

Addressing barriers to hepatitis C care faced by individuals who use drugs

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Acknowledgements

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Conflict of Interest

- No conflicts to report

Learning Objectives

- Demonstrate innovative strategies to address stigma and misconceptions among healthcare professionals who could treat hepatitis C patients.
- Describe the barriers and solutions to implementing an intervention to increase hepatitis C knowledge among people who use drugs.
- Describe a unique collaboration of a national non-profit organization and three harm reduction organizations addressing barriers to HCV treatment.

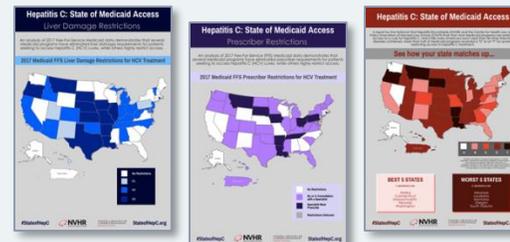
National Viral Hepatitis Roundtable (NVHR)

- National coalition of about 500 members
 - Mission: working together to eliminate hepatitis B and C in the U.S.
- NVHR advocates at the federal and state levels for increased access to hepatitis B and C prevention, testing, treatment, and care.
 - Expand access to syringe service programs, to link people who use drugs with HBV/HCV screening/testing and treatment.
 - NVHR partnered with the Center for Health Law and Policy Innovation of Harvard Law School (CHLPI) to create the first-ever comprehensive assessment of state Medicaid restrictions on hepatitis C cures.
- NVHR provides hepatitis C education, technical assistance, coalition building, & capacity building
 - Webinars, Fact Sheets & Online Resources
 - Working Groups for HCV Treaters & Pharmacists
 - Programs: Hepatitis C – it’s about More than Liver Disease; More than Tested, Empowered Project
 - Community Stakeholder Engagement in PCORI Studies
 - Mini-Grants - Technical assistance & \$10K of financial support
- www.nvhr.org

Background – Hepatitis C: State of Medicaid Access

The **National Viral Hepatitis Roundtable (NVHR)** and the **Center for Health Law and Policy Innovation at Harvard Law School (CHLPI)** launched “**Hepatitis C: State of Medicaid Access**” – a report and interactive project grading all 50 state Medicaid programs, as well as the District of Columbia and Puerto Rico, according to restrictions preventing access to treatments for hepatitis C, *including:*

- **Sobriety / History of Alcohol or Substance Use Restrictions**
 - **Liver Damage (Fibrosis) Restrictions**
 - **Prescriber Restrictions**
- The interactive report is available at www.stateofhepC.org featuring all 52 state-by-state report cards, advocacy resources and materials, and a petition urging widespread access to a cure.



- Since we launched the report, **16 states** have announced less restrictive HCV treatment policies.

Idaho



Grade: D

- Idaho Medicaid maintains liver damage, sobriety and prescriber restrictions that limit many people with hepatitis C from accessing treatment.
- **Currently, Idaho Medicaid requires that a patient does not have a history of alcohol or substance use within six months prior to treatment.**
- Idaho Medicaid also requires at least moderate liver damage (fibrosis) of F2 or greater and that a patient must be under the care of or in collaboration with an experienced hepatitis C practitioner.

Oregon



Grade: D

- Oregon Medicaid Fee-for-Service (FFS) program and nine Managed Care Organizations (MCOs) inquire about the beneficiary's alcohol abuse and substance abuse status in the previous six months and the enrollment in substance treatment program if applicable.
- Oregon Medicaid Fee-for-Service (FFS) program and nine Managed Care Organizations (MCOs) require at least moderate liver damage (fibrosis) of F2 or greater.
- Oregon Medicaid Fee-for-Service (FFS) program and nine Managed Care Organizations (MCOs) require that treatment for F3 and F4 patients be prescribed by or in consultation with a specialist. Treatment for F2 patients does not have prescriber restrictions.
- *Nine MCOs do not provide hepatitis C coverage requirements publicly.*

