2018 Annual Evaluation

Results & Lessons from END HEP C SF’s Third Year

Prepared for End Hep C SF by
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Executive Summary

Launched in 2016, End Hep C SF is a multi-sector initiative committed to a vision of a San Francisco in which HCV is no longer a public health threat, and HCV-related health inequities have been eliminated. Having mobilized a broad-reaching array of public, nonprofit, and private partners, End Hep C SF works to expand testing, treatment, and cure for people with HCV infection, and to address disparities in HCV identification and care. End Hep C SF employs a “Collective Impact” framework, which involves people working together to address complex social issues that require a coordinated response from stakeholders from across multiple sectors. These include local government, academia, community-based and private programs, and patient advocacy groups, including individuals with direct lived experience with HCV.

Progress Towards Annual Goals

In its third year (2018), the annual evaluation found that the initiative saw progress towards its overarching goals, with the following achievements in the development of its core infrastructure and each of the initiative’s three primary strategies to address HCV:

PREVENTION, TESTING AND LINKAGE

During 2018, the number of community-based, rapid HCV antibody tests conducted by End Hep C partners reached 5,732, exceeding the annual goal of 5,000 and increasing testing levels by 64% over the prior year. The number of testers who are PWID reached 1,685, below the annual goal of 3,000, and reflecting a general three-year trend of decreasing proportion of testers with most HCV risk factors. The reduction in risk factor concentration is likely associated with overall expansion in the numbers of people and neighborhoods reached by testing efforts.

Shifts in the demographics of individuals participating in testing in year three (2018) continued the trends from Y1-Y2, with an increase in representation of Whites and Asians amongst testers and a decrease in African Americans. An increase in the proportion of males testing and decreases in the ratios of female and transgender testers were also seen. When comparing demographics and risk factors for all testers to those testing antibody positive, over-representation is seen for people with at least one known risk factor for HCV, and for Whites, American Indian/Alaska Natives, and women.
As part of the initiative’s strategy to increase equitable care, community-based providers offer linkage services in collaboration with clinic and testing sites. In 2018, the linkage program served 355 people, 69% of whom were successfully linked to care. Of those, 51% achieved successful treatment of HCV, an increase from 34-35% in the first two years, despite staff and partner reports of increased barriers to care/support needs for these individuals as compared to Years 1-2.

**TREATMENT ACCESS**

For people receiving care within the San Francisco Health Network (SFHN, SFPDH’s network of safety-net clinics), data on annual treatment initiation is available. Within the SFHN, 245 people initiated treatment in 2018, a decrease from the prior year, though still more than double the number of people who initiated treatment in 2015, the year prior to the launch of End Hep C SF. Partners report that the initial years of the initiative saw a rush of treatment starts due to successful remediation of barriers that had created a bottleneck of people waiting to begin treatment. Demographics for people starting treatment in 2018 were largely male (71%) and either Black/African American (42.4%) or White (38.0%).

While people receiving care through the SFHN represent a subset of San Franciscans, with a more concentrated number of people with HCV, a slightly broader population is represented by those accessing treatment through the San Francisco Health Plan, which manages 87% of Medi-Cal eligible people residing in San Francisco. These include both people receiving care through the SF Health Network (described above) and those in care with other private or nonprofit providers. According to SFHP records, 417 people enrolled in the plan initiated treatment in 2018. Treatment completion rates for the year increased slightly over 2017 to reach 85.1%.

**EDUCATION AND OUTREACH**


End Hep C SF also continued distribution of the educational materials created in years 1-2 and developed new materials to address gaps in public and provider awareness, reaching a total of 10 educational materials in circulation tailored to consumers, providers, initiative partners, and the general public. The initiative also conducted an intensive training series for 23 community navigators and partner organization staff around outreach and education techniques.

**RESEARCH AND SURVEILLANCE**

Many of the major activities carried out successfully through the Research and Surveillance workgroup in year three relate directly to the need for significant improvements in data and reporting around HCV, a priority that was identified during planning and early implementation stages. In 2018, these efforts aligned with the overall goal of developing measures and tools for HCV data that can be used to monitor progress and align efforts towards elimination of HCV:

- Development of a refined definition of HCV elimination around which to measure the initiative’s success, including specification of data sources to be used for metrics on HCV incidence, prevalence, morbidity, and mortality. Preliminary identification of baseline metrics.
- Acquisition of funding through the National Institute of Health to support research that will build on the citywide HCV seroprevalence estimate completed in 2016 and develop a continuum of care model focused on high-risk subgroups of people with HCV infection.
• Completion of targeted research on HCV “hot spots” in San Francisco, mapping HCV case reports to neighborhoods. Findings included a need for more HCV testing in the Bayview and Haight neighborhoods, where the analysis showed higher prevalence of HCV than other sectors of the city, but lower testing rates.

