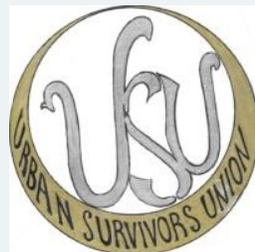


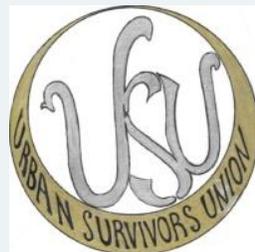
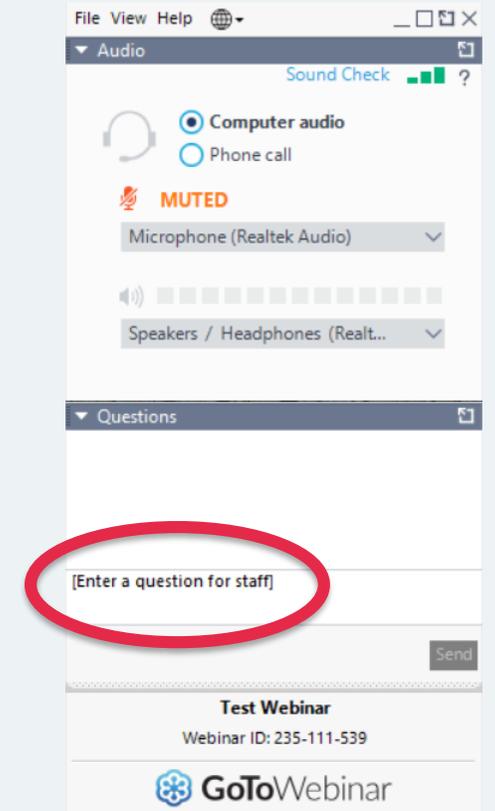
Engaging Active Drug Users about Hepatitis C: from Testing through Cure and Beyond

February 6, 2018



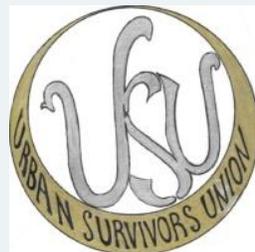
Housekeeping: GoToWebinar

- Slides and a recording of the webinar will be sent to everyone who registered and posted on our website.
- Please use the question box to submit your questions and comments
- The Q&A session will follow the last presentation



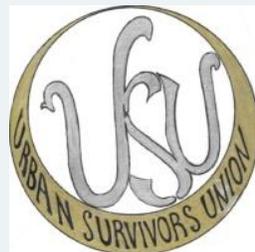
Webinar Overview

- About NVHR
- Project accomplishments & evaluation for year 1
- Project presentations:
 - Urban Survivors Union
 - People’s Harm Reduction Alliance
 - Atlanta Harm Reduction Coalition
- Discussion and questions and answer



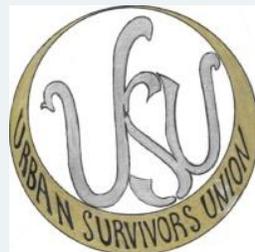
About NVHR

- National Viral Hepatitis Roundtable
 - working together to eliminate hepatitis B and C in the U.S.
- ~500 coalition members
 - community-based, advocacy, and grassroots groups
 - healthcare providers
 - health departments
 - other government and industry partners
- www.nvhr.org



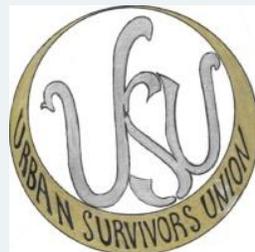
NVHR's Program Department

- Capacity-Building and Technical Assistance
 - Support for groups conducting screening in community-based settings
 - Templates and support for implementing routine screening
- Webinars, Fact sheets, online resources
- Working Groups HCV Treating & Pharmacists
- Community stakeholder engagement in PCORI studies
- Mini-grants
 - Technical assistance and \$10K financial support



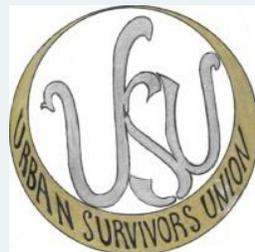
Collaborative Model

- Wrote grant proposal jointly
- Project calls twice monthly
- Worked with evaluation consultant
- Replication at local or national level
- Disseminated findings nationally
- Learn more at [www.nvhr.org/programs/more than tested cured](http://www.nvhr.org/programs/more_than_tested_cured)