Washington



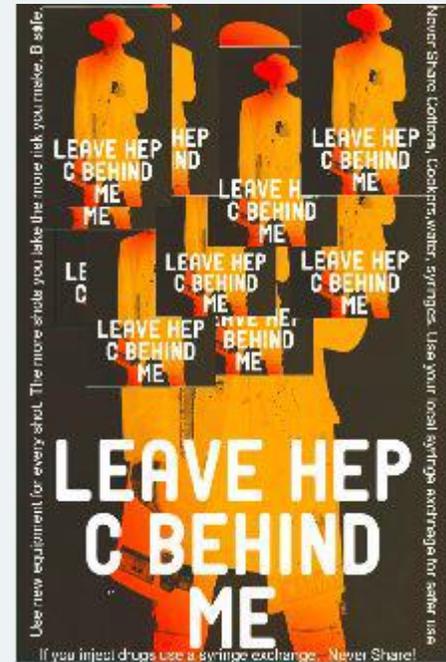
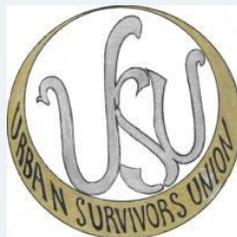
Grade: A-

- Washington has significantly improved access to hepatitis C medications and removed most barriers to treatment in all three categories of restrictions.
- **As a result of legal action and patient advocacy, Washington Medicaid does not have any liver damage (fibrosis) requirements or sobriety restrictions.**
- Alaska Medicaid requires a prescription be written by or in consultation with a specialist.
- Due to the prescriber restrictions, a “minus” has been added to the state’s “A” grade.

More than Tested, Empowered

A Novel Project to Meaningfully Engage Drug Users in hepatitis C (HCV) Work

- collaboration between NVHR & three harm reduction organizations with local focus
- overcoming barriers requires input of directly impacted individuals
- unique model of a partnership
 - Shared grant writing and project management responsibilities
 - Disseminated findings locally and nationally
- www.nvhr.org/programs/more_than_tested_cured



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



HCV Treatment Barriers Among Drug Users

- **Patients:**

- ❖ Stigma associated with drug use
- ❖ Prior rejection for drug treatment
- ❖ Lack of knowledge of current HCV treatment options
- ❖ Distrust of health care providers
- ❖ Difficulty navigating through healthcare system

- **Provider Concerns:**

- ❖ Not keeping up with appointments/dropping out of care
- ❖ Suboptimal adherence
- ❖ Acquiring drug resistance
- ❖ Getting re-infected



People's Harm Reduction Alliance (PHRA)

- Peer-run organization promoting harm reduction and safer drug use
- Provides need-based syringes and safer smoking supplies
- Active drug users at all levels
- Fixed and delivery sites
 - Seattle, Everett, Olympia, and Bremerton, WA
 - Portland, OR



HCV Program: Year 1 (Seattle)

- Needs assessment
 - 20 interviews
- Provider engagement and client education
- Increased testing
 - 66% increase
- Began case management

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

HCV Program: Year 2

- Case management
 - 4 clients since March
- Expanding testing and linkage to care
 - Kitsap, Olympia, Portland
- Survey of WA providers
 - Opinions & barriers to treating drug users
 - Current knowledge & information needs





