

More Than Tested, Cured – A User-led Model

6th International Symposium on Hepatitis Care in
Substance Users

September 8,
2017



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About NVHR

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



NVHR's Program

- Capacity-Building and Technical Assistance
 - Support for groups conducting screening in community-based settings
 - Templates and support for implementing routine screening
- Webinars
- Fact sheets
- HCV Working Group
- Pharmacy Working Group
- HCV Treeters Group
- Community stakeholder engagement in PCORI studies
- Mini-grants
 - Technical assistance and \$10K financial support



NVHR's Policy Priorities

- Increased access to hepatitis B and C prevention, testing, treatment, and care services
- Oppose repealing the ACA
- All people living with hepatitis C deserve lifesaving treatment
- Other public policy priorities
 - increasing federal funding
 - urging state and federal agencies to expand access to syringe service programs
- More information about Policy:
 - www.nvhr.org/policy



State Medicaid HCV Treatment Access

- NVHR partnered with Harvard Law for report on HCV treatment access restrictions in all 50 states, DC, and Puerto Rico.
 - includes Fee-For-Service and Managed Care Organizations
 - focuses on restrictions in 3 areas: liver damage, sobriety, prescriber
 - Based on surveys sent to Medicaid Directors (about 1/3 completed the survey), information on state Medicaid websites, and review of prior authorization forms.



7

Collaborative Model

- Wrote grant proposal jointly
- Project calls twice monthly
- Working with evaluation consultant
- Replication at local or national level
- Findings will be disseminated nationally
- Learn more at

www.nvhr.org/project/medicaid-treatment-access-more-than-tested-cure



Workshop Overview

- Project presentations
 - Urban Survivors Union
 - People's Harm Reduction Alliance
 - Atlanta Harm Reduction Coalition
- Moderated discussion
- Q & A session



DEVELOPING HCV EDUCATION WITH PEOPLE WHO INJECT DRUGS

From Interviews and Focus Groups to
Social Marketing Messaging

Louise Vincent, MPH
Director
North Carolina Chapter
Urban Survivors Union

Urban Survivors Union

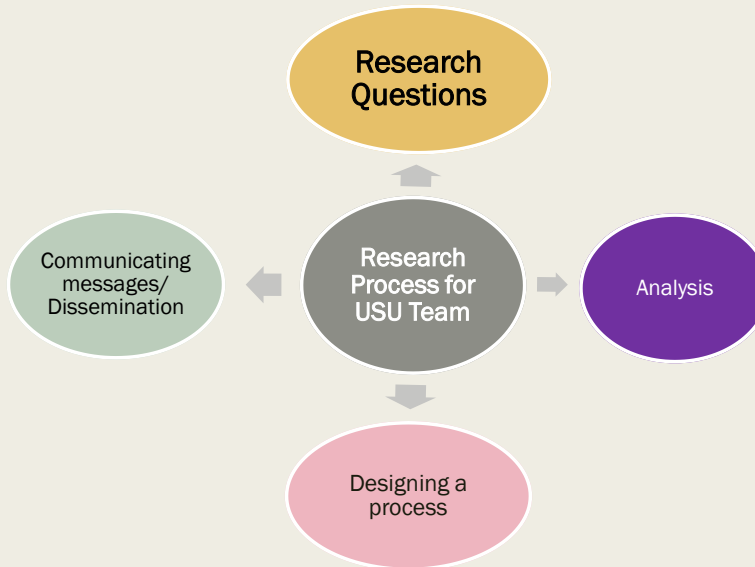
The Urban Survivors Union (USU) is a community organization providing direct health services to people who use drugs (PWUD). We work with communities to improve individual and public health by engaging people who use drugs and their friends and family. Our goal is to move people from passive recipients of health services to active service providers who care for themselves and their communities. We focus on community health, community organizing and mobilization, education and advocacy.

Problem: HepC messaging is often not based on PWID's health needs

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 HepC free
- ❖ *Clarify* how peer relationships and PWID social networks increase and decrease HCV infection risk

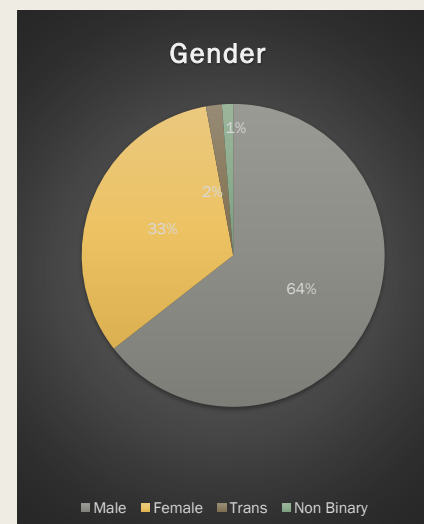
How do we improve HCV-related health outcomes for PWID?



