Title: Interview Project with People Who Inject Drugs, Community and Health Care Staff to Explore Community-Driven Education, Prevention and Healthcare Systems Improvement

Project Investigator:

Jessica Leston, MPH

Northwest Portland Area Indian Health Board

NW Tribal Epidemiology Center

Clinical Programs Manger, Project Red Talon

2121 SW Broadway, Suite 300, Portland, OR 97201

907-244-3888 jleston@npaihb.org

Co- Investigator:

Elizabeth Rink, PhD MSW

Montana State University

Associate Professor

Department of Health And Human Development

318 Herrick Hall, Bozeman, MT 59715

406-600-0297 elizabeth.rink@montana.edu

Human Subjects Training: NIH online tutorial: “Protecting Human Research Participants” and/or

Certificate of Completion: CITI Human Subjects Education training

(Investigator CVs Attached – Appendix A)

**Funding Source:** Indian Health Service and Minority AIDS Initiative

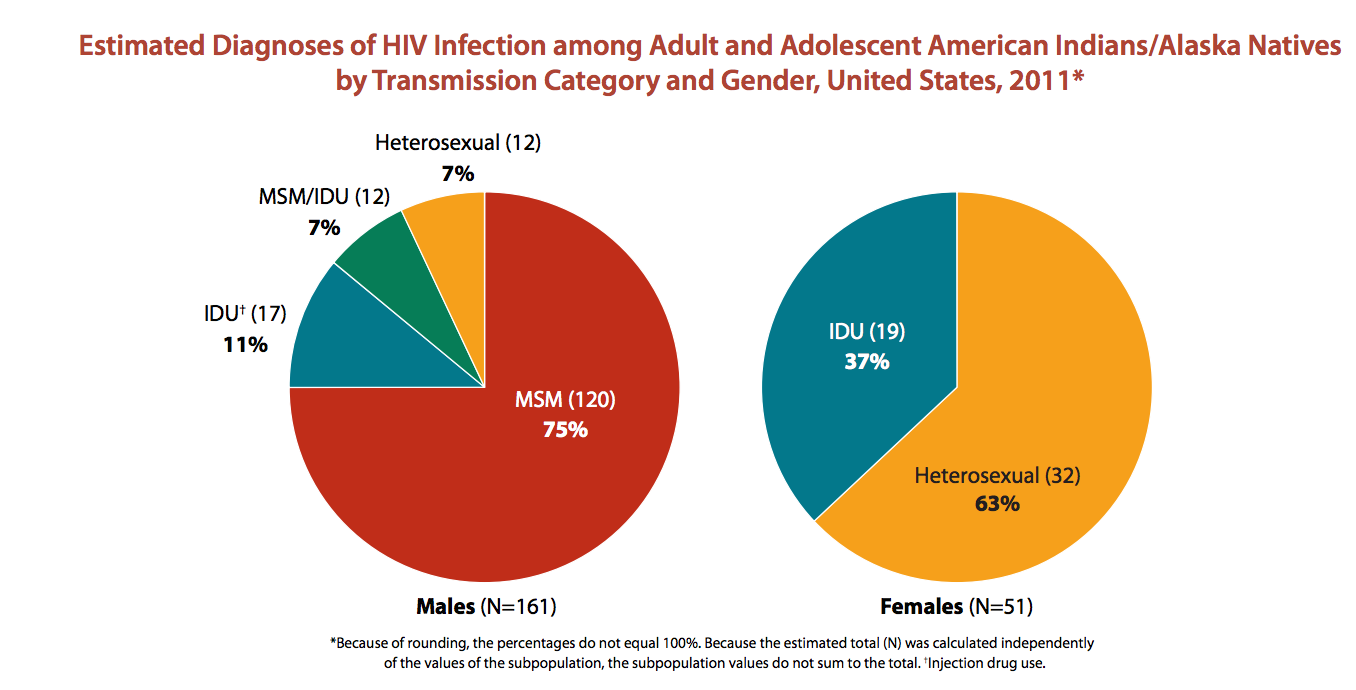
**Project Summary:** People who inject drugs (PWID) are at increased risk for contracting and transmitting Hepatitis C virus (HCV) and Human Immunodeficiency Virus (HIV). This project will gather opinions, attitudes and beliefs from American Indian and Alaska Native (AI/AN) PWID, people who have injected drugs in the past (PWHID) community members and healthcare providers to build knowledge for future programing and planning efforts around injection drug use, HIV and HCV.