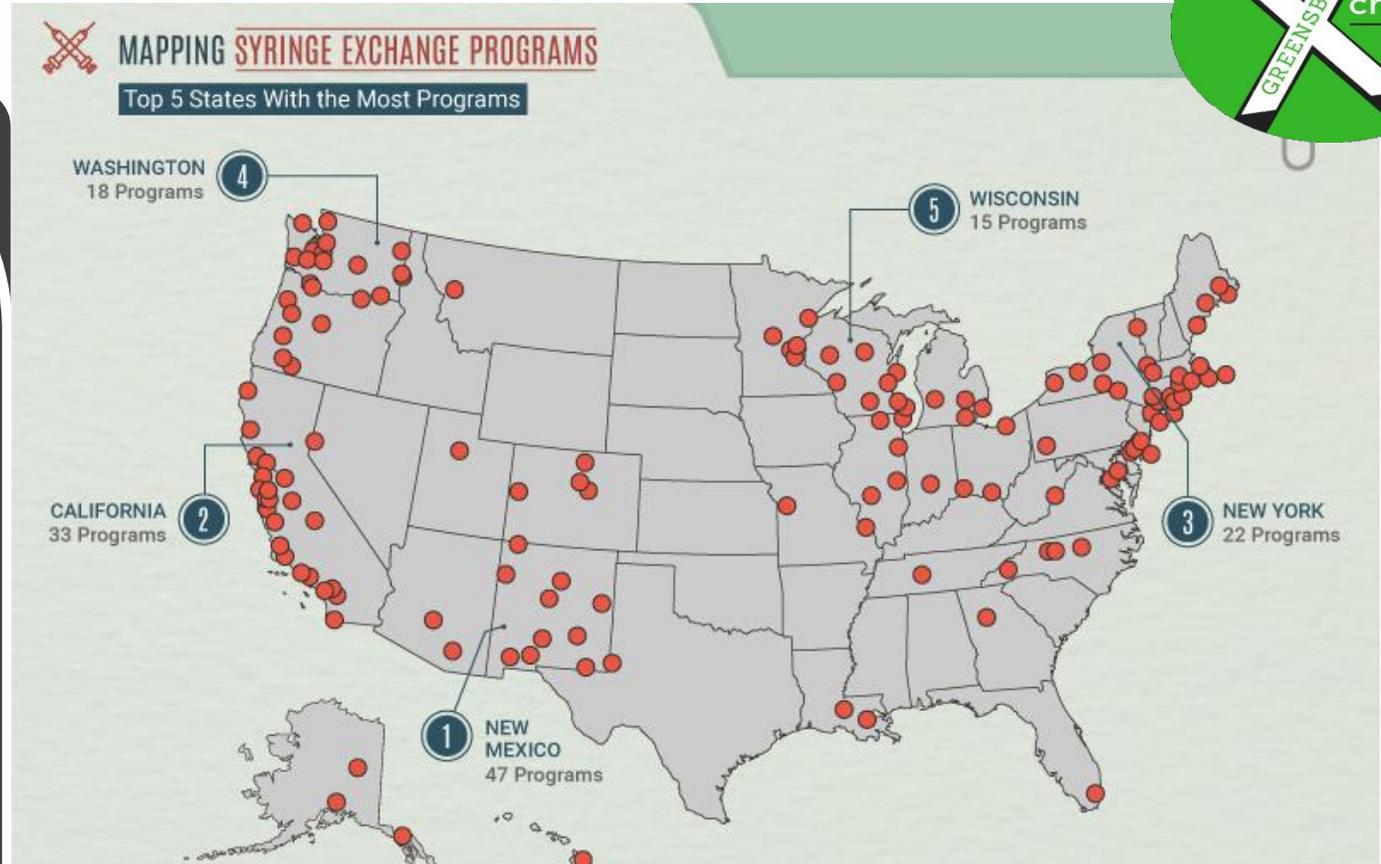
Urban Survivors Union's Greensboro Xchange



Drug Users Do Care about their Health.

Urban Survivors Union: A National Organization made up of people who use drugs (both former and active) dedicated to improving lives and ending the war on drugs

Our Theory of Change: We are community organizers who believe that as long as the most basic services are not provided for people who use drugs we cannot have effective robust community organizing



WE CANNOT ELIMINATE HEP C WITHOUT HARM REDUCTION, SYRINGE ACCESS AND ACTUAL DRUG USER INVOLVEMENT

POWERLESS NO MORE

User Involvement

Moving from Peer to Professional
(Directly Impacted Health Educators)

Stigma: Internalized
 Symbolic
 External

Sounds Good

BUT HOW DO WE ACTUALLY DO
THIS???

Drug users should be involved in all prevention efforts related to Hepatitis C. We cannot eliminate without our expertise and knowledge.

Drug Users have been taking care of their health and running effective programs for the last 3 decades.

User unions have implemented syringe exchanges worldwide and safe injection facilities.

What we do - WORKS!

User Unions are Powerful.

Do You Support Your Local User Union?