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 Results

- 28% believed HCV infection can occur by reusing one's own injection equipment.
- 32% believe being sanitary and washing hands can prevent hepatitis C
- 53% reported not wanting to be in an intimate relationship with an HCV-infected person
- 86% believe strongly that HCV infection can occur via unprotected sex



Syringe Access in NC

- Syringe exchange was made legal in NC in July of 2016.
- USU administered clandestine syringe exchange services from 2008- until legalization.
- There are now 18 legal exchanges in NC.

Survey Finding

96% of respondents reported they would reuse used injection equipment if there was no syringe exchange

FOCUS GROUPS & IN-DEPTH INTERVIEWS

Focus Group Discussions
are group discussions intended to identify the beliefs and opinions of a selected group of people on a specific topic.



In-depth Interviews
are one-on-one discussions designed to provide a detailed picture of an individual participant's views about the area of interest.



People who inject drugs
(n=8)

Women who inject drugs
(n=6)

People using stimulants
(n=12)

HEALTH IN THE PIEDMONT



WHERE DO PEOPLE WHO USE DRUGS ACQUIRE HEALTH-RELATED INFORMATION?

- INTERNET
- PHARMACUTICAL COMMERCIALS
- FRIENDS
- THE PIEDMONT XCHNAGE 😊
- METHADONE CLINIC
- DRUG TREATMENT PROGRAMS
- PARENTS & FAMILY
- 12 STEP MEETINGS
- SCHOOL

Social Marketing Messages

Engage people who inject drugs (PWID)

PWID acquire useful information to stay healthy

Health promotion increased among PWID population

Reduced HCV incidence
HCV elimination now possible

Beyond Tested, Cured! A Social Marketing Campaign Delivered by USU

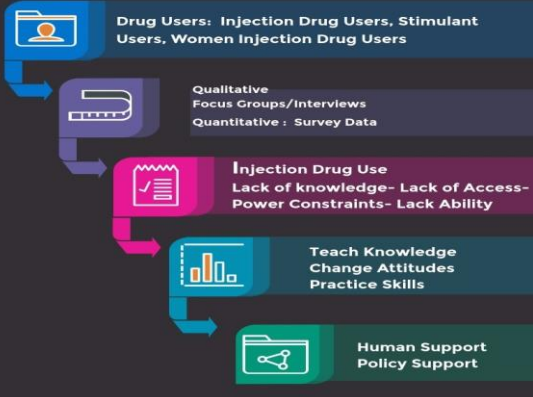


Increase connections to bring in people instead pushing them out!

Defined by me, Not by C

Hep C, Not my Reality

Urban Survivors Union - Peoples Harm Reduction Alliance, Atlanta Harm Reduction Coalition & National Viral Hepatitis Roundtable present: Beyond Tested, Cured: A Project designed to uncover barriers to care among drug users with Hepatitis C



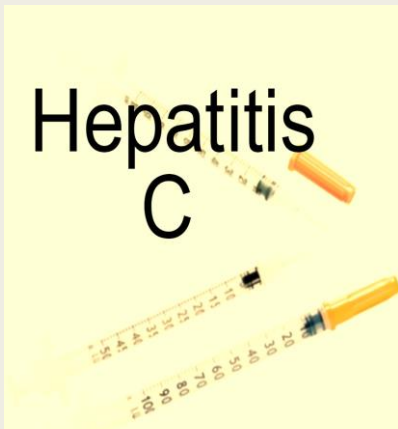
Defined BY Me Not BY C
Making Drug User Health A Reality
Urban Survivors Union - The Peoples' Drug User Union
338-669-5543
www.nbcurbansurvivorsunion.org

Active engagement in health advocacy with others has been demonstrated to sustain one's own healthy behavior and to maintain one's own reduced risk ([Ramirez-Valles, 2002](#)).

Directly Impacted health educators (peers) used this community outreach activity as a mechanism to support their own individual level, drug use and their exposure to multiple health risks in their environment ([Dickson-Gomez et al., 2006](#)).