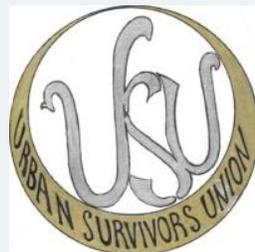
Year 1 Evaluation Findings

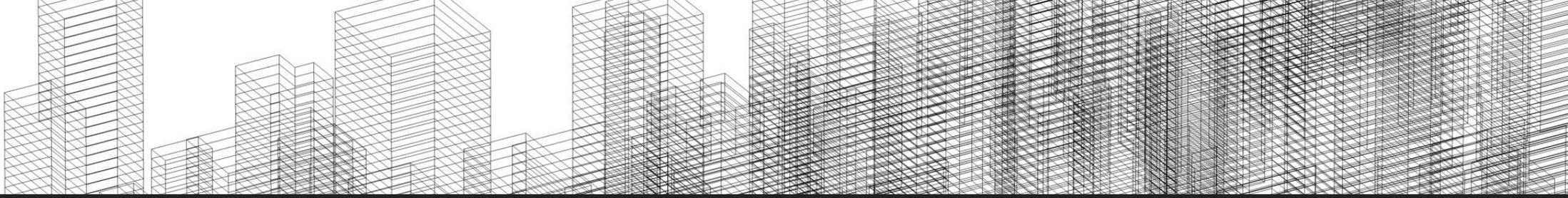
- *“Make sure that what you are doing is drug user led and that you are incorporating perspectives from drug users in every level of your project. It will greatly improve how responsive you are to the problems that people who use drugs are facing.” --project staff member*
- *“Involving the people who...have the disease in the conversations and hearing why people aren’t getting access to care is the only thing that will tell us what people’s actual barriers are.” --project staff member*



Overview of Year One Accomplishments

- I. Engaging Individuals who use Drugs in Defining the Solution
- II. Developing and Disseminating Culturally Appropriate HCV Education Materials
- III. Expanding Access to HCV Services for Individuals Who Use Drugs:
 - a. Expanding Services available at Syringe Exchange Sites
 - b. Reducing Stigma and Barriers for Specialists to Treat Active Users
- IV. Strengthening the National Network



