More than Tested Cured: Meaningful Engagement of Participants in Hepatitis C Work

November 14, 2017
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
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

• 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 for Community, HCV Treaters, 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
- Working with evaluation consultant
- Replication at local or national level
- Findings will be disseminated nationally
- Learn more at www.nvhr.org/programs/more_than_tested_cured
Webinar Overview

Project presentations

1. Atlanta Harm Reduction Coalition
2. People’s Harm Reduction Alliance
3. Urban Survivors Union

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

Mojgan Zare, MD, MPH
Atlanta Harm Reduction Coalition

• 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)
Scope of Work

• Identifying relevant research previously conducted: Active PWIDs are great candidates for HCV treatment and rate of re-infection is low.

• Interviews with HCV providers within 5 miles radius of AHRC: More than half indicated willingness to treat and almost all indicated not using scale/slide fee.

• Interview with Grady Liver Clinic: The only site who provides scale/slide fee and treating active drug users. Results indicated complete treatment of one successful case. Criteria for treatment is adherence to hospital appointments of patients in the past.

• Identification of providers who treat HCV within 5 miles radius of AHRC to provide Harm Reduction education and share findings with: Piedmont Hospital agreed to presentation and agreement of 6 providers to treat active drug users.
National convening and Presentations in 2017

• INHSU: Presentation
• NVHR: Webinars
• Fulton County Department of Public Health: Discussion
• Piedmont Hospital: Presentation and Discussion
New Findings

• Need for Harm Reduction presentation among providers

• Need for ongoing access to syringe exchange programs

• Need for addiction counseling

• Need for linkage to care model
Future efforts

- Continuing effort to reach out to rest of providers
- Link patients to providers who agreed in seeing patients
- In-house treatment
- Sharing findings at national and local convenings and conferences
Things to consider

• Importance of meaningful involvement of Peer navigators
• Challenges with getting physicians hearing from community members
• Reaching out to organizations for advice on garnering feedback from community members
• Is there a successful model out there?
Thank you!

Mojgan Zare, MD, MPH
mojganz@ahrc-atl.org
People’s Harm Reduction Alliance

Drug-User Led
The People’s Harm Reduction Alliance (PHRA) is a peer-run organization that promotes the philosophy of harm reduction and safer drug use.

Active drug users at all levels of PHRA facilitate our need-based needle distribution program, serving the Cascadia region since 2007.

PHRA has both fixed and delivery sites in

- Seattle, Everett, Olympia, and Bremerton, Washington
- Portland, Oregon
How PHRA is Drug-User Led

- Definition of drug user: any person who can utilize our services
- At least 51% of all positions (including leadership) are filled by drug users
- All volunteers, staff, and board members are screened for attitudes and beliefs about drug users prior to involvement
- Drug users are decision makers: inclusion of new services are decided by elections
- Focus is on love and acceptance – zero tolerance for stigma
Benefits of Being Drug-User Led

- Staff, volunteers, and board members provide:
  - Expertise and knowledge
  - Lived experience
  - Up-to-date information about local drug use
  - Understanding of realities of drug use
  - Innovative participant-centered ideas
  - Decreased stigma
  - Peer support
  - Rapport with the community PHRA serves
Hepatitis C Project: Summary of Activities

- In 2017, we achieved a lot:
  - Interviewed 20 participants about barriers to receiving Hepatitis C care
  - Linked participants living with Hepatitis C to treatment in Seattle
  - Educated local providers about working effectively with people who use drugs
Hepatitis C Project: Moving Forward

Key Recommendations:

– Must involve drug users in leadership from day 1 across all levels
– In work plan, make explicit how to include drug users
– Your funding and budget must reflect this priority
– Include active drug users as budgeted positions
– Aim to support development of peer-leaders across all PHRA sites
Thank you!

PHRA Staff
Lisa Al-Hakim       Shilo Jama
Kara Bensley       Vanessa McMahan

And many thanks to all of the PHRA participants!

For further information, please contact us!
vanessa@peoplesharmreductionalliance.org
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 drug users, their families and their communities.
Most organizations are Community Based Organizations. USU has directly impacted people at the center of decision making.

DRUG USER UNIONS EXIST ALL OVER THE WORLD.

USER RUN, USER LED: Its hard to turn off your work when your work is your life and your participants are your community.
4:00 on Sundays

We provide trainings for our members every Sunday.

We keep a record of trainings people have attended and have a list of people who are trained in core harm reduction concepts.

TEAM BASED WORK:
Core Classes
Injection 101 universal precautions
Outreach 101
Oppression
Civil Liberties and personal Safety
Being a drug user does not make you an expert. You must be trained.

Working with drug users takes patience and practice. No one said it was going to be easy!!!