Use Your Local Syringe Exchange



Exchange For Health: Safer Drug Use through Syringe Access

We would like people who use drugs to use their local syringe exchange to get education about new treatment for HCV infection: it is very effective with very few side effects

BEYOND TESTED, CURED

XCHANGE 4 NEW INFORMATION ABOUT HEPATITIS C

NO ABSTINENCE REQUIRED

NO AWFUL SIDE EFFECTS!

99% Effective
8-12 Weeks

**X CHANGE
OLD INFO ABOUT
HEP C**

PHONE: 336-669-5543
Urban Survivors Union

People who use drugs want to be healthy and have access to the most up to date information about Hep C, a disease that affects so many people who inject drugs.

Hep C,
not my
reality

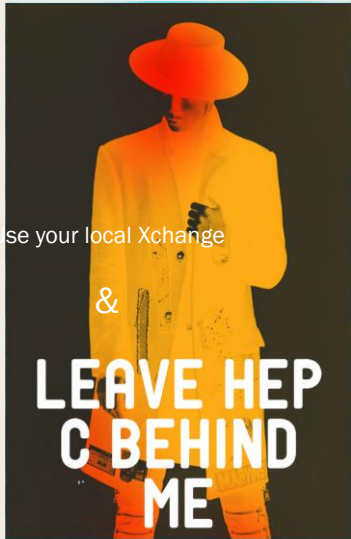
The Power of Exchange.

Syringe Exchange Programs are proven to reduce risk of contracting Hep C.

Hep C,
not my
reality

The Power of Exchange.

Syringe Exchange Programs are proven to reduce risk of contracting Hep C.

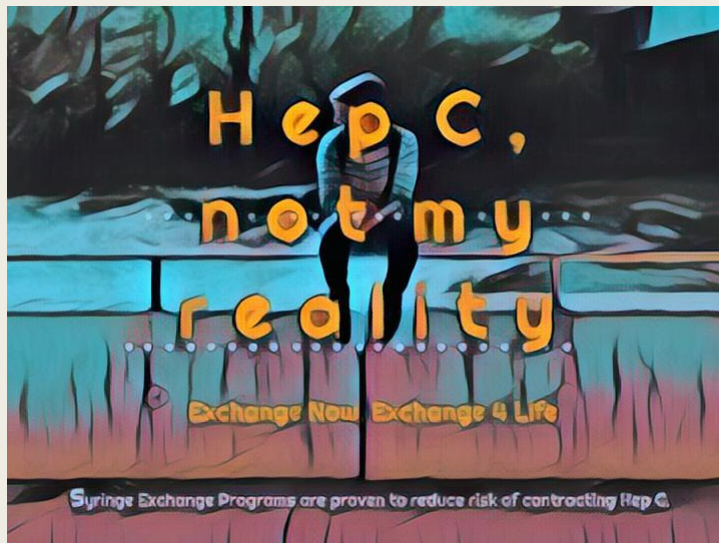


Get Educated
Get Tested
Get Cured



Leave HepC Behind

Hep C, Not My Reality Exchange Now—Exchange for Life



Marketing for Women Who Inject Drugs

- Women who use drugs can share love and care for partner in a way that is *mutually* respectful
- Social Marketing Message: Improves women's ability to care for self. Feelings of empowerment; able to act on own behalf.
- Women learn to inject and care for their own drug-related needs
- Empowerment to protect oneself.
- Women do not share injection supplies with partner and do not allow others to inject them
- Reduced HCV rates among women

Inject yourself. Protect Yourself

He Might. You Will.

Never leave your health in someone else's hands.

