Drug User Engagement and HCV Elimination: End Hep C SF’s Values in Practice

KATIE BURK, MPH
VIRAL HEPATITIS COORDINATOR
SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH
Presentation Objectives

1. Review foundation of End Hep C SF
2. Discuss End Hep C SF mission, vision, and values
3. Explore the actualization of the participant involvement principle in the End Hep C SF context
VISION STATEMENT: End Hep C SF envisions a San Francisco where HCV is no longer a public health threat, and HCV-related health inequities have been eliminated.
Collective Impact is a framework to tackle deeply entrenched and complex social problems. It is an innovative and structured approach to making collaboration work across government, business, philanthropy, non-profit organizations and citizens to achieve significant and lasting social change.

**Common Agenda**
--Keeps all parties moving toward the same goal

**Common Progress Measures**
--Measures that get to the TRUE outcome

**Mutually Reinforcing Activities**
--Each expertise is leveraged as part of the overall

**Communications**
--This allows a culture of collaboration

**Backbone Organization**
--Takes on the role of managing collaboration

Source: http://www.collaborationforimpact.com/collective-impact/
Community partners

Community Partner Sign-On Notification

[content from image]

Signed,

[signatures]

Name, Title

Organization

Date
Vision, Mission, Values, and Strategies

VISION
End Hep C SF envisions a San Francisco where hepatitis C is no longer a public health threat and HCV-related health inequities have been eliminated.

MISSION
To support all San Franciscans living with and at risk for hepatitis C to maximize their health and wellness. We achieve this through prevention, education, testing, treatment, and linkage to reduce incidence, morbidity, and mortality related to hepatitis C.

- All people living with hepatitis C deserve access to a cure
- Everyone living with or at risk for hepatitis C should have equal access to prevention and care
- Draw on the wisdom of those most impacted by HCV
- Engage populations that have been characterized as “difficult to engage”
- Address health disparities
End Hep C SF Overall Accomplishments—Evaluation

Year Two Evaluation Highlights

✓ 40 people representing 20 organizations regularly participate in monthly meetings

✓ 52% increase in community-based rapid testing from 2016-2017

✓ 15 new HCV treatment sites in added in 2017

✓ 28% increase in citywide treatment access from 2016 to 2017
Harm Reduction Principle: Participant Involvement

Ensures that drug users and communities impacted by drug use have a real voice in the creation of programs and policies designed to serve them.

→ What does this look like in a HCV elimination initiative?
End Hep C SF Design

End Hep C SF Coordinating Committee

Prevention, Testing and Linkage

Research and Surveillance

Treatment Access

Executive Advisory Committee

Consumer Advocates

HCV Elimination
Coordinating Committee Strategy:
Representation of Impacted Communities

Katie Burk, MPH
SFDPH

Kelly Eagen, MD
Tom Waddell
Urban Health

Perry Rhodes III
Alliance Health Project

Pauli Gray
SFAF

Andrew Reynolds
Project Inform

Isaac Jackson, PhD
Urban Survivors Union

Joanne Kay
End Hep C SF

Annie
Luetkemeyer, MD
UCSF

Meghan Morris, PhD
UCSF

Melissa Sanchez, PhD
SFDPH

Robin Roth
SF Hep C Task Force

Courtney Mulher-Pearson, SFAF

Brian Clear, MD
BAART Methadone Programs
End Hep C SF launch: Visibility and Inclusiveness
Education Strategy:
Early Engagement of Impacted Communities

Sharing equipment spreads Hep C
Come get sterile stuff

We can’t treat Hep C if we don’t know we have it.

Living with Hep C?
New treatments have changed the game.

No podemos tratar la Hep C si no sabemos que la tenemos

New Treatments Have Changed the Game
Messages for and by drug users
Inclusion Strategy: Create Multiple Platforms for Storytelling

Voices of End Hep C SF: A blog series
http://www.endhepcsf.org/category/voices/

HCV Care Navigation at Shanti
by Jordan Akerley  April 2, 2018  Voices 0
After conducting a needs assessment in 2015, the Shanti Project moved to expand its care navigation services to include individuals mono-infected with HCV. At the...

CONTINUE READING →

Treating HCV at Magnet and the 6th Street Harm Reduction Center
by Pierre-Clédrick Crouch  October 16, 2017  Voices 0
Treating HCV at Magnet and the 6th Street Harm Reduction Center “We really don’t have many people left with hep C at Ward 86.” I...