Treat this like a job- you are paid like a job.

We have to remember that it takes a certain level of trust to be honest about what’s going on in your life. Sometimes it takes testing the waters first. After a lifetime of being punished for telling the truth, it can be scary to do it.

Our most serious and important message is that there is never something so bad that you cannot show your face again.
How can you support community led groups?

1. Support the self-organization of drug users

Take the time to really understand why this is important and what the benefits of this are.

2. Promote the involvement of drug users in drug user services.

Adopt policies that are supportive

Build strong alliances between harm reduction groups and drug user unions. Drug users and professionals should be equal partners. People must learn to listen and learn from PWUD.
Make sure:

You are clear about why you have chosen the people you have chosen.

Participants are trained thoroughly and praised often. People need positive reinforcement.

Examine your resistance - are you worried about how drug users will affect the direction of the program, the reputation...why are you resistant?
Baby Steps:

You don’t have to do it all at once, but make a commitment to do it!

Some of the activities that provide a great jumping off place:

1. Mixed Support Groups/Member support and advocacy groups

2. FOCUS Groups

3. Drug User Council - policy /organizing group (work either with staff or without to help shape policies and develop creative strategies for improving services).

4. Peer Educators - health educators who have direct life experience as well as training to assist with health programs.
Focus Groups

- All focus groups were conducted with at least 1 person who actively uses drugs
- Each group had 2 facilitators and at least 1 note taker, a health educator to provide HCV training, and a technology expert
- Groups were audio recorded
- Focus group training was provided to facilitators and a guide was provided to ensure consistency and continuity
- At the close of each focus group, we reviewed and evaluated our performance
<table>
<thead>
<tr>
<th><strong>Men (Focus)</strong></th>
<th><strong>Women (Focus)</strong></th>
<th><strong>Stimulants (Focus)</strong></th>
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<tbody>
<tr>
<td>&gt; likely to share if woman needs help</td>
<td>Poor Veins</td>
<td>&gt; to stay up for days</td>
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<tr>
<td>more likely to inject alone</td>
<td>&gt; blood</td>
<td>Frustration</td>
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<td>inject at earlier age</td>
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<td>often in control of women’s drug use.</td>
<td>overlapping sex networks</td>
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<td>Power and control often results in</td>
<td>overlapping drug user networks</td>
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<td>&gt; likely to have a sex partner who is an injector</td>
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<td>sharing needles is not considered high risk when it is a sex partner</td>
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<td><strong>YOUTH (Focus)</strong></td>
<td>worry that refusal to share= lack of trust</td>
<td><strong>FAMILY (Focus)</strong></td>
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<td>Youth more likely to share</td>
<td>1st exp is often with a male they are having sex with</td>
<td>PWIDs will share syringes and supplies with family members</td>
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<td>Believe that friends would reveal positive status</td>
<td>Having a spouse that you inject with increases sharing</td>
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<td>Living in underground economy makes safety far more complex</td>
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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 for self 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 self
- Living in an underground economy and inability to deal with abuse
- Not having control of injection supplies and drugs
- Need to letting others inject them
- Not wanting track marks to show
- Fear of going to doctor or 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 self; to worried about taking care of everybody else
Findings: Stimulant Users

■ Confusion over how HCV infection is acquired.
■ No real understanding on how increasing injecting 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).
Individual Level Change: Increase Knowledge around HCV & Drug User Health - Increase awareness about syringe exchanges, safe injection practices, access to harm reduction strategies.

Increase the skills that new injection drug users possess, ensuring our participants have knowledge around drug user health.

Community Level Change: 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.

Policy Level Change: Community Naloxone, syringe exchange exchange legislation,
- We know that “Just say no” does nothing to protect drug users from the harms of drug use but we waste precious time sharing abstinence-based messages that are not relevant. We should incorporate harm reduction messages which are crafted for members at multiple stages of drug use.
HCV education should be incorporated into standard health education for youth.
Different drugs = Different risk

- Stimulant Users are at higher risk for HCV. We should meet these needs to better reduce risk.
- Pill injectors are at higher risk for HCV. We should meet these needs to better reduce risk.
WOMEN need women specific services

• Women should have programs designed with their needs in mind. Power is always one of the issues for people that use drugs. Women who inject should have access to vein care and a phlebotomist to help choose veins and practice self care.

• Women also need to feel safe and feel they can be honest without putting family at risk.
Beyond Tested, Cured!
A Social Marketing Campaign Delivered by USU

Increase connections to bring in people instead pushing them out!
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](http://www.ncurbansurvivorsunion.org)
Thank You!

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Questions?

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

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www.nvhr.org/programs/more_than_tested_cured