www.ncurbansurvivorsunion.org



**DO IT LIKE A PRO
HEP C FREE MY REALITY**

**DON'T DO HIS WASH OR HIS LAUNDRY
BAD BITCHES NEVER SHARE SHIT!**

PROTECT YOURSELF



BE PRO-SELF

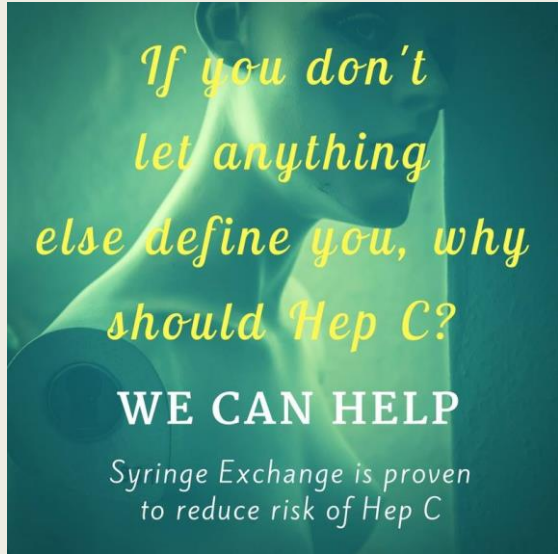
NEVER let anyone prepare your shot or shoot you up. People who do **DOUBLE** Their risk for infection!!!

NEVER SHARE:
SYRINGES
COTTONS
COOKERS
WATER
ANYTHING

INJECT YOURSELF



REAL BITCHES DON'T SHARE SHIT!
REDUCE THE SPREAD, & RISK OF CONTRACTING HEP-C & HIV USE YOUR LOCAL SYRINGE EXCHANGE
(RIGS, COTTONS, COOKERS, WATER, PARTNERS)



*If you don't
let anything
else define you, why
should Hep C?*

WE CAN HELP

Syringe Exchange is proven
to reduce risk of Hep C



75% OF PEOPLE
WITH HEP C
DON'T KNOW IT

IF YOU USE INJECTION
DRUGS, YOU'RE AT A
HIGHER RISK

**WE'RE
IN YOUR
CORNER**

**Stay Safe:
Get Tested,
Get Cured**



Protect Yourself at All Times



If you inject drugs, create a ritual that includes, cleaning your area and injection site, using new supplies for every shot, preparing your own shot, and injecting yourself. No one will protect you like you will. Get educated at your local syringe exchange. **DO IT LIKE A PRO!**





Urban Survivors Union

Thanks!



Patient-identified Provider Level Barriers to HCV Treatment

Lisa Al-Hakim

Kara Bensley, PHD MSc



People's Harm Reduction Alliance (PHRA)

- Peer run
- Need based syringe access program
- Five counties in Cascadia Region (Washington and Oregon)
- Drug user advocacy



PHRA Services

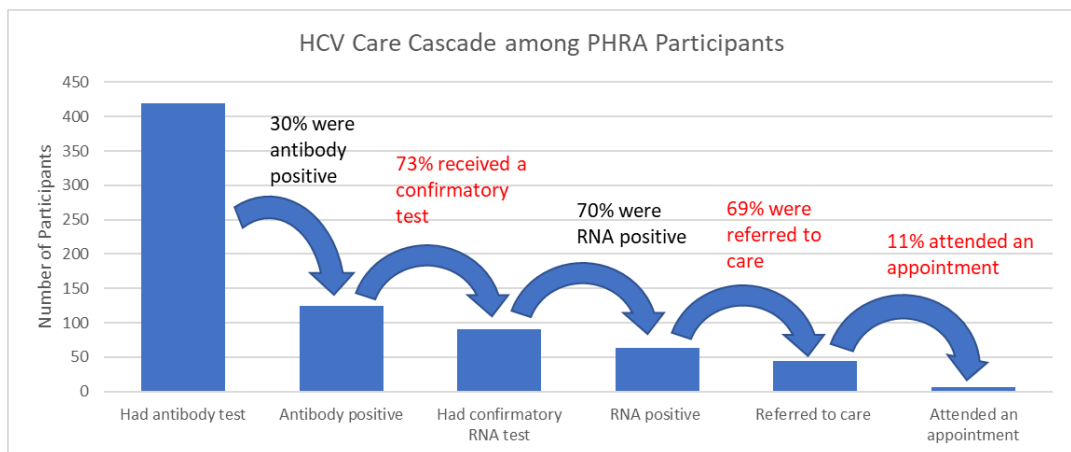
- Distributes syringes and works as well as Crack kits, Meth pipes, and Snorting kits, Naloxone, and pregnancy tests
- Partners with other programs to have regular and on-site Hepatitis C, HIV/AIDS, and drug reagent testing, as well as bimonthly primary care



HCV care landscape in Seattle

- In Washington:
 - Insurance does not have a fibrosis score requirement
 - Care must be provided by a specialist or a provider who participates in *Project ECHO*, a teleconsultation program
- In Seattle:
 - A number of local providers are willing to treat people who are actively using drugs for Hepatitis C
 - A local advocacy organization, *Hepatitis Education Project (HEP)*, provides case management and advocates for access to care
 - HEP provides weekly Hepatitis C antibody and confirmatory testing at the needle exchange