CONTINUE READING →

“Tales from the Cured”: Ending Hepatitis C in San Francisco
by Janelle Silva  September 25, 2017  Voices 0
As members of GLIDE’s HIV & Hep C Harm Reduction Programs, the Hepatitis C navigators and I get the pleasure of being part of the...

CONTINUE READING →

Treating HCV in Jail Health Services
The Pharmacist’s Role in Hepatitis C Elimination
Curing Hep C Without Walls
by Jessica Naugle  March 17, 2017  Voices
The evolution of hepatitis C policy advocacy (and my professional evolution) in the
The Trans*National Study: Addressing Hep C Risk and Care for Trans women in the
The Opiate Treatment Outpatient Program: Treating HCV in a One-Stop Shop
Inclusion Strategy: Create Multiple Platforms for Storytelling

Grant Funding Opportunity and Request for Proposals (RFP)
for
New Treatments Have Changed the Game
Video Content Creation and Launch

Key Dates:

<table>
<thead>
<tr>
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<th>Date</th>
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<tbody>
<tr>
<td>RFP Issue Date:</td>
<td>May 14, 2018</td>
</tr>
<tr>
<td>E-Question Period:</td>
<td>May 14 – June 20, 2018</td>
</tr>
<tr>
<td>Proposals Due Date:</td>
<td>June 20, 2018</td>
</tr>
<tr>
<td>Award Decisions Announced:</td>
<td>July 16, 2018</td>
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<tr>
<td>Project Period:</td>
<td>Aug 1, 2018 – March 31, 2019</td>
</tr>
</tbody>
</table>
Meeting People Where They Are: Community-Based HCV testing

Increased or added community-based HCV testing at several venues:

• Homeless shelters
• SF County Jail
• Single room occupancy hotels
• Syringe exchange programs
• Methadone treatment programs
• Residential drug treatment programs
• Transgender wellness group
• STD clinic
Meeting People Where They Are: Colocation of Services for Drug Users

Drug User Health

- HIV and HCV testing
- Syringe Access
- HCV tx and PrEP
- Naloxone provision
- Suboxone induction
Prevention Testing Linkage Success: Community Engagement

Get Cured, Stay Cured meeting 3.8.18, Testing Day Rally 5.19.18
Funding Community-Led HCV Leadership programs

Peer linkage Programs

Community members recruited for HCV testing and treatment

Peers Trained
Research and Surveillance Strategy: Making Data Readily Available to the Community

END HEP C SF

HEPATITIS C IN SAN FRANCISCO

What is hepatitis C?
The hepatitis C virus (HCV) is easily transmitted between people through blood-to-blood contact and, if left untreated, can cause chronic liver disease. While some people who are infected with HCV are able to get rid of the virus on their own, without treatment, about 80% develop chronic infection, and 2 to 3 develop liver disease unless they are tested and treated. Living with HCV for several decades without treatment often results in cirrhosis (severe liver scarring), with some cases progressing to liver cancer. In fact, San Francisco has the highest rate of liver cancer in the nation, largely due to HCV and another virus, Hepatitis B.

How many people have hepatitis C in San Francisco?
End Hep C SF estimates that approximately 22,000 residents of San Francisco have antibodies to HCV — this is about 2.5% of all people living in San Francisco in 2016 according to the U.S. Census. Some people with antibodies have cleared the virus naturally or have taken treatments to be cured, but we estimate that around 12,000 people (a little less than 2%) of the population have active viruses in their bodies. People with active viruses can transmit the virus to others and their infusion may progress toward liver disease, they would benefit from HCV treatment. A few thousand San Franciscans have been treated and cured with new medications, but the exact number is not easy to determine. The true number of active HCV infections could be lower than our estimate. However, we would rather conservatively estimate the number of residents who have been treated than miss counting people who need treatment.

ARE SOME PEOPLE MORE LIKELY TO BE LIVING WITH HCV THAN OTHERS?

Yes. Some groups of people are much more likely to be infected than others. Approximately 68% of active HCV infections in San Francisco are among people who inject drugs, despite people who inject drugs making up less than 3% of the population, yet account for 54% of active HCV infections. Baby boomers (people born between 1945 – 1965) make up 21% of the population, but about 53% of active HCV infections. About 72% of active HCV infections in San Francisco are among men. If you have ever injected drugs, are a man who has sex with men, are a transgender woman, or were born between 1945-1965, End Hep C SF recommends talking to your medical provider about testing for HCV.