• Collaboration with the Center for Disease Control’s National HIV Behavioral Surveillance program, focusing in 2018 on people who inject drugs (PWID). The workgroup’s involvement allowed for meaningful inclusion of HCV questions, as well as antibody and confirmatory testing for the first time in San Francisco.

• Development of a study design for rapid initiation of HCV treatment for PWID, funded for implementation in 2019 by a private foundation.

END HEP C SF INFRASTRUCTURE
The collective impact structure relies upon strong processes for engagement and coordination amongst End Hep C SF’s stakeholders and partners. Year three (2018) marked the completion of the initiative’s second full year of implementation, during which coordinating processes and norms have become well-established.

Progress in 2018 included increased participation and meeting frequency across the majority of workgroups and committees, elevated public visibility of the state of HCV in San Francisco and End Hep C SF’s work through publications in community-reviewed journals, higher levels of presence/presentations at conferences, and a modest increase in funding secured to support the initiative, with 11% more funds raised than the prior year.

Community Navigator Pilot Program

While many people with HCV are able to comfortably and smoothly access care in San Francisco, others face barriers to getting tested and accessing (or completing) treatment, such as people who use/inject drugs, people of color, and people who are LGBTQIA or unhoused. The experiences of End Hep C SF’s affiliated providers – and a growing body of evidence in the field – indicate that outreach and engagement by people with lived experience of HCV infection and treatment is a key success factor for serving these communities. In 2018, End Hep C SF increased community-based outreach and testing/treatment engagement through a pilot community navigation program, which was selected for a focus area in the annual evaluation process.

The pilot provided mini-grants to community-based agencies in order to develop and/or expand outreach, education, and navigation programs that are delivered by community navigators with personal, lived experience with HCV disease and treatment. Three organizations were selected to receive mini-grants of $20,000 to support pilot programs: Glide, the San Francisco AIDS Foundation, and St. James Infirmary. While the three pilot programs shared a common overarching design, there were differences in the target populations and outreach and navigation methods employed. A portion of the training and support for community navigators was delivered jointly by End Hep C SF in large-group format for all three funded programs. Each organization also designed an ongoing model for support, training, and supervision for the navigators.

Over the period of the pilot program, a total of 16 community navigators across the three programs carried out a variety of outreach/education, accompaniment, and referral activities. Collectively, the group reported 1,875 service contacts and provided 332 hours of services and support.
The duration of service contacts varied substantively by type of interaction, with average accompaniments to testing or treatment access points – not surprisingly – lasting nearly six times as long as the average conversation to provide HCV education. The nature of navigator outreach/education and referral services necessarily presents challenges to data collection in general, and particularly for tracking outcomes. Nonetheless, for a subset of 216 service interactions, community navigators documented known short-term outcomes resulting from their interactions:

![Diagram showing known testing and treatment outcomes](Image)

To find out more about the work the community navigators were doing and the successes in the pilot program’s implementation, 16 community navigators were asked to share their experiences and views via 1:1 interviews or a small focus group discussion. Several main themes emerged from their experience with the program:

**PROGRAM IMPACT FOR CLIENTS AND NAVIGATORS**

Navigators witnessed the pilot program’s benefit to their clients, taking satisfaction and pride in seeing clients respond to outreach, take next steps around testing and treatment, and in seeing how accessing testing/treatment can be associated with other positive changes, such as safer drug using practices, improved health, and pursuing personal goals.

Navigators report shifts in perceptions of HCV disease and treatment, including more widespread knowledge of the ease and effectiveness of current treatments and decreased stigma around HCV among their clients and community peers. Some also reported continued common misconceptions, particularly among older generations, such as that HCV cure requires lengthy treatment or previous sobriety.

Navigators appreciated how their recognizable and unique role as community navigators allowed for connections with people to “open the door” and make a conversation about HCV possible. They cited their ability to relate to their clients and quickly assess what may be the right opening as key strengths. They also shared that the best outreach required using good judgment about the client’s receptivity, including being attuned to the fact that each navigator may be more effective with certain people than others.

“The stigma is worse than the disease itself. But these days, people are coming out of the closet, so you can understand now more that there are different ways to deal with it. I worried about it for 25 years and didn’t think it was going to be something I could do since interferon was so bad. I can tell people that.”
CHALLENGES

Engagement with clients proved to be one of the most difficult aspects of the program, and navigators made suggestions for program improvements to assist them in making initial contact with clients, including providing visual aids or sample basic dialogues/guidelines for initiating engagement. Navigators found it challenging or disappointing not to know for sure whether their efforts led to later action on the part of their clients. Others were frustrated by limited community-based testing hours, proposing that it is essential to be able to walk an interested client to testing in the outreach neighborhood immediately.