HCV and our Participants



Focus of Project

- Our focus of this project is to improve access to treatment of Hepatitis C among people who inject drugs by increasing access to providers who treat Hepatitis C among those who test positive
- Three pronged approach:
 - **Provider-level changes (primary focus)**
 - Systems-level changes
 - Patient-level changes

Provider-level Changes

- Increase provider understanding of barriers to Hepatitis C treatment among drug users
 - Interviewed 20 needle exchange participants about experiences with healthcare in April – July
 - Developed messages to guide provider education

Participant Interview Methods

- Interviews were short (10-30 minutes) and participants received \$10 for participation
- 10 participants were recruited on weeknights from the University District Needle Exchange in Seattle WA
- 10 participants were recruited during a weekday shift when Hepatitis C testing is also offered among patients who had lifetime history of Hepatitis C diagnosis



Summary of Interview Participants

- Of 20 participants, 11 had confirmed or probable Hepatitis C
- Of 9 participants without known Hepatitis C, only four reported being tested in the last year (although all reported going to the doctor at least once in the last year)
- Of 11 participants with known Hepatitis C, only two reported receiving Hepatitis C treatment

Reasons Participants with HCV did not receive care

- Doctors require people to stop using drugs before they receive Hepatitis C Care – sometimes for an extended period of time

“My doctor said, ‘We can give you treatment but you have to be clean’”

- Participant from University District, Seattle

Reasons Participants with HCV did not receive care

- Doctor stigma of drug users: they don’t want to talk about treatment with patients because “it won’t benefit them”

“She said that I am ‘Not going to die of Hepatitis C, I will die of something else’”

- Participant from University District, Seattle

Reasons Participants with HCV did not receive care

- Doctor tell patients that they have to be housed to be eligible for HCV care

“I wanted to, but the doctor told me I ‘had to have housing’”

- Participant from University District, Seattle

Reasons Participants with HCV did not receive care

- Patients are choosing to not get a confirmatory test because they don't see a clear linkage to care

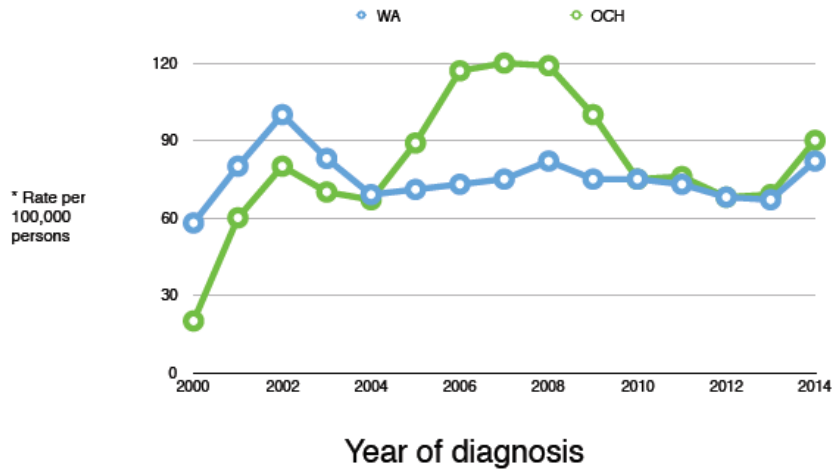
“Ignorance is bliss... but I would like to get treatment”

- Participant from University District, Seattle

Rural Access to Care: Olympic Peninsula



Figure 1. Number of acute hepatitis C infections in the OCH region, 2000–2014
 Source: Public Health Issues Management System (PHIMS)



Rural Access to Care: Olympic Peninsula

Based on a recent provider survey, the following barriers exist:

- Most doctors have a lot of misinformation about treating Hepatitis C among drug users
- Lack of access to Hepatitis C testing and treatment
 - Few providers
 - Transportation barriers


Key Messaging for Doctors

- *Patients who use drugs can start treatment today – and should*
 - Increased public health benefit by treating those most at risk
 - Needle exchanges and education help prevent re-infection
 - All participants who have received treatment with support of needle exchange have successfully completed and remained HCV-free (limitation: n=3)
- *Patients may have been previously denied HCV treatment and thus continued regular testing and conversations about treatment options are important*
 - Treatment options have changed
 - Medicaid reimbursement guidelines have changed
 - Conversations need to be ongoing