Some groups of people bear a DISPROPORTIONATE BURDEN of HCV in San Francisco

This figure illustrates some groups of people who bear a greater burden of HCV in San Francisco than others. The higher the difference between the orange and the blue, the greater the health disparity for that group.

10% of active HCV infections

10% of general population

People who inject drugs make up 68% of active HCV cases

Men who have sex with men make up 14% of active HCV cases

Baby boomers make up 35% of active HCV cases

but only 5% of the total SF population

but only 5% of the total population

but are only 21% of the total SF population

While transgender women make up a small percentage of the total populations, many transgender women are currently living with HCV.

Note that the above groups do not add up to 100% — there is likely a person who is in more than one group.

Research Article

Estimated hepatitis C prevalence and key population sizes in San Francisco: A foundation for elimination

Shelley N. Fiscorle1(2, *), Eduard Gimbó2, Katie Burt1, Meghan D. Morris3, Edward L. Murphy5,1, All Mirzaie4,1, Aaron A. Smith1, Melisa A. Sanchez2, Jennifer L. Evans2, Amy Hathaway1,4, Henry F. Raymond2,5, on behalf of End Hep C SF

1 Pacifier Consulting, Richmond, California, United States of America; 2 University of California, San Francisco, California, United States of America; 3 South African Centre for Epidemiological Modelling and Analysis (SACEMA), Stellenbosch University, Bell Street, 7602, South Africa; 4 South African Department of Public Health, San Francisco, California, United States of America; 5 Blood Systems Research Institute, San Francisco, California, United States of America.

OPEN ACCESS


Editor: Yuri K. Wohler, Centers for Disease Control and Prevention, UNITED STATES

Received: October 27, 2017

Revised: May 16, 2018

Accepted: April 11, 2018

Published: April 11, 2018

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Abstract

Background

Estimated in 2015, End Hep C SF is a comprehensive initiative to eliminate hepatitis C (HCV) infection in San Francisco. The introduction of direct-acting antivirals to treat and cure HCV provides an opportunity for elimination. To properly measure progress, an estimate of baseline HCV prevalence, and of the number of people in various subpopulations with active HCV infection, is required to target and measure the impact of interventions. Our analysis was designed to incorporate multiple relevant data sources and estimate HCV burden for the San Francisco population as a whole, including specific key populations at higher risk of infection.

Methods

Our estimates are based on triangulation of data found in case registries, medical records, observational studies, and published literature from 2010 through 2017. We examined subpopulations based on age, sex, and HCV risk group. When multiple source data were available for subpopulation estimates, we calculated a weighted average using inverse variance weighting. Credible ranges (CRs) were derived from 95% confidence intervals of population size and prevalence estimates.

Results

We estimate that 21,756 residents of San Francisco are HCV seropositive (CR: 10.274–42.067), representing an overall seroprevalence of 2.9% (CR: 1.1–4.9%). Of these, 16,406 are estimated to be chronic (CR: 6.508–31.401), though this estimate includes
# Treatment Access Success: Provide Treatment Outside Traditional Settings

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Number of Treatment Starts</th>
<th>Treatment Completion</th>
<th>Date Treatment Program Initiated</th>
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<tr>
<td>Opiate Treatment Outpatient Program (UCSF)</td>
<td>153</td>
<td>140</td>
<td>August 2016</td>
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<tr>
<td>San Francisco County Jail</td>
<td>100</td>
<td>77</td>
<td>March 2017</td>
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<td>Residential Drug Treatment (HealthRIGHT 360)</td>
<td>86</td>
<td>80</td>
<td>January 2016</td>
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<td>Syringe Exchange (San Francisco AIDS Foundation)</td>
<td>52</td>
<td>38</td>
<td>August 2017</td>
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<tr>
<td>Street Medicine</td>
<td>16</td>
<td>13</td>
<td>May 2016</td>
</tr>
<tr>
<td>Shelters</td>
<td>10</td>
<td>10 (we think)</td>
<td>Dec 2016</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>417</strong></td>
<td><strong>348</strong></td>
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End Hep C SF Lessons Learned