Overcoming complacency was seen as a main challenge faced in community navigation and hepatitis C programs in general. Several navigators shared that while attitudes are shifting, people are less concerned about HCV than HIV, and that they found it difficult to motivate their clients to take action. Sharing their experience proved a helpful tool for motivation, and they recommend the use of incentives for future programs.

Holding boundaries with clients during outreach work was challenging for some community navigators, particularly those identifying as women.

EXPERIENCE WITH PARTICIPATION

Navigators were motivated to participate by past positive experiences of receiving HCV support, whether in terms of the impact that HCV treatment had on their own lives, or out of appreciation for other supports and services from CBOs operating the pilot program. Many were already engaged as a volunteers, and shared that the community navigation project was a logical “next step,” to increase their service to the organization and their community.

Training and support for the community navigators were well received – both the joint training offered by End Hep C SF and the support provided by each organization. Formal training sessions with all navigators were appreciated for the quality of detailed information on HCV, literature and references provided, and practical information on effective outreach. Direct one-on-one support from CBO staff members was equally well-regarded, and for some, the opportunity to connect with others in their cohort was a positive factor that supported persistence and skill development.

PROGRAM STAFF PERSPECTIVE

Program staff from the three community-based organizations (CBOs) operating the community navigator programs shared reflections on the pilot’s effectiveness and potential, including:

Staff reported positive outcomes in testing and treatment that occurred as a direct result of the community navigator program, particularly for people who have barriers to accessing treatment. Navigators had brought outreach into spaces that would otherwise not have been reached, such as a particular alleyway where navigators had been carrying out street outreach in evening hours, as well as figurative social “spaces” where HCV education could be offered directly by navigators to people they knew.

“This one [client], he has a lot of street cred… and he doesn’t trust the medical system. One of the [navigators] used to sleep in an alley with him. He says it was it was because this guy was someone he knows that he decided to get treated. [The navigator] got him the bus tokens, brought him in, and then went back out and checked on him when he missed his follow-up. No one has a phone – this is one of four cases we had of people who were totally non-accessible that they were able to get them in.”
The community navigator program added value for the grantee organizations by extending and building on existing program models. CBOs saw the pilot as providing needed resources to test the potential for increased reach of their existing services delivered by community members with relevant experience. CBOs expressed the desire to continue navigation programs, but noted that the End Hep C grants covered only the direct costs of the program (stipends, incentives, and program supplies) and that it will be challenging to continue the program absent support for more dedicated staffing.

Workgroup and Committee Perspectives

In March of 2019, members of the initiative’s workgroups and committees were asked to complete a survey to provide feedback and perspectives on the functioning of End Hep C’s groups, the progress made during 2018, and priorities for the future. A total of 36 people responded, for a 90% response rate.

Respondents were asked to rate agreement with whether End Hep C SF had helped to advance specific areas of focus previously identified via the prior-year survey, ranging from improving the availability of testing, to making HCV data more available, to improving resource-sharing among initiative partners. Over 90% of respondents agreed or strongly agreed that End Hep C SF helped to advance all six focus areas.

Respondents further identified End Hep C SF’s most important successes in the past year:

• The initiative is achieving increased access to treatment and testing, as well as cure of HCV, through expanded treatment and testing in community-based settings, as well improved accessibility for specific communities.

• End Hep C SF has made progress in advancing knowledge and understanding of HCV in San Francisco and best practices in the field, such as developing HCV data capacity, advancing knowledge and practices in the field, and creation of new research and tools.

• The targeted projects developed by End Hep C SF in Year Three are highly valued and seen as notable accomplishments, including the community navigator program, the video series created to raise visibility and awareness, the academic detailing program, and the work towards an HIV/HCV micro-elimination plan.

• End Hep C SF is maturing in positive directions, with expanded collaboration and coherence, stronger infrastructure, and better ability to build engagement and public awareness.

Survey respondents were also asked to rate the success of the priority projects that End Hep C SF undertook in Year Three. Among those who felt sufficiently engaged with each effort to provide a rating, production of the video series was the most highly regarded, followed by the community navigation program and dissemination of the End Hep C SF brand and model.
Looking back on the past year, respondents identified several areas where the initiative could have been improved, and where End Hep C SF can draw lessons that will strengthen the work ahead:

- **End Hep C SF will benefit from continued evolution**, including ongoing revisiting and recalibrating of priorities and goals, as well as moving to address gaps in HCV-related efforts such as opportunities for advocacy, better engagement with private-sector partners, or reach to specific populations.

