More than Tested, Cured - Overcoming Barriers to HCV Care

Project Update Webinar

June 15, 2017
Welcome and Project Overview

National Viral Hepatitis Roundtable – coalition working to end hepatitis B and hepatitis C in the U.S.  
www.nvhr.org/join

Slides and a recording of the webinar will be sent to everyone who registered and posted on our website

Questions and discussion will be at the end of the webinar – please submit via the webinar question function

Project Overview: More than Tested, Cured: Overcoming Barriers to Hepatitis C Care
• collaboration between NVHR & three harm reduction organizations with local focus
• overcoming barriers requires input of directly impacted individuals
• unique model of a partnership
• Learn more at www.nvhr.org/programs/more_than_tested_cured
BEYOND TESTED, CURED

Urban Survivors Union
Promoting Drug User Health
Safer Drug Use & Hepatitis C Elimination
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<th>No.</th>
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Health Messages & Prevention

4 People who use Drugs

Problem: There are not strong messages aimed at encouraging positive change and healthy behaviors among people who use drugs.

THIS COMMUNITY LED AND DIRECTED PROJECT WILL

• Describe how drug users (specific emphasis on IDUs, stimulant injectors, and women injectors) search for information and or learn about safe injection practices, Hepatitis C, and drug use education.
• Determine the process each group decides whether or not to use safe injection methods and determine what behavior prevents people from making good decisions around their use.
• Identify why people don’t talk about Hep C. Identify reasons these groups don’t get tested, and/or treated
• Clarify how peer relationships and drug using networks affect safer drug use and health choices.
Literature Review: Health programs that focus only on singular issues are not effective. We are whole people living in a society.

**Individual Level Factors**
- Knowledge around individual HCV status. Health knowledge in general.
- Negative perceptions about how HCV is treated. Negative attitudes about Hepatitis C in general.
- Low health literacy – limited ability to get to health providers
- Fear of death, fear of stigma, fear of unknown
- No Money – No Insurance- No understanding of medical system
- Medication is expensive

**Community Health Care Related Factors:**
- There are not very many places for drug users to learn about safer drug use or drug user health.
- DRUG USERS DON’T FEEL COMFORTABLE telling the truth to their providers.
- Misconceptions that drug users don’t care about their health. Sometimes we give up on our health but we all care about our health.
- Misconceptions that sobriety must come before treatment
- Too often we think we can’t care about our health unless we stop using.

**Policy Level**
- **Policy and Institutional Level Factors**
  - Policies that are restrictive around syringe access
  - Insurance policies which restrict treatment because of drug use/reinfection etc.
  - Lack of coordinated efforts- comprehensive care
PEOPLE WHO INJECT DRUGS SHOULD HAVE AT THE VERY LEAST THESE SUPPORT SERVICES:
WHERE DO PEOPLE WHO USE DRUGS GET THEIR HEALTH INFORMATION?

- INTERNET
- PHARMACUTICAL COMMERCIALS
- A FRIEND
- THE PIEDMONT XCHANGE 😊
- METHADONE CLINICS
- DRUG TREATMENT CENTERS
- PARENT
- 12 STEP MEETING
- SCHOOL
SURVEY INFORMATION
We surveyed 67 active drug users age 18 – 51 using an anonymous google form.

- 91% of the people we surveyed indicated that they had either witnessed an overdose or been in a situation where there was an overdose. This underscores the need to integrate health messages that touch on multiple issues related to injection drug use.

- 70% believed that people with Hepatitis C posed a dangerous health risk to others.

- 41% stated that Hepatitis C could be spread through sharing food and water.

- 17% stated that IDUs should not be treated for HCV because they could not take care of their health.

- 35% said they would not want to be in a sexual relationship with someone who was HCV positive.

- 33% said that most people get hepatitis C from themselves.
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 18 legal exchanges in NC
- Harm Reduction Organizations are essential if we are to increase knowledge
FORMATIVE EVALUATION

Focus Group Advertisement
- Posted sign-up sheets at the Piedmont Xchange
- Advertised on Facebook
- Hung signs at the methadone clinics
- Gave flyers to our outreach workers who work in the county and the surrounding cities
- Craigslist ad
- Told the directors of a number of different organizations

Three Groups
- Women who inject drugs
  - 12-14 enrolled, 6 attended
- People who inject stimulants (methamphetamine & cocaine)
  - 13 enrolled, 12 attended
- Injection drug users
  - 14 enrolled, 8 attended
WANTED: Active Injection Drug Users

- We are conducting research at Piedmont Urban Survivors Union which we believe will result in a more complete understanding about Hepatitis C in this area among people who use drugs.

- We need the expertise of active users. We believe that you are the experts of your lived experience.

- We will pay by the hour. All attendees must be interviewed and approved before they are able to participate in the project.