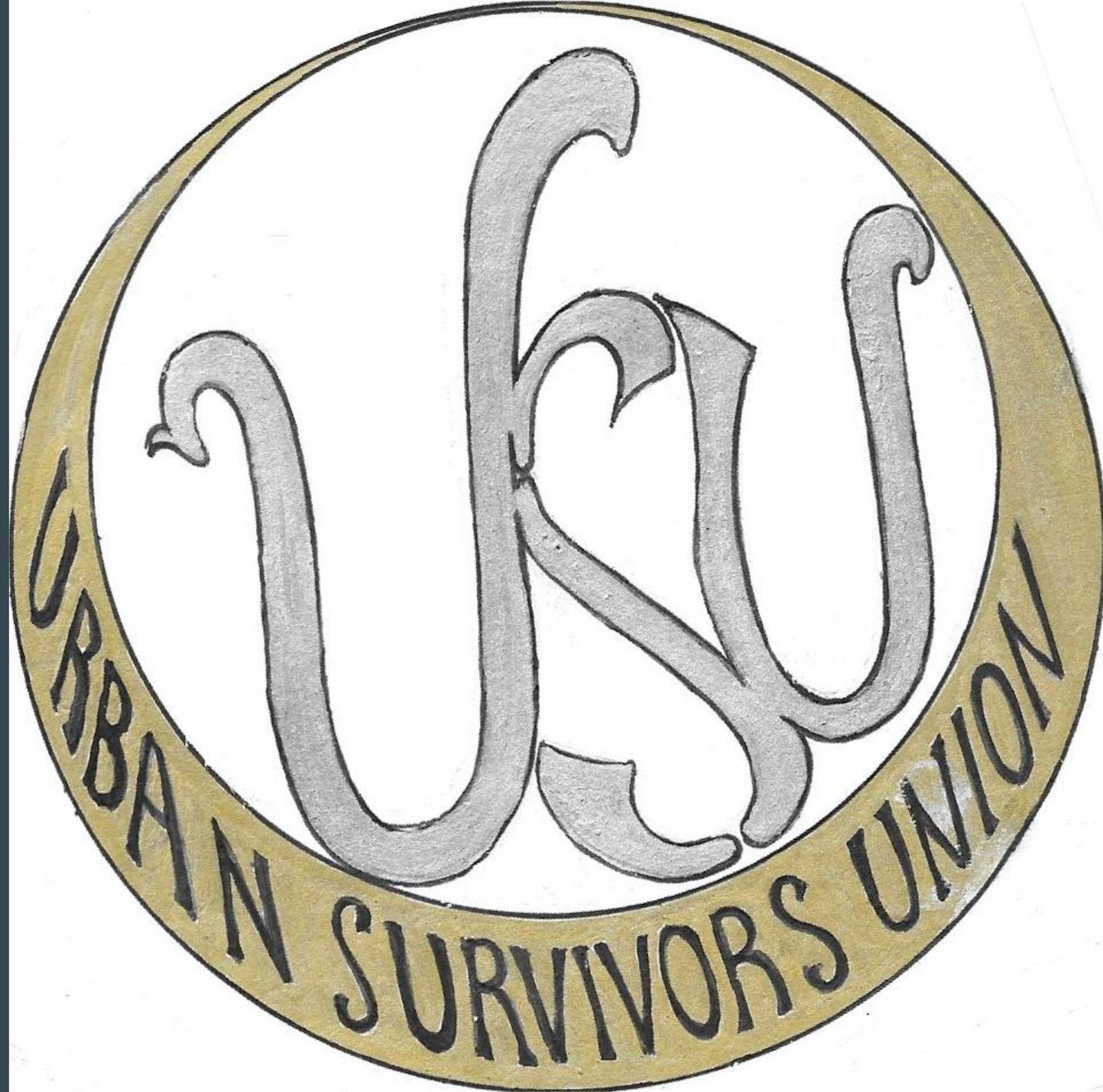


Barriers to Treatment & Testing

Urban Survivors Union
Promoting Drug User Health
Safer Drug Use & Hepatitis C Elimination

Urban Survivors Union Mission:

Urban Survivor's Union is a grassroots coalition of drug users (former and active) dedicated to ensuring the respect, dignity, and social justice for people with substance use experiences. We contest the dominant culture's misguided attitudes and biases about drug use and drug users. USU stands for a new direction in drug policy. Our programs are centered on improving conditions for people that use drugs, their families, and communities.



Piedmont Chapter

Greensboro, High Point,
Winston-Salem

N=320 new participants this
year

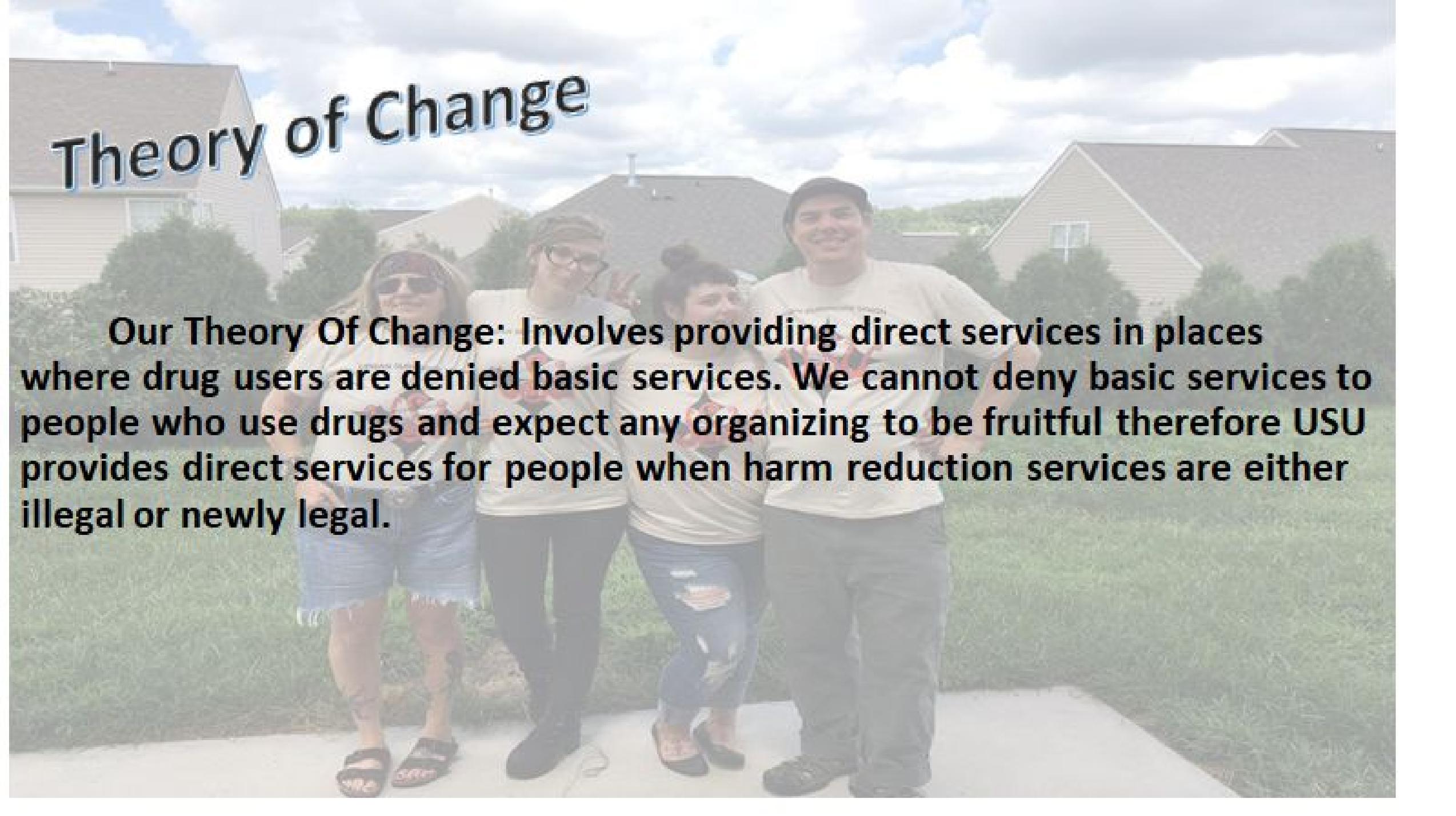
Distributed over 435,000
syringes this year