- Focus on leadership development efforts and understand HCV leadership can come in many forms
- Create multiple thresholds for participation
- Prioritize inclusion of people most impacted by HCV, and get creative about how to involve them
- At every opportunity, ask how the initiative could be doing better (reaching more people, being more inclusive, etc.)
- You are never done figuring out your participant involvement strategies
For More Information:
www.EndHepCSF.org

Katie Burk, MPH
Viral Hepatitis Coordinator
SFDPH
katie.burk@sfdph.org
Patient Navigation to Promote Hep B Linkage to Care Among Perinatal Hepatitis B Program Patients

Jessie Schwartz, RN, MPH
Viral Hepatitis Program, NYC Health Department
jschwartz2@health.nyc.gov
Hepatitis B (Hep B): A Global Health Issue

- Globally, 240 million people live with Hep B (130-150 million live with Hep C)
- 20-30% adults with Hep B will develop cirrhosis and/or liver cancer
- Mother to infant (perinatal) is one of the most common modes of transmission
- Dynamic infection: liver damage may be intermittent and can accelerate rapidly over a relatively short time period
- Lifelong monitoring is required; vaccination and treatment are available
- Antiviral therapy improves Hep B viral suppression and reduces perinatal transmission of Hep B in women with high viral load
VIRAL HEPATITIS B IN THE WORLD

- **257m** GLOBAL
- **21m** EASTERN MEDITERRANEAN
- **39m** SOUTH-EAST ASIA
- **115m** WESTERN PACIFIC
- **60m** AFRICA
- **39m** SOUTH-EAST ASIA
- **15m** EUROPE
- **7m** AMERICAS

Source: World Health Organization
Over 100,000 New York City (NYC) residents are diagnosed with chronic Hep B infection.

Source: France AM et al., 2012.
8,439 people were newly reported with Hep B in 2016.
The majority of people with Hep B in NYC live in Brooklyn and Queens.
Characteristics of Perinatal Women Reported to NYC with a Positive Hep B Test

1, 518 pregnant women were reported with hepatitis B in 2016

Place of birth of perinatal women reported with Hep B in 2016

- China, 56%
- Western Africa, 14%
- Caribbean, 5%
- Other, 25%

Post-exposure prophylaxis of infants born to women with Hep B in 2016

- Received Hep B post-exposure prophylaxis (PEP), 99.5%
- Did not receive PEP, 0.5%
Why Perinatal Women?

- Only 1 in 5 pregnant women with Hep B receive appropriate follow up after delivery
- Half of providers do not educate women about hepatitis B or refer to specialty care
- One in 4 women with Hep B have flares after delivery
- Many women lose health insurance soon after delivery (2 months in New York State)

Source: Chang et al. 2015; IOM Report 2010; ACOG Practice Bulletin, 2007; February 8, 2018; AASLD 2018 Hepatitis B Guidance
Barriers to Care

Women face many individual, legal and health care system-level barriers to care

Health care provider-related barriers
- Limited Hep B health literacy
- Patient not informed what tests were done and what results were
- Provider tells patient “everything is fine”
- No referrals given for follow up Hep B care

Health literacy and cultural barriers
- Lack of awareness (they don’t feel sick)
- Lacks knowledge about infection (feel powerless to intervene)
- Hep B care is not a priority
- Doubt about western medicine and search for alternatives
- Stigma and lack of support

Health care system-related barriers
- Additional visits and documents are required to receive sliding fee scale
- Advised not to use any government programs (including subsidized sliding scale fees), concern it will affect green card/visa applications
- No time to visit the doctor/coordinate care
- Lacks access to childcare/transportation

Linguistic barriers
- No interpretation services provided at front desk or over phone
What is the Hep B Moms Patient Navigation Project?

Introduction of telephone-based patient navigation services in the NYC Health Department Perinatal Hepatitis B Prevention Program

- **Goal:** Increase maternal engagement in Hep B medical care after delivery

- **Population:** Adult women who complete a postpartum interview with Perinatal Hepatitis B Prevention Program (NYC Health Department Bureau of Immunization)

- **Intervention:** Modeled on “Project SAFe” a telephone patient navigation program delivered by staff in health centers and hospital. Provides:
  - Culturally and linguistically appropriate Hep B patient navigation, education and support (including scheduling appointments)
  - Assistance to overcome barriers, such as enrolling in patient assistance programs
  - Help for sexual/household contacts to find testing/Hep B-directed care

Required full IRB approval and informed consent

- **Duration & Funding Source:** ~2 years, Gilead Sciences grant
Why Patient Navigation?