YEAR ONE: More Than Tested Cured Nothing About Us, Without Us!

Tools of Discovery:

- SURVEYS
- FOCUS GROUPS
- INDIVIDUAL INTERVIEWS
- SOCIAL MARKETING MATERIALS
- VIDEO/ WEB info
- PROCESS VS. PRODUCT

Main focus group findings:

- Syringe exchange is vital for well being
- Confusion over HCV transmission & treatment
- Distrust of medical system
- Effects of unemployment & underinsurance
- Most have untreated mental health issues

Women

- Lack of control over injection supplies and drugs
- Concern regarding welfare of children

Stimulant users

- Lack of understanding that staying awake for days could negatively impact health
- Increased sex & associated risks

Importance of drug user involvement

“To be part of Planning, implementing and evaluating a program in partnership with other groups with similar missions created a learning environment unlike I have experienced.”

“Being employed, being seen, being truly listened to has given me a reason to keep living and fighting, I love USU”

THE USU SITE WITH OUR WORK

<https://sites.google.com/urbansurvivorsunion.org/usucampaigntoendhcv/home?authuser=0>

YEAR 2

A true examination of barriers to care. We are utilizing a rights based approach to educate around Hepatitis C and health while exploring how access to health care and previous trauma with the medical system creates barriers beyond the obvious.

**The Health Diary Video Project
Led By USU Participants.**

**Barriers Beyond the
Obvious...**

CHANGE THE FRAMEWORK

“A RIGHTS BASED APPROACH”

We As Humans Have A Right To Health



A Necessary Look at Women's Health

Exploration of Barriers to Care with women who use drugs (mothers / pregnant women) who have HCV or are at risk for HCV. We will explore the barriers to health care related to Hepatitis C.

Atlanta Harm Reduction Coalition, Inc (AHRC)

AHRC is a community based wellness organization committed to promoting health and dignity by reducing the impact of HIV/AIDS, Hepatitis C, STI, and Substance Use within vulnerable communities.

Linkage to Care Model

- Harm Reduction Therapy
- Specialty Education
- Syringe Exchange Program
- Existence of Specialty Pharmacy (340B)



Removing Barriers

Step 1: Education

- Patients:
 - Education on the virus, course of disease, complications, and treatment options
- Providers:
 - Education on Harm Reduction, Linkage to Care, and Syringe Exchange Services

Step 2: Case Management/Linkage

- Patients:
 - Removing underlying barriers: Housing/Food/Transportation
 - Active Linkage to Medical Care
 - Linkage to Syringe Service Programs
- Providers:
 - Linkage to Harm Reduction Agencies
 - Linkage to Syringe Service Programs

Step 3: Peer Navigation

- Patients:
 - Education on receiving care and linkage to care through stories from peers who have completed treatment



Achievements at AHRC

2014:

- Creation of HCV program at AHRC via educational groups

2015:

- Offering preliminary HCV testing through collaboration with GDPH and Orasure Technologies
- Linkage to Grady Liver Clinic

2017:

- Offering confirmatory HCV testing
 - Providing education to HCV providers
 - Becoming 340B participant
- 

Achievements at AHRC

2017

- Conducted needs assessment (n=25)
 - 68% would not provide HCV treatment for active drug users
 - 96% did not offer sliding scale fees for services
- Worked with 16 specialists to increase willingness to treat HCV among PWID
- Built relationships w/ charity organizations, connected 25 clients w/ financial assistance
- Increased:
 - confirmatory testing (0 to 6)
 - Specialists treating drug users (2 to 9)
 - Injectors with referrals to HCV treatment (1 to 9)

2018: Ongoing relationship building, including linkage to Piedmont Hospital

Lessons Learned & Key Considerations

- Incorporate testing and linkage to treatment at point of contact
- Collaborate with community partners and providers
- Educate drug users on new treatment options
- Promote activities that decrease stigma
- Engage providers regarding treatment guidelines & re-infection data
- Engage drug users at all levels and compensate them for their time
- Provide case management/referrals to help overcome barriers to treatment (e.g., insurance navigation, transport)

Thank you!

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