User Run and User Directed

**Our board and staff are made up
of people that use drugs.**



Theory of Change

A photograph of four people standing on a concrete sidewalk in front of a row of houses. From left to right: a woman with sunglasses and a headband, a woman with glasses, a woman with her hair in a bun, and a man in a baseball cap. They are all wearing light-colored t-shirts. The background shows several houses with brown roofs and green lawns under a cloudy sky.

Our Theory Of Change: Involves providing direct services in places where drug users are denied basic services. We cannot deny basic services to people who use drugs and expect any organizing to be fruitful therefore USU provides direct services for people when harm reduction services are either illegal or newly legal.

USU's Community Response to the HCV Epidemic

- ❖ **Community Led and Directed Services** for people who use drugs (PWUD)
 - Drop-in center
 - Syringe Exchange (Newly legal in the North Carolina)
 - OD prevention with naloxone
- ❖ **Community Based Advocacy and Community Mobilization**
 - USU is the only drug user union in the US South
 - Groups in NC: Greensboro, High Point, Raleigh, Charlotte, and Asheville
 - Outside NC: Seattle, San Francisco
- ❖ **Community Based Research- Participatory Action Research**
 - Collaborations with public health researchers
 - PWUD participating in every stage of the research process.

Meaningful Engagement

Growing Grassroots Groups led
by Impacted People

Foundations need to be experimental. They need to take risks . . . and face some of the more critical and controversial issues. We must be prepared to venture into areas of uncertainty if we are to remain a vital instrument in the field of philanthropy.

*– Nancy Susan Reynolds, ARCA
Foundation*

- Working as a Team with Similar Groups
- “Grant Parents” – having an organization really take us in, sees us as true partners, and trains us.
- Planning, implementing, evaluating– good public health (teaching us to use to tools of public health, ie logic models, gantt charts)
- Sharing our story/ telling our story

This community-administered project will:

- ❖ Describe how PWID acquire information of HCV risk factors and HCV treatment
- ❖ Determine the process people use to gauge transmission risk and reduce unsafe injecting behaviors
- ❖ Identify challenges and barriers to staying Hep C free
- ❖ Clarify how peer relationships and PWID social networks increase and decrease HCV infection risk

Increasing awareness of HCV among individuals who use drugs:

Urban Survivors Union (USU) developed HCV education materials created by and for people who use drugs, including videos and social marketing messages, and disseminated the materials locally and nationally.

**WE PUT OUR \$\$
WHERE OUR
MOUTH IS**

EVERY PERSON INVOLVED IN THE PROJECT WAS PAID.

FOCUS GROUP FACILITATORS, FOCUS GROUP ATTENDEES,
INTERVIEWS, SURVEY PARTICIPANTS, VIDEO TEAM,
PROJECT COORDINATOR, NOTETAKERS, HEALTH
EDUCATORS, PROJECT ASSISTANT

ALMOST EVERY PERSON INVOLVED IN THIS PROJECT
IDENTIFIES AS A PERSON THAT USES DRUGS.

PAYING PEOPLE IS ABOUT SHOWING PEOPLE YOU BELIEVE
THEIR TIME IS VALUABLE.

How can we learn from people who use drugs?

- How do you know which people to work with?
- How do you know if they will actually show up?
- How can we make sure they care as much about getting the work done as we “the people who initiated the project” do?
- Is it really worth it?
- Should we pay them cash? Won't they buy drugs with the money?
- I have worked with this population before and I'm worried people won't follow through.