Recommendations for Primary Care Doctors

- *Regular HCV screenings should be routine among people who use drugs*
 - Some participants thought that HCV screenings were part of all blood panels and thus they did not have HCV if they did not talk about it in a clinical encounter
 - Decreasing stigma is important
- *If testing for HCV, links to HCV treatment must be available to patients*
 - Two participants declined confirmatory testing because they didn't feel like they had access to treatment so didn't want to know
 - Systems may be based on previous drug regimens and must be adapted to increase accessibility to new lower-barrier medication

Release the "Happy Drug" in your brain! Make a donation to the People's Harm Reduction Alliance today!

THE PEOPLE'S HARM REDUCTION ALLIANCE  NEWS LOCATIONS / HOURS HEPATITIS C ADVOCACY VOLUNTEER DONATE SHOP

HEPATITIS C ADVOCACY

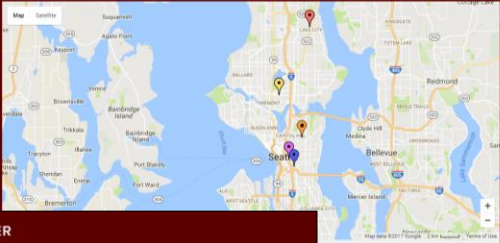
FOR OUR PARTICIPANTS (IN WASHINGTON)*

INTERESTED IN FREE HEPATITIS C TESTING?

The Hepatitis Education Project provides free and confidential Hepatitis C screening and confirmatory testing at our University District Needle (Seattle) on Friday from 5-9pm.

DO YOU HAVE HEPATITIS C AND ARE INTERESTED IN GETTING CURED?

NOT SURE WHERE TO GO TO RECEIVE CARE? THERE ARE A NUMBER OF DOCTORS IN SEATTLE WHO PROVIDE HEPATITIS C TREATMENT AND OTHER IMPORTANT SERVICES TO DRUG USERS



OTHER

ARE YOU A PROVIDER INTERESTED IN BEING ADDED TO OUR MAP OR LEARNING MORE ABOUT THE BENEFITS OF TREATING HEPATITIS C AMONG DRUG USERS?

Email Kara at kara@peopleharmreductionalliance.org or call (206) 251-0295 to learn more.

ARE YOU A NEEDLE EXCHANGE OR HARM REDUCTION ORGANIZATION WANTING TO PARTNER WITH OTHER ORGANIZATIONS IN IMPROVING ACCESS TO HEPATITIS C CARE AND TESTING?

Email Kara at kara@peopleharmreductionalliance.org or call (206) 251-0295 to join monthly advocacy calls and be added to our mailing list.

© 2016
The People's Harm Reduction Alliance
PO Box 85028 Seattle, WA 98145
(206) 330-3777

Next Steps

- Improve linkage to care with existing providers
- Continue to educate participants and providers on HCV among drug users
- Expand access to HCV testing and care to other sites

“When they ask if you are a drug user, all of the care and empathy go out the window”

- Participant from University District, Seattle

Thank you!



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.

TRANSMISSION
HCV is spread through blood contact.

PREVENTION
Protect yourself! Avoid spreading or getting HCV.

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

Transmission can happen through things like needles, needle sharing, unsterile tattoo, blood transfusions done before 1992, and occasionally, unprotected sex.

-Don't Share needles, cookers, cottons, snorting equipment
-Avoid intimate tattoos/piercings
-Sexual contact with HCV positive partners -cocci can cause HCV to damage your liver faster

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.

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

Tx HCV Treatment

HCV is curable

WHAT TO EXPECT & how to advocate for yourself

Substance use does not disqualify you

Providers must ask about substance use as part of a routine check up. You can decide how much or how little to share.

Your provider cannot refuse you treatment due to substance use according to treatment guidelines.

If you have questions or problems with this, contact PHRA or HEP. Case managers are available to help you get treatment.

New medications make HCV treatment fast and effective without painful side-effects.