- If you are not chosen for this project please don’t take it personally. We have limited space. We want your input and value your thinking...there will be more opportunities soon!
Created notebooks for participants

- Personal experience release
- Consent to Participate in a study
- Stipend Documentation
- Evaluation
- HIV/ HCV testing Confidentiality form
- W-9
Developed HCV Prevention Presentation

- Short (15-20 min.) max.
- High Energy
- Relevant
- We felt that we needed to go over the basics because there was such low knowledge scores.
- The majority of focus group participants were unsure of their HCV status and had not ever been tested for HCV.
We chose a combination of directly impacted people and harm reduction professionals as focus group facilitators. A handout was made for each focus group facilitator to read so they would have a clear understanding of how the session should be conducted.

Our participant planning group helped us decide what questions to focus on and this process was an awesome opportunity for everyone to work together.
We recorded all 3 focus groups & 6 individual interviews

- We are currently reviewing all of the focus group data.
- We have a first copy of the video which highlights the need for groups like USU and syringe exchanges.
- Drug User Unions across the country will give us feedback on the video and print companion pieces we will be developing over the next 4 months. We are truly excited!
More than Tested, Cured Project
People’s Harm Reduction Alliance (PHRA)

Kara Bensley, PhDc MSC
Marjorie Wilson, MSW
Focus of Project

• The focus of this project is to improve access to treatment of Hepatitis C among people who inject drugs by increasing the number of PCPs who either initiate HCV treatment for their patients or who refer them to specialty treatment

• Three pronged approach:
  • Systems-level changes
  • Provider-level changes
  • Patient-level changes
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
Provider-level Changes

• Increase provider understanding of barriers to Hepatitis C treatment among drug users

• Interviewed 15 needle exchange participants about experiences with healthcare in March – May

• Developing messages to create materials for provider-level education to disseminate this fall
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

• 5 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 15 participants, 6 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 6 participants with known Hepatitis C, only one reported receiving Hepatitis C treatment
Reasons Participants with Hepatitis C did not receive care

• Doctor wanted participant to have housing first
• Doctor told participant he/she only brought it up because he/she had to, and that participant had to be clean prior to initiating treatment
• Doctor told participant that the participant must be clean/sober “for extended period of time”
• Additionally, one patient chose not to start treatment as focused on “just surviving”, and one patient had not seen doctor since acquiring Hepatitis C
Next steps

• Determine key messaging for providers to improve:
  • Understanding of barriers to Hepatitis C care and public health benefits of providing Hepatitis C treatment as prevention among drug users
  • Cultural competency for working with drug users to improve patient experience

• Develop educational and dissemination materials
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
UW Student Group Project

• Created interview guide and conducted qualitative interviews with 14 providers and HCV professionals
• Compiled list and map of providers based on interviews for PHRA participants
• Created pamphlet and infographic educating participants on how to access care and what is involved in the process
• Established partnership between School of Public Health and PHRA for sustainability of the documents and resources
<table>
<thead>
<tr>
<th>Clinic Name</th>
<th>Address</th>
<th>Hours</th>
<th>To make an appointment:</th>
<th>To apply for insurance, charity care or sliding scale fee:</th>
<th>What services do they offer?</th>
<th>Doctors who treat Hepatitis C:</th>
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<tbody>
<tr>
<td>Neighborcare Health at 45th Street</td>
<td>1629 N 45th St Seattle, WA 98103</td>
<td>M, T: 8AM-7PM, W, Th, F: 9:5-5:30 PM, Sat: 10AM-2PM</td>
<td>Call (206) 633-3350</td>
<td>Ask for the “Eligibility” department when call to schedule an appointment.</td>
<td>Hepatitis C: Yes</td>
<td>John Olson</td>
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<td>(206) 633-3350</td>
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<td>Suboxone: Yes</td>
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<td>Primary Care: Yes</td>
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<td>Neighborcare Health at Lake City</td>
<td>12721 30th Ave, NE, Seattle, WA 98125</td>
<td>M, T, Th: 8-7:30PM, W: 9AM-6PM, F: 8AM-5PM</td>
<td>Call (206) 417-0326</td>
<td>When you go in for your first appointment, can meet with financial department.</td>
<td>Hepatitis C: Yes</td>
<td>Richard Waters</td>
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<td>(206)-417-0326</td>
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<td>Suboxone: Yes</td>
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<td>Primary Care: Yes</td>
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<td>Seattle Indian Health Board</td>
<td>611 12th Ave. S, Ste. 200 Seattle, WA 98144</td>
<td>M-F: 8:30AM - 6:30PM, Sat: 9AM-2PM</td>
<td>Call (206) 324-9360. Walk-ins accepted.</td>
<td>Will help with insurance enrollment or other coverage. Serves both tribal and non-tribal members.</td>
<td>Hepatitis C: Yes</td>
<td>Madeline Turner</td>
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<td>(206) 324-9360</td>
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<td>Suboxone: Yes</td>
<td>David Sapienza</td>
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<td>Primary Care: Yes</td>
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<td>Country Doctor</td>
<td>500 19th Ave E, Seattle, WA 98112</td>
<td>M, T, F: 9AM-5PM, W, Th: 9AM-8:30PM</td>
<td>Call (206) 299-1600</td>
<td>Ask when call to schedule about help applying to Medicaid/Apple Health at your first appointment.</td>
<td>Hepatitis C: Yes</td>
<td>Kate Stanley, NP</td>
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<td>(206) 299-1600</td>
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<td>Suboxone: Yes</td>
<td>Jocelyn James Medical Residents (Starting in July)</td>
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<td>Primary Care: Yes</td>
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<td>Harborview Adult Medicine</td>
<td>325 9th Ave., Ground, Seattle, WA 98104</td>
<td>M-F: 8-4:30</td>
<td>*Call 206-520-5000 to register. Tell them you are seeking Hepatitis C treatment, and want to be seen at Harborview Adult Medicine.</td>
<td>*Call financial assistance at 206-744-3084 to make an appointment with them.</td>
<td>Hepatitis C: Yes</td>
<td>Judy Tsui</td>
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<td>Suboxone: Yes</td>
<td>Jocelyn James Medical Residents (Starting in July)</td>
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1. **Hepatitis C, or HCV, is completely curable.** New medications have made HCV treatment fast, effective and without painful side-effects. Today, people can be cured of HCV with as little as one pill a day for 12 weeks.