Survey to assess knowledge and attitudes around HCV behavioral risk and treatment

N=126

RACE

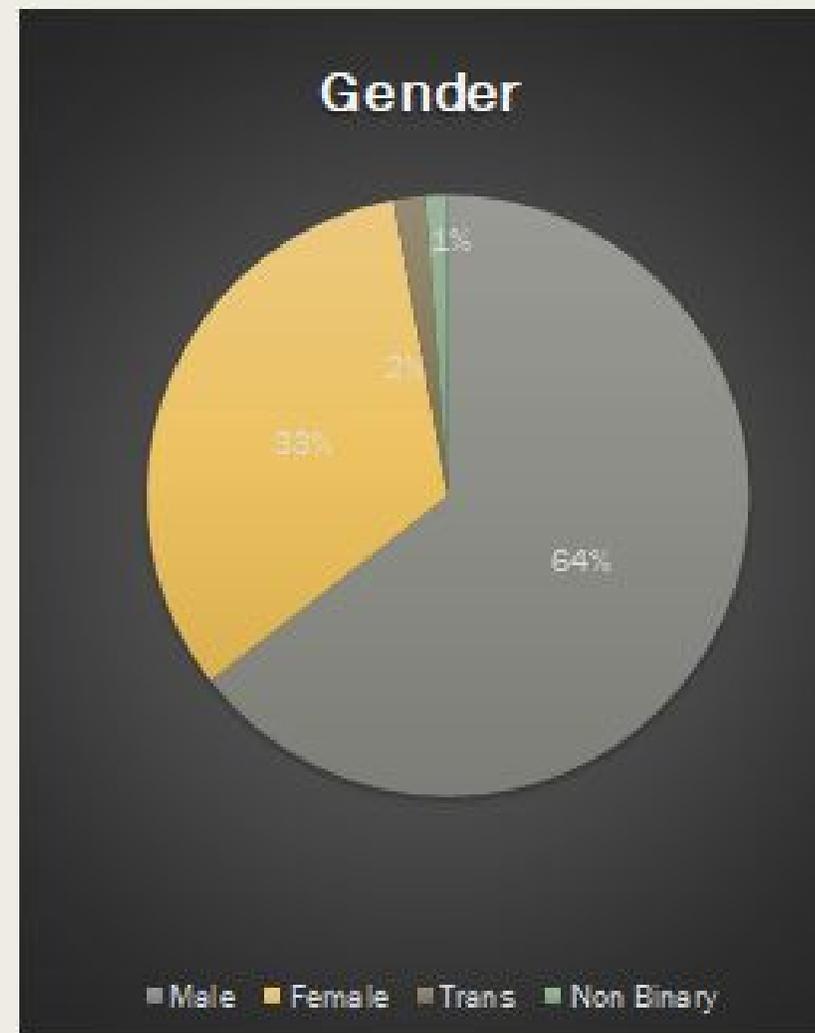
81% White

13% Black

2% Asian

3% Mixed

1% Other



Survey Questions

USU staff implemented a survey (126 respondents)

- 67% of respondents reported concern about being in relationships with people who had HCV
- 32% believed that regular hand washing would help them prevent HCV
- 86% Believed that sex was how HCV was transmitted



MAPPING SYRINGE EXCHANGE PROGRAMS

Top 5 States With the Most Programs



■ From the same survey:

96% said if there was no syringe exchange they would probably have to reuse old syringes and they would not be able to be so healthy

SYRINGE ACCESS

- Syringe Exchange was made legal in July of 2016 in NC. USU provided underground services from 2008- until legalization.
- There are now 29 legal exchanges in NC.
- Harm Reduction Organizations are essential if we are to increase knowledge

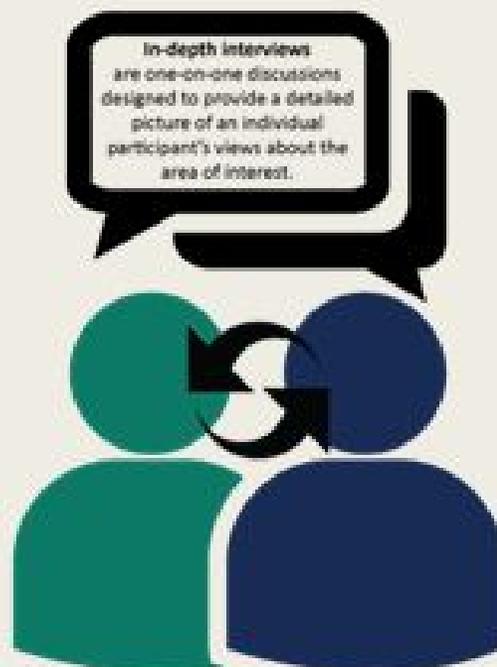
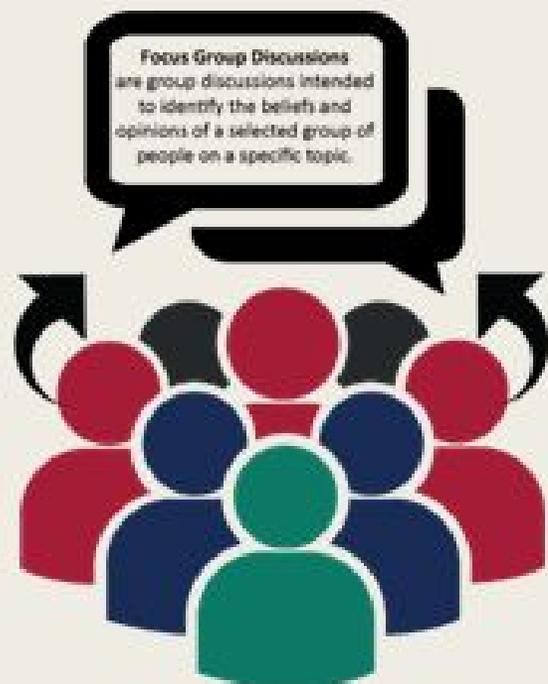
HEALTH IN THE PIEDMONT