Today, people can be cured of HCV with as little as one pill a day for 12 weeks.

insurance approval for **HCV specialty care & medication** can take 4 weeks

Primary Care

- Don't wait until you feel sick
- Establish care with a primary person who can run tests that screen for HCV and potential liver damage

Testing

- Anti-body test: exposed to HCV
- Viral load test: confirms HCV
- Lab work & liver scans to see if and how HCV has impacted body

Referral to HCV Provider

- Specialist care
- Requires insurance approval/prior authorization
- Provider will review lab work & discuss best treatment options for you

HCV Treatment

- Specialty medication daily
- Need insurance approval
- May generate HCV meds sent
- Type of meds depend on your strain/genotype
- Guard when viral loads undetectable

INSURANCE | HCV

PRIOR AUTHORIZATIONS

- HCV is considered a SPECIALTY and needs prior insurance coverage
- HCV specialty meds often aren't available at regular drug stores & pharmacies
- Specialty meds typically require mail order pharmacies
- Don't have a safe place for meds to be delivered? PHRA & HEP can help!

up to 30 days

- In approval once a provider submits a request for meds
- If insurance denies a request, you can submit an APPEAL. Contact your provider

Questions? PHRA & HEP want to support you!
PHRA: (206) 330-5777
HEP: (206) 752-0311

Systems-Level Changes

- Taking steps to create a drug-user health center at needle exchange
 - Drug-user led health services ensures respectful source of healthcare
 - Increases availability and accessibility to needle exchange participants
 - Improves local partnerships with government, healthcare, and service organizations
- Advocating for healthcare changes to improve access to care across health systems in Seattle
- Organizing with other need based exchanges that are interested in improving access to Hepatitis C care

Patient-level Changes

- PHRA partners with Hepatitis Education Project to provide Hepatitis C testing on-site at needle exchange one day per week
- PHRA is providing case management and advocate support for drug users seeking Hepatitis C treatment
- Partnered with University of Washington School of Public Health graduate students to create materials to support participants seeking Hepatitis C care

Specialty Education Training on Harm Reduction for People Who Inject Drugs (PWID) at High-Risk for Hepatitis C Virus (HCV) Contraction

Mojgan Zare, MD, MPH



Previous Findings from publications

- Intravenous drug use continues to drive the HCV epidemic.
- Active drug use...
 - Is a strong predictor for healthcare providers denying users HCV treatment and patients never receiving treatment¹.
 - Presents challenges at the patient, provider, and community levels that strengthen when examined in the context of people actively using intravenous drugs².
- Active drug users reported the reason for not receiving HCV treatment as mainly as a lack of HCV-related knowledge¹.
- Harm reduction education and training needs to be provided to HCV treatment providers in order to ensure that active drug user patients receive the treatment they need.

1. [Maryam Alavi, Jason Grebely, Michelle Micallef, Adrian J. Dunlop, Annie C. Balcomb, Carolyn A. Day, Carla Treloar, Nicky Bath, Paul S. Haber, Gregory J. Dore, on behalf of the Enhancing Treatment for Hepatitis C in Opioid Substitution Settings \(ETHOS\) Study Group: Assessment and Treatment of Hepatitis C Virus Infection Among People Who Inject Drugs in the Opioid Substitution Setting: ETHOS Study. *Clin Infect Dis* 2013; 57 \(suppl. 2\): S62-S69. doi: 10.1093/cid/cit305](#)

2. [Esther J. Aspinall, Stephen Corson, Joseph S. Doyle, Jason Grebely, Sharon J. Hutchinson, Gregory J. Dore, David J. Goldberg, Margaret E. Hellard: Treatment of Hepatitis C Virus Infection Among People Who Are Actively Injecting Drugs: A Systematic Review and Meta-analysis. *Clin Infect Dis* 2013; 57 \(suppl. 2\): S80-S89. doi: 10.1093/cid/cit306](#)

Findings from AHRC Hepatitis C Patients

Reasons behind not seeking treatment:

- Stigma associated with drug use and rejection for treatment
- Lack of knowledge and stigma associated with Hep C treatment
- Lack of trust among health care providers
- Difficulty navigating through healthcare system