To capture the heterogeneous experience of AI/AN PWID and PWHID, the project will be conducted in four geographically dispersed AI/AN communities in the United States using semi-structure interviews. The project will be based on indigenous ways of knowing, community-based participatory research principles and implementation science.

## Introduction

Injection drug use (IDU) is a predominant risk factor for Human Immunodeficiency Virus (HIV) and Hepatitis C Virus (HCV) exposure in American Indian and Alaska Native (AI/AN) people. In 2011, the Centers for Disease Control and Prevention (CDC) estimated that 11% of new Male HIV diagnoses were associated with IDU risk and 7% of were associated with MSM/IDU risk factors. In the same year, 37% of new Female HIV diagnoses were associated with IDU. (Figure 1) (1)

Figure 1

****

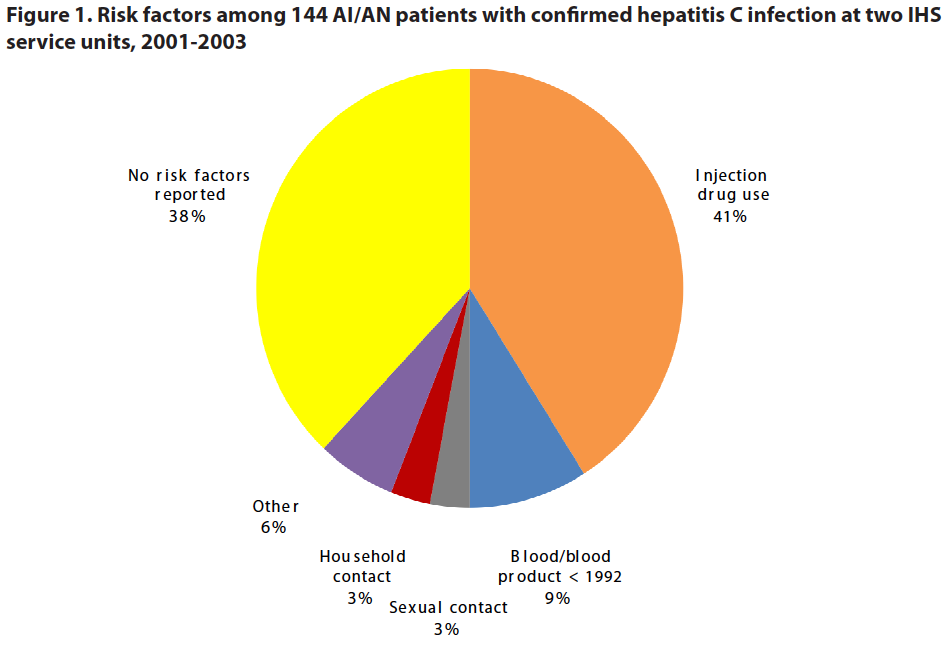
Hepatitis C virus (HCV) infection is the most common blood-borne infection in the United States. Percutaneous exposure to contaminated blood is the most efficient mode of transmission, and in the United States, injection drug use (IDU) is the primary risk factor for infection. (3) In a 2009 review of 35,712 AI/AN primary care patients living with a HCV diagnosis, IDU was the most common documented risk factor associated with HCV acquisition. (Figure 2)

Figure 2

Recent national reports indicate a strong correlation among opioid abuse, drug injecting, and HCV infection and surveillance demonstrates that AI/AN people are at particular risk for acquiring IDU-related HIV and HCV infection. (4) Education, outreach and prevention programs and resources, as well as integrative services strategies are critically needed for injection drug, and HIV and HCV infection.

There is also compelling need to build programing that uses Indigenous Ways of Knowing in its design and is guided by Community Based Participatory principles - to create programs, projects and systems that are significant to AI/AN people. (5,6) AI/AN people have ways of viewing the world that extends beyond the Western European paradigms of knowing. By developing programs and systems within methodological constructs that acknowledges and uses this as a foundation, there is a greater chance for sustainable change in health and care. The Interview Project with People Who Inject Drugs, Community and Health Care Providers will use the Community Involvement to Renew Commitment, Leadership, and Effectiveness (CIRLCE) framework for program design and community development (7). CIRCLE is a four-step (building relationships, building skills, working together, promoting commitment) model that incorporates Western concepts of community capacity building and parallels the values of community-based participatory research. By using the CIRCLE framework, AI/AN Communities participating in this project will define and develop their own health care services and strategies for positive change.