WHERE DO PEOPLE WHO USE DRUGS GET THEIR HEALTH INFORMATION?

- INTERNET
- PHARMACEUTICAL COMMERCIALS
- A FRIEND
- THE PIEDMONT XCHANGE 😊
- METHADONE CLINICS
- DRUG TREATMENT CENTERS
- PARENT
- 12-STEP MEETING
- SCHOOL

FOCUS GROUPS & IN-DEPTH INTERVIEWS



**People who inject drugs
(n=8)**

**Women who inject drugs
(n=6)**

**People using stimulants
(n=12)**

Media and Print

Advocacy Video: Importance of Syringe Exchange (N=60) viewed video

Safer Injection Video: goes over injecting safer

Social Marketing Materials (N=42) viewed video

Powerpoint Training (N=66) viewed

General Focus Group Findings

- Syringe exchange is vital for the health and well being of PWUD. Each group came to this conclusion. Participants were deeply grateful for our harm reduction center and felt like it was a great benefit to their health.
- Wide confusion over new all-oral HCV treatments.
- Confusion over how HCV infection is spread, treated and whether there is a cure
- Frustration over not being able to care of themselves even when they wanted very much to take care of their health.
- Frustration regarding the lack of information received over the years; even after being exposed to treatment, jail, prison, and other mandatory programs.
- No trust in medical system; no desire to go to doctor even when they know they need to.
- Unemployment affects ability to go to doctor; long-term lack of health insurance
- Medicaid impossible to get; Medicare and Disability also impossible to access; most participants diagnosed with mental health issues, yet have no access to medication or evidence-based treatment. Doctors at county-run clinics refuse to prescribe medication that actually has any effect or benefit.

Findings: Women Who Inject Drugs

- Veins – struggle to inject themselves
- Living in an underground economy and inability to deal with abuse
- Not having control of injection supplies and drugs
- Need to let others inject them
- Not wanting track marks to show
- Fear of going to doctor for treatment due to children
- Not able to talk to anyone about drug use- social services involvement
- Isolation; feeling stuck
- Doing what you have to do to take care of family; kids have to be taken care of; you do whatever it takes
- Self-hatred
- No way to stop using drugs without making things worse
- Not able to take care of themselves; too worried about taking care of everybody else

Findings: Stimulant Users

- Confusion over how HCV infection is acquired.
- No real understanding on how injecting more often increases HCV risk.
- No real understanding why staying up for days increases health risks. After some discussion it made sense to everyone in the group but none of them had ever thought about how their risk was increased by their stimulant use.
- Women all complained about inability to inject themselves; report trying unsuccessfully for hours. Described conditions as becoming quite messy and bloody. Described frustration leading to loss of desire to be careful.
- Adderall prescriptions helped control cocaine use but most doctors will not prescribe amphetamines to patients they know use illicit stimulants.
- Stimulants increase sex drive and this increases risk. Reports of having sex for extended periods of time (due to uppers).

Website - Hepatitis C 4 people who use drugs

<https://sites.google.com/urbansurvivorsunion.org/usucampaigntoendhcv/home?authuser=1>

Beyond Tested, Cured!

A Social Marketing Campaign Delivered by USU

<https://youtu.be/Ke0LBGkXx48>



Increase connections to bring in people instead pushing them out!