- **Limitations of the data available on HCV and related efforts are an ongoing concern, and efforts to address this gap should continue or increase**. Respondents noted that without access to timely and accurate HCV data, the initiative cannot assess progress with confidence or improve performance.

- **Some challenges from the past year may be beyond End Hep C SF’s immediate sphere of influence.** While commenting on the issues outlined above, some respondents shared the view that these challenges relate to the outside context and environment within which the initiative must operate, such as engaging with medical providers not yet invested in the initiative in order to gain their participation.

- **There are opportunities to make improvements around engagement, both in terms of who participates in End Hep C SF, and how the groups and individuals engage with each other.** Greater connection and coordination across workgroups was proposed, particularly structured processes to ensure knowledge of the other groups’ efforts. In addition, respondents called for increased diversity of participants, with interest in greater representation from drug users, HCV patients, and minority organization representatives.

Members had identified several areas of focus for improvement in workgroup functioning for Year Three; workgroup and committee members assessed the extent to which their groups moved these forward. Areas of perceived strength or for improvement in common across the various groups were identified via weighted averages as follows: scores closer to 4 indicate more positive views, while averages closer to 1 indicate less positive assessments. On average, each group’s respondents generally scored their group positively, with one noteworthy common area for improvement: all committees assessed their progress as least favorable around expanding workgroup representation to include under-represented key stakeholder groups.

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<thead>
<tr>
<th>Area</th>
<th>Treatment Access</th>
<th>Prevention, Testing &amp; Linkage</th>
<th>Research and Surveillance</th>
<th>Coordinating Committee</th>
<th>Executive Committee</th>
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</thead>
<tbody>
<tr>
<td>Clarify group goals and purpose</td>
<td>3.53</td>
<td>3.8</td>
<td>3.92</td>
<td>3.54</td>
<td>3.7</td>
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<td>Make progress towards current priority projects</td>
<td>3.47</td>
<td>4</td>
<td>3.42</td>
<td><strong>3.85</strong></td>
<td>3.8</td>
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<tr>
<td>Make progress towards strategic plan goals</td>
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<td>3.87</td>
<td>3.5</td>
<td>3.77</td>
<td>3.6</td>
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<tr>
<td>Assess and organize meeting dates, times, and ways to participate</td>
<td><strong>3.6</strong></td>
<td>3.73</td>
<td>3.83</td>
<td>3.46</td>
<td>3.6</td>
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<tr>
<td>Increase support to keep workgroup on track</td>
<td>3.47</td>
<td><strong>3.93</strong></td>
<td><strong>3.92</strong></td>
<td>3.77</td>
<td><strong>3.9</strong></td>
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<tr>
<td>Expand workgroup representation</td>
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<td><strong>3.33</strong></td>
<td><strong>3.08</strong></td>
<td><strong>3.15</strong></td>
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<tr>
<td>Balance agenda and discussion topics</td>
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<td>3.73</td>
<td>3.75</td>
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ORGANIZATIONAL BENEFITS OF PARTICIPATION IN END HEP C SF
Members responding to the annual survey were asked to reflect on whether and how the initiative had impacted their organization. **Stronger collaboration with other providers and/or SFDPH** was the most highly agreed-with response, with **resource-sharing with other organization** and **increases in staff awareness, understanding, and advocacy around hepatitis C** also scoring highly.

FUTURE DIRECTIONS FOR END HEP C SF
Participants provided their perspective on where they would like to see End Hep C SF go in the coming year:

- **End Hep C SF should develop and strengthen partnership with key allies beyond the current membership,** particularly by working more closely with private sector providers, as well as other stakeholder groups working to address HCV. In addition, the initiative could engage in more external advocacy and outreach.

- **End Hep C SF can continue to develop and integrate the current participants and groups, building internal coherence.** These suggestions focused on finding ways to build connections between the partners, sharing resources and referrals, bringing private sector partners into the membership, and strengthening collaboration across areas of focus.

- **Continue to focus on testing and treatment, building on progress End Hep C SF has made to date.** Increase funding and support to expand current treatment and testing access work, such as bringing “mobile test and treat” services to syringe access programs. In addition, suggestions pointed to leveraging what is working better, such as engaging primary providers, building community organizations’ support for people around completing treatment, and exploring new or underutilized methods for treatment access.

- **End Hep C SF should prioritize improving capacity to collect and utilize quality data related to HCV.** Suggestions in this area generally called for improving data capture and use, with specific recommendations focusing primarily on a need to work more closely with SFDPH and advocate for improved HCV data capacity within the department.

- **Respondents shared enthusiasm around the specific projects and programs planned or proposed for the coming year,** including the community navigator and academic detailing programs, developing the plan for a micro-elimination effort targeting HIV/HCV co-infection, and mobile/low-barrier and syringe access co-located treatment efforts.