**Disease Intervention Specialist (DIS) model**
- Disease-centered model
- Designed to prevent disease transmission
- Investigates and collects data on disease occurrence/outbreak
- Not always by consent, often enforced through public health laws

**Patient Navigation (PN) model**
- Patient-centered model
- Designed to promote linkage to care and treatment by helping patients overcome barriers to care
- Meets the needs of the individual beyond preventing the spread of disease (e.g. psychosocial assessment conducted)
- Requires consent, not mandated
- Often requires patient advocacy
Project Development

Cross-bureau collaboration between Bureau of Immunization (Perinatal Hepatitis B Prevention Program) and Bureau of Communicable Disease (Viral Hepatitis Program), requiring:

• Commitment of Health Department leadership
• Obtaining external funding
• Cultivation of strong referral relationships between community partners
• Well-designed implementation strategy – including standardized referral process, protocols, and evaluation plan – with predetermined outcomes and indicators
• Regular meetings with stakeholders
• Building and training a patient navigation team able to provide culturally and linguistically appropriate care
• Monitoring process outcomes and implementing corrective actions
Project Workflow

Call women
Use language line if language other than English, Cantonese, French, Mandarin, Wolof

Informed consent
Oral Consent Form

Decline

Cannot reach woman
3 call attempts

Assessment

Contact referred

No contact referred

Linkage to care planning/services provided

Follow up: initial appointment & every 6 months

Satisfaction Survey
Of those enrolled at least 3 months, \textbf{84\%} attended a Hep B medical appointment.

Project Outcomes and Patient Characteristics (to Date)

273 women were enrolled and received patient navigation services.

- Needed help scheduling an appointment: 33\%
- Had no source of medical care: 28\%
- Uninsured (or had temporary insurance): 27\%
- Had concerns about the cost of medical care: 22\%
- Had trouble filling out basic medical forms: 13\%
Patient Characteristics

100% of women were foreign-born and 51% could not read or speak English

Preferred language spoken by patients enrolled in program

- Mandarin: 52%
- English: 21%
- Cantonese: 14%
- Wolof: 4%
- French: 2%
- Spanish: 2%
- Bangali: 1%
- Russian: 1%
- Other: 2%
Did the introduction of patient navigation services into the Perinatal Hepatitis B Prevention Program increase the proportion of women who attended a medical appointment within 6 months after delivery?

Evaluation Plan

Interviewed pre-intervention
Jan 2016-Jan 2017

No Intervention (matched group)

Lab Report

No Lab Report

Interviewed post-intervention
Feb 2017 – Feb 2019

No Intervention

Lab Report

No Lab Report

Intervention group

Declined intervention

Delivery Date

7 months post-delivery
Lessons Learned: Patients Need Help

- **People need help navigating the health care system**, but don’t know who to ask or what resources exist
  
  Ask patients if they have concerns about cost of medical care, if there is anything that makes it difficult to follow up with their care, and what would help them to be able to do so; offer referrals to other community-based services; stay in contact with patient until they have access to the resources and services they need

- **Language interpretation is often unavailable** in health care facilities or by health insurance companies/exchanges
  
  Multi-lingual navigators, phone interpretation services, and 3- or 4-way conference calls ensure patient is able to communicate with health insurance company, front desk, medical provider, pharmacist, etc.

- **Focusing on the person, and not the disease, is less stigmatizing**
  
  Inquire about the individuals circumstances to help them overcome obstacles, not about their disease & potential impact of infection

- **Limited Hep B health literacy** (transmission, prevention, management) is prevalent
  
  Ask if the patient has any questions about Hep B

- **“Free and low-cost health care”**, though available, is very difficult to access in practice; application process complex and burdensome
  
  Maintain close relationships with federally-qualified health centers and public hospitals; ensure women have all the documentation they need to be approved for low cost sliding scale or free medical care
This project is supported by the great work of:

Farma Pene & Liz Tang
Perinatal Hepatitis B Prevention Program
Julie Lazaroff & Ariba Hashmi
Check Hep B Patient Navigation Programs
Umaima Khatun & Nirah Johnson
And many others!