Hepatitis C Program and Engaging People who Use Drugs

People's Harm Reduction Alliance
Seattle, Washington



People's Harm Reduction Alliance (PHRA)

- PHRA is a peer-run organization that promotes the philosophy of harm reduction and safer drug use.
- A need-based program serving the Cascadia region since 2007.
- Needle distribution and safer smoking and snorting supplies.
- PHRA has both fixed and delivery sites in
 - Seattle, Everett, Olympia, and Bremerton, WA
 - Portland, OR



People's Harm Reduction Alliance (PHRA)

- PHRA is a drug-user led organization
- At least 51% of all positions are filled by drug users
- Drug users are decision makers (e.g., new services decided by elections)
- All volunteers, staff, and board members are screened for attitudes and beliefs about drug users prior to involvement



PHRA Hepatitis C Program in 2017

Hepatitis C

the most common bloodborne infection in the U.S. is curable!

HCV Basics

WHAT IS HEP C VIRUS (HCV)?
A virus that lives in the blood & attacks the liver.

SILENT KILLER
HCV is a slow progressing disease that can cause liver damage, liver failure and liver cancer.

TRANSMISSION
HCV is spread through blood contact.
Transmission can happen through things like fights, needle sharing, unsterile tattoos, blood transfusions done before 1992, and occasionally, unprotected sex.

PREVENTION
Protect yourself. Avoid spreading or getting HCV.
-Don't Share: needles, cookers, cottons, snorting equipment
-Avoid:
-unsterile tattoos/piercings
-unprotected sex with HCV positive partners
-alcohol: can cause HCV to damage your liver faster

Different Strains of HCV exist!
Even if you have HCV, follow prevention strategies to reduce risk of transferring and catching more than one strain/genotype of HCV

Get Tested
TWO TYPES OF TESTS:
Antibody Test: Checks if you've been exposed to Hep C virus (HCV).
Viral Load Test: Counts how many HCV virus is in your blood.

Check Viral Load
Sometimes, the body can fight off Hep C on its own, within 6 months after exposure.
If a viral load test finds Hep C virus in your blood 3-6 months after an antibody test, you may have chronic HCV that needs medicine to go away.

Find Care
If you test positive for Hep C, there are medications that can cure the virus.
See what to expect during treatment on the back.

hepc@peoplesharmreductionalliance.org (206) 330-5777

- Needs assessment
- Client education
- Provider engagement
- Expanded testing services and linkage to care

Needs Assessment

- Added questions regarding seeking and receiving HCV treatment to annual survey
- 20 in-depth interviews
 - 11 HCV-positive and 9 HCV-negative clients
 - Identify methods to support drug users in accessing HCV treatment
 - <50% of those with HCV who were asked, had talked to their providers about treatment
 - None felt encouraged to pursue treatment



Needs Assessment

- Stigma and competing priorities were barriers to seeking treatment
- Critical to provide more case management, engage providers, and reduce stigma

“I just haven’t gotten there, [my] priority is surviving. Moving camps. Right now I am squatting in a shed. I want to go get treatment but first I need work.”

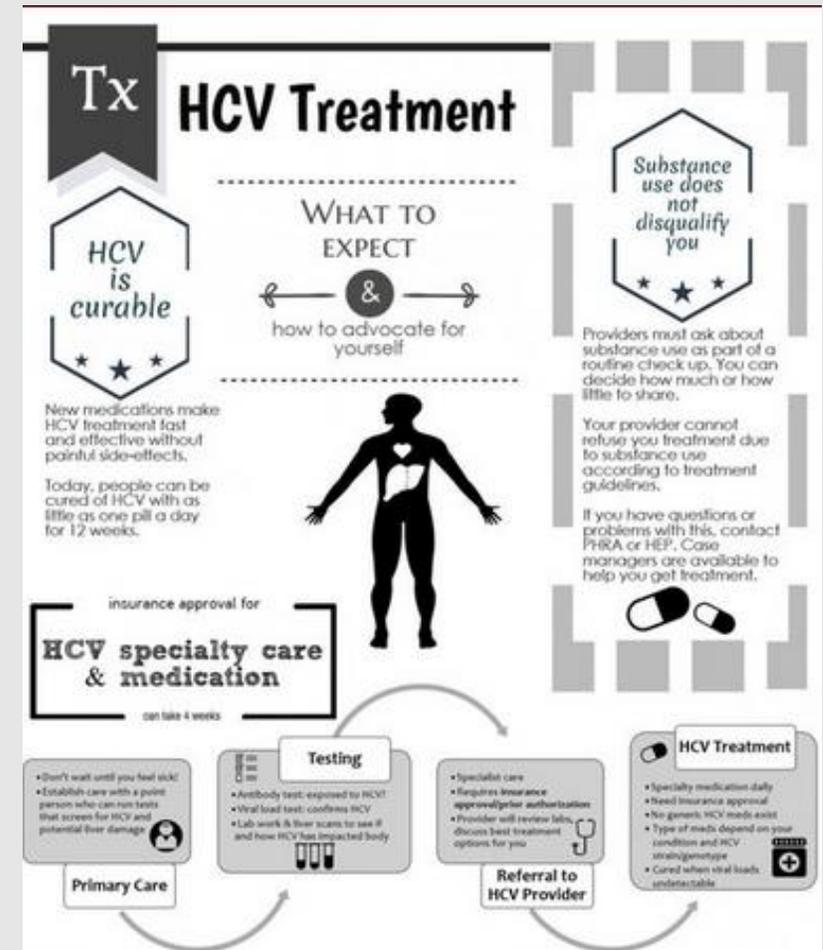
“I have other medical issues... If I feel comfortable, I might ask about hepatitis C, but if I am made to feel like a drug user, I won’t ask.”