## Project Description

The aim of this project is to work with local communities using the CIRCLE framework, to define and develop their own health care services and strategies for positive change around injection drug use and HIV and HCV infection. The project will build a formative understanding of the context of AI/AN PWID and PWHID *and* community and healthcare provider’s understanding of injection drug use and HIV and HCV infection. By utilizing a approach grounded in Indigenous Ways of Knowing and Community Based Participatory principles, the ultimate goal of this project will use the communities understanding injection drug use, HIV and HCV to create a plan with the community for projects and programs moving forward.

**Goal**: To build a formative understanding that answers the following questions:

1. What is the level of knowledge, attitudes, and beliefs AI/AN PWID have/hold regarding injection drug use, HIV and HCV infection?
2. What health care services and strategies for change are needed around injection drug use, HIV and HCV infection?

**Activities:**

Figure 3

We will:

* conduct 40-48 interviews in 4 AI/AN communities with PWID and/or PWHID to build knowledge and understanding around AI/AN PWID, and health care services and change strategies around injection drug use programming and prevention interventions (10-12 interviews at each site);
* conduct surveys with PWID and/or PWHID interview participants to gather basic demographic information;
* conduct 40-48 interviews in 4 AI/AN communities with community members and healthcare providers to better understand needed health care services and change strategies around injection drug use programing and prevention interventions (10-12 interviews at each site).
* Recruitment strategy – Figure 3

The information gathered from the interviews and surveys will be used to create a plan with the community for projects and programs moving forward.

Community based participatory research (CBPR) principles will be used that balance research, action, and education. Our research will involve AI/AN community members in the study design, data collection, and interpretation, which will help build local capacity and improve trust in the research at hand. This collaborative process will be described in detail in subsequent sections.

## Project Collaborators

The target “population” (hereafter referred to Project Collaborators) for the study will vary based on the research method employed, as described in the following section. Populations will be PWID, PWHID in the past, community members, healthcare providers and advocates.

At least four tribes will be solicited to participate through the NPAIHB’s Tribal Epidemiology Center

(EpiCenter) and will be selected based on the tribe’s expressed interest, their willingness to participate in planning meetings, and their geographic location. Each site will be purposefully selected to represent different geographies and tribal experiences.

A tribe’s agreement to participate in this project will be obtained from the Tribal Health Director and/or Tribal Council. Letters of approval in the form of a memorandum of understanding, or other document as desired by participating tribe, will be submitted to the Portland Area Indian Health Service Institutional Review Board (IRB) upon receipt (Appendix G). All confidentiality and data sharing limitations set by participating tribes will be honored by NPAIHB and the EpiCenter. Additionally all tribes will have an opportunity to review and approve all reports and publications.

**Participant Recruitment**

Upon IRB approval, local site contacts will begin to identify and recruit participants within their own site. When approaching potential participants, they will describe the purpose, general design, and enrollment criteria to eligible persons. They will provide participants with informational packets including an Introductory Project flyer (Appendix I) and consent forms (Appendix E and/or Appendix F).

**Note: Although we will be enrolling participants throughout Indian Country and will be focusing on AI/AN PWID 18-40, we will not turn away non-AI/AN participants if they fit all other enrollment criteria and reside in our project areas.**

Successful recruitment and retention will begin with the first interaction that a potential participant has with the project. Thus, the first impression the public has is very important.  A person-centered approach will be adhered to for this project to ensure participant satisfaction.

Due to the difficulty of reaching PWIDs with traditional sampling methods, a non-probability sampling, chain-referral sampling method will be used. This method involves identification and recruitment of a small number of “seed” participants via word of mouth, who then provide contact information for other potential participants.(8,9) Ideal seed participants will have large social network sizes, be respected by members of the target population, be able to convince others to participate in the study, and have some interest in the study goals. (10) Seeds will then recruit other participants based on “knowing” them through either weak ties (acquaintances) or strong ties (friends). Each seed will have a fixed number of coded coupons (up to 3) to recruit peers from their social network. Positive experience and social influence during the survey process will promote further recruitment. Once each seed’s recruits have participated in the survey, they in turn will be given a set of coupons to recruit a second wave of peers. This process will result in expanded sampling, until the sample size goal is obtained. (11)