2. **The first step** to getting treated is getting into primary care, or finding a primary care doctor who also treats HCV (see list below for this type of doctor). Your provider will do a few tests, including lab work and a liver scan to see how, if at all, HCV has affected your body. If you already have a primary care doctor who does not have training to treat HCV themselves, they can refer you to a specialist who is trained to treat HCV. *Sometimes the timing isn't right for treatment. HCV is a very slowly progressing disease, and people can live a long time without getting sick from HCV. If you want to wait to get treatment, talk with your doctor about how your condition might progress.*

3. **Substance use** does not disqualify you from treatment. Doctors will ask you about drug use as part of their routine check up, and you can decide how much or how little to tell them. Your doctor cannot refuse you treatment due to drug use according to treatment guidelines. If you have questions or problems with this, contact PHRA or HEP. There are case managers available to help you get treatment.

4. **Once you have been referred to a doctor who treats HCV,** they will review your labs and liver scan, and talk to you about which treatment is best for you. There are different types of medications that work differently for each person’s body. Once you and your doctor have picked a treatment plan, your insurance company has to approve the medication.

5. **HCV medication** is considered a “specialty” medication, which means your insurance company has to approve the treatment before they will pay for the prescription. Your doctor will submit a request for the medication, sometimes this paperwork process can take up to 4 weeks! Once your medication is approved by your insurance company, you can start treatment.

6. **HCV treatment** will be pills that you will take daily. You will not need to take any shots or interferon with today's treatment. Current medication has minimal side effects and very high success rates. You will have to visit your doctor a few times during treatment to get lab work done to check your progress. After you have finished treatment, you will visit your HCV doctor one last time to confirm that there is no HCV in your blood and you have been cured!
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.
Transmission can happen through IV drug use, needle sharing, unstable needles. Blood transfusions done before 1992, and occasionally, unprotected sex.

PREVENTION
Protect yourself. Avoid spreading or getting HCV.
- Don’t share: needles, cookers, cottons, smoking equipment.
- Avoid: unsanitary tattooing/piercing.
- Use nonshared sex with HCV positive partner.
- You can cure HCV to damage your liver better.

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

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.

HCV Treatment
WHAT TO EXPECT
& how to advocate for yourself

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

HCV Treatment

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 & HEP. Case managers are available to help you get treatment.

Questions?
PHRA: (206) 330-5777
HEP: (206) 739-0311

VPD: (206) 255-8655

Check out the HCV Care Coordinator at: peoplesharmreductionalliance.org

(206) 330-5777
Specialty Education Training on Harm Reduction for People Who Inject Drugs (PWID) at High-Risk for Hepatitis C Virus (HCV) Contraction

Dr. Mojgan Zare
Previous Findings

• 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 treatment\(^1\).
  
  • Presents challenges at the patient, provider, and community levels that strengthen when examined in the context of people actively using intravenous drugs\(^2\).

• Active drug users reported the reason for not receiving HCV treatment as mainly as a lack of HCV-related knowledge\(^1\).

• Harm reduction education and training needs to be provided to HCV treatment providers in order to ensure that HCV positive active drug users 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

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
Dr. Lesley Miller’s Experience

- Medical Director of the Grady Liver Clinic
- Screening was used to determine whether or not the patient actively using intravenous drugs would receive the Hepatitis C treatment
- In order to determine treatment eligibility, staff examined how many appointments the patient actually attended
- Only 1 successful case so far, but model shows promise
The Next Steps

Atlanta Harm Reduction Coalition will…

• Use previous research and our own findings in order to develop a harm reduction educational training program

• Reach out to Hepatitis C treatment providers

• Provide recommendations and training to healthcare providers when determining the best possible method for treating active intravenous drug users with Hepatitis C virus
Questions?

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

Save the date for our next project webinar – Thursday, August 10th

Special thanks to our sponsor GILEAD