“[Doctors] need to be more respectful and treat us like humans.”



Client Education & Provider Engagement

- Created educational materials
- Worked with 14 providers and 20 graduate students
- 6 new referral relationships
- Two new releases of information (ROI)
- Presented to providers at 2 conferences



Expanded Testing & Linkage Services

- Offer HCV testing on Fridays during needle exchange in Seattle
 - ~73 clients per week approached
- 66% increase in HCV testing in 2017
- Mobile medical clinic at needle exchange bimonthly since May
- Offered case management for treatment
- Adding testing at other PHRA sites



Testing/Treatment	Number (%)
Number screened	166
HCV +	41 (25%)
Returned for confirmatory test	30 (73%)
Confirmed positive	23 (77%)
Linked to treatment	3 (13%)

Lessons Learned & Key Considerations

- Inclusion of drug users in all phases and activities
 - Actively seek and budget positions for drug users
- Incorporate testing and linkage to treatment at point of contact
- Collaborate with community partners
- Help overcome barriers to accessing care
 - Engage providers to reduce stigma towards drug users
 - Provide nonjudgmental case management, including services to help with competing priorities (e.g., transport)
 - Collaborate with providers for patient care (e.g., ROIs)



Thank you!

PHRA

Lisa Al-Hakim

Kara Bensley

Shilo Jama

Vanessa McMahan

Hepatitis Education Project

Madi McPadden

Chelsie Porter

PHSKC Mobile Medical Clinic

Seattle Indian Health Board

And many thanks to all of the PHRA participants!

For further information, please contact us!

vanessa@peoplesharmreductionalliance.org

Peer Navigation for Hepatitis C Positive Patients

MOJGAN ZARE, MD, MPH

AHRC

- AHRC is a community-based wellness organization committed to promoting health and dignity by reducing the impact of HIV/AIDS, Hepatitis C, STIs, and Substance Use within vulnerable communities.
- Linkage to Care Model
- Harm Reduction Therapy
- Specialty Education
- Syringe Exchange Program
- Existence of Specialty Pharmacy (340B)



Linking Active Users to Care

Successes:

- Grady Liver Clinic
- Piedmont Hospital

Challenges:

- Transient life style
- Lack of Insurance
- Trust



Adherence

How to help increase adherence?

- Case management
- Warm Transfer
- Marta Cards

- **Story of Calvin**



Peer Navigation

- Navigators are NOT counselors, medical experts, or social workers.
- Peers are friends or members of the same community as the target population.
- Peers MUST receive training from existing peers and/or coaches within the organization.
- Peers serve more than one role. (e.g. serving on community advisory board).
- Peers provide feedback on organization's work.
- Peers MUST get paid.
- Peers' opinions matter and MUST be heard.

Benefits

- Help with increased access to care (e.g. HCV care)
- Sharing experiences
- Supply distribution (e.g. condoms)
- Low cost
- Increasing society productivity



Stigma and Peer Navigation

Three types:

- Staff to Peers
- Peers to Peers
- Peers to clients
- Solution: Education and Training



Training

- **Harm reduction** - a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use.

Harm Reduction is also a movement for the rights of people who use drugs.

- **Cultural Competency** involves understanding and appropriately responding to the unique combination of cultural variables and the full range of dimensions of diversity that the professional and client bring to interactions.
- **Cultural humility** is the ability to maintain an interpersonal stance that is other-oriented in relation to aspects of **cultural** identity that are most important to the person.

Challenges

- Communication
- Expectations
- Health Issues



The End

- Thank you
- Mojgan Zare, MD, MPH
- mojganz@ahrc-atl.org



Questions?

Please submit questions for any of the presenters via the webinar question function or send an email to tbroder@nvhr.org

Slides and a recording of the webinar will be sent to everyone who registered and posted on our website. [www.nvhr.org/programs/more than tested cured](http://www.nvhr.org/programs/more_than_tested_cured)