Findings from HCV Treatment Providers Perceptions

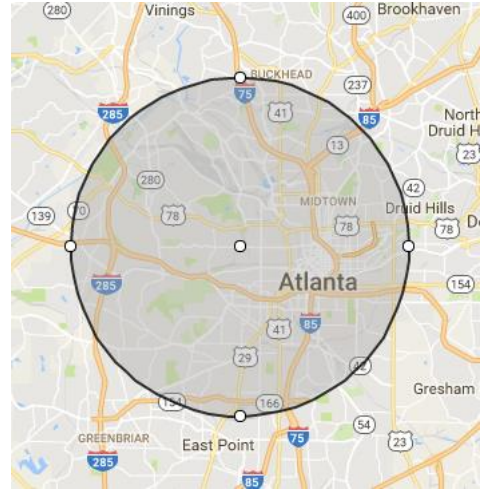
Reasons behind not providing treatment to active drug user patients:

- Not keeping up with appointments
- Drug Resistance

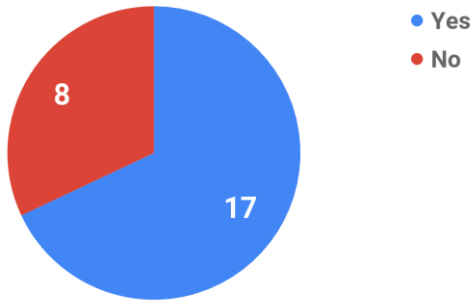


Specialty Providers Who Treat Hepatitis C

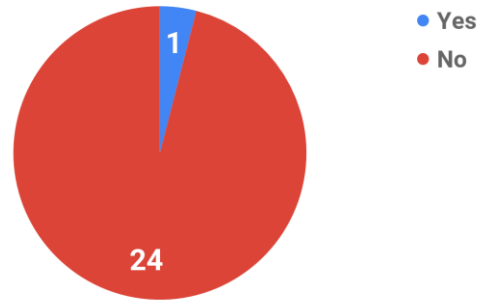
- Atlanta Harm Reduction Coalition identified and reached out to 25 hepatologists within a 5 mile radius of AHRC (Atlanta, GA 30314)
- Providers were asked for:
 - Their phone number
 - Location
 - Whether or not they treat active drug users for Hepatitis C virus
 - Whether or not they provide treatment based on a scale/slide fee



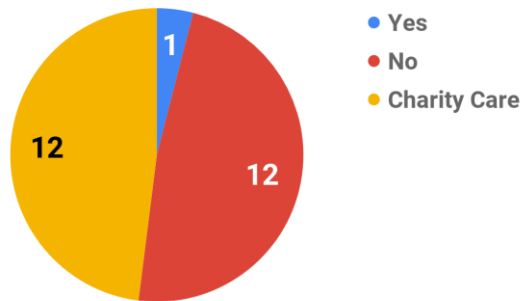
Do You Treat Active Drug Users for Hepatitis C?



Do You Provide Treatment Based on Scale/Slide Fee?



Do You Provide Treatment Based on Scale/Slide Fee?



Grady Liver Clinic

- Only known hepatology department to treat active users in atlanta
- Treatment eligibility is based on past successfully attended appointment by patients in the hospital
- In process of using a new system to determine eligibility that uses patient personality to determine adherence



Providing education to patients

- Linkage to Care Model at AHRC provides:
 - Education on Hepatitis C and treatment options
 - Importance of adherence to Syringe Exchange Programs
 - Importance of adherence to Hep C treatment
 - Removing underlying barriers (e.g. food)

Providing Education to Hep C Treatment Providers

- AHRC's effort in decreasing re-infection and enhancing adherence:
 - Effective Syringe Exchange Program
 - Effective Linkage to Care Model
 - Comprehensive Training on Harm Reduction to specialty providers
- First Successful Case: Piedmont Hospital with 6 Hepatologists on Staff, training is scheduled on Sept 12th, 2017



The Next Steps

- Continuing to provide education to Hep C Providers
- Provide recommendations and training based on findings to:
 - Healthcare providers
 - Harm reduction agencies
 - Similar entities (e.g. Drug Treatment Facilities)

References

1. Maryam Alavi, Jason Grebely, Michelle Micallef, Adrian J. Dunlop, Annie C. Balcomb, Carolyn A. Day, Carla Treloar, Nicky Bath, Paul S. Haber, Gregory J. Dore, on behalf of the Enhancing Treatment for Hepatitis C in Opioid Substitution Settings (ETHOS) Study Group; Assessment and Treatment of Hepatitis C Virus Infection Among People Who Inject Drugs in the Opioid Substitution Setting: ETHOS Study. *Clin Infect Dis* 2013; 57 (suppl_2): S62-S69. doi: 10.1093/cid/cit305
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Moderated Discussion



Q & A Session

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