

Benefits of working with a collective impact initiative to inform research: Developing paths to hepatitis C elimination for young adults who inject drugs

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Background

Nested within End Hep C SF, a collective impact hepatitis C elimination initiative in San Francisco, our research group embarked on a two-year NIH-funded research project on evidence-based elimination approaches for young adult (≤ 30 years of age) people who inject drugs (PWID).



We created new estimates of a hepatitis C care cascade for young adult PWID, using a meta-analysis approach for data shared collaboratively from three sources:

- 1 The UFO Study (adult PWID age 30 and under)
 - Self-report and serologic data
- 2 National HIV Behavioral Surveillance (NHBS) in 2019 (PWID wave)
 - Self-report and serologic data
- 3 Peer-reviewed literature from 2013 – 2019
 - For estimating population size and for modeling

We also created draft projection models using parameters derived from these sources to assess progress toward HCV elimination targets.

Model of Care / Research

We aimed to disseminate preliminary results of our research to members of the community and learn how they relate to on-the-ground experiences, to inform subsequent model projections and ensure future interventions capture the needs of young adult PWID (Figure 1).

Our initial approach included a series of in-depth interviews and community forums; however, the COVID-19 pandemic forced us to transition in-person activities to a 90-minute virtual group consensus meeting instead, using the Zoom platform.

Figure 1. Research and stakeholder engagement work together to support HCV elimination.

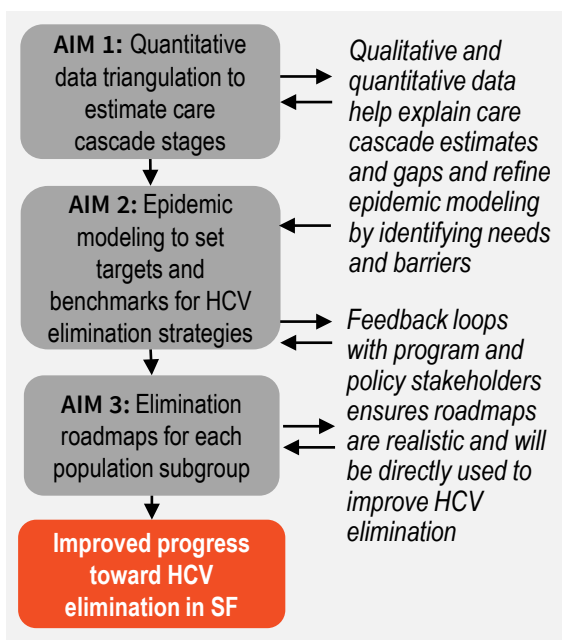
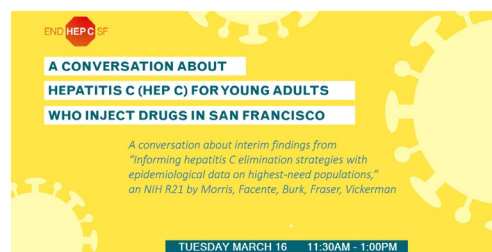


Figure 2. Consensus meeting advertisement.

We advertised the event via End Hep C SF, the University of California San Francisco, and multiple service-providing organizations throughout the city (Figure 2).



Effectiveness

Thirty-seven people (13 researchers, 19 service providers, 5 health department staff) attended the 90-minute virtual consensus meeting. Unfortunately, despite multiple recruitment efforts—including offering an incentive for time and expertise—no young adult PWID attended.

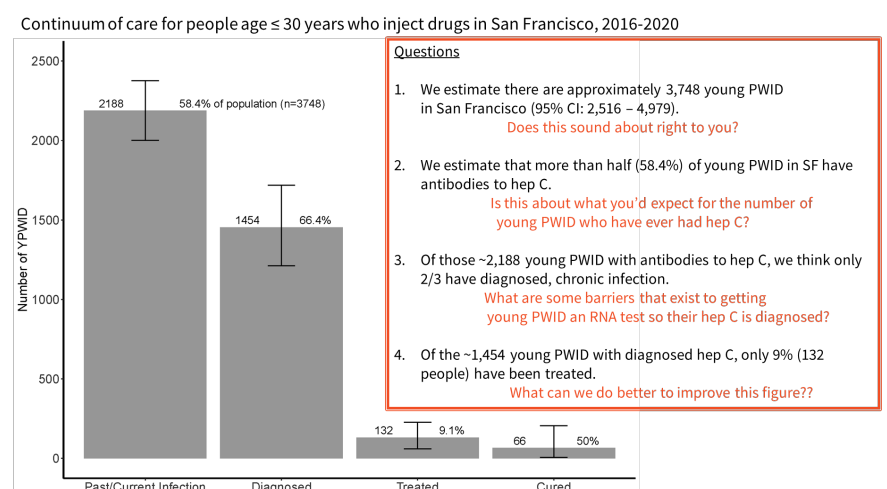
Figure 3. Thirty-seven stakeholders (but no PWID) participated in the meeting.



The process of sharing research findings and prompting stakeholders to discuss them (Figure 4) fostered rich dialogue that surfaced information valuable for subsequent research aims. There was consensus on the importance of focusing on young adult PWID. Many attendees noted that testing and treatment patterns change as PWID age; therefore, failing to disaggregate research findings by age may lead to gaps in service provision for younger PWID.

Participants also noted that the lack of a point-of-care RNA test in the US makes it nearly impossible to streamline diagnosis of active infection, inhibiting linkage to care and hampering hepatitis C elimination efforts.

Figure 4. Slide used at consensus meeting to spark discussion and feedback.



Conclusion and Next Steps

Transmission models will be updated to reflect comments from the meeting, and projections will be used to inform programmatic next steps by End Hep C SF.

As COVID-19 vaccination coverage increases, we will hold future in-person activities to engage young adult PWID.

Real-world perspectives of participants in a collective impact initiative can directly inform transmission model parameters and other epidemiological research, thus improving accuracy, relevance, and reach of academic research findings.



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