

## 1 BACKGROUND

The need to center the patient voice has long been discussed in our healthcare system. Often the credentials and experiences of clinicians and public health professionals overshadow the lived experience and expertise of patients.<sup>1</sup> This disconnect perpetuates the stigma that is frequently associated with a diagnosis of viral hepatitis. Despite the availability of a cure, hepatitis C rates continue to rise and many people are unaware that they are infected. Injection drug use is a driving factor of increasing rates.<sup>2</sup> The World Health Organization has set a goal to eliminate viral hepatitis by 2030.<sup>3</sup> As jurisdictions develop elimination plans to meet this goal, it is imperative that people with lived experience inform strategies for elimination. This study describes how people with lived experience were engaged in hepatitis elimination efforts in Hawaii, New York, San Francisco, and Washington.

## 2 METHODS

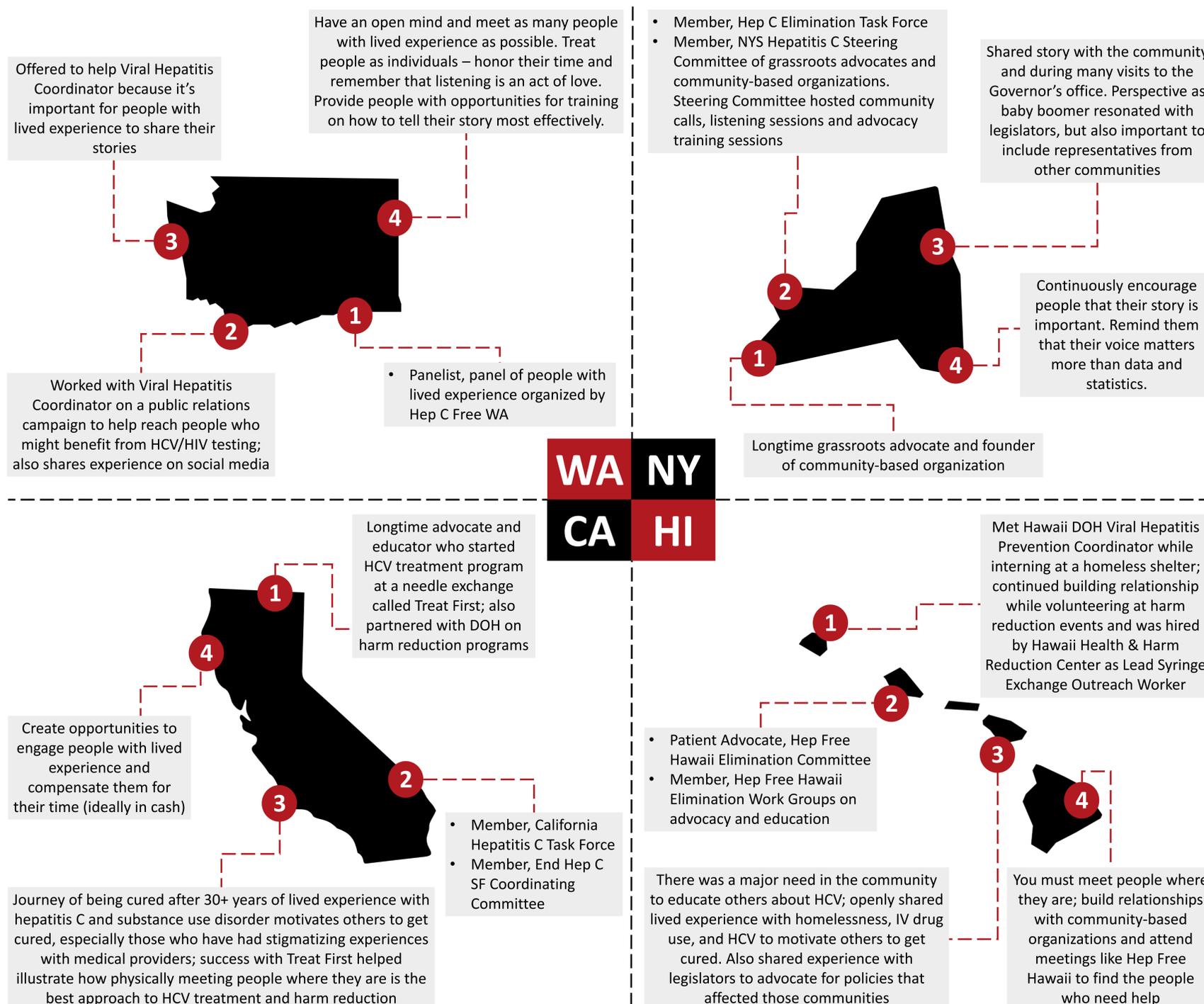
Four people who have lived experience with hepatitis were interviewed regarding their experience with elimination planning in the following Hawaii, New York, San Francisco, and Washington. Each participant was asked the following questions:

- 1 How did you initially get involved with elimination planning?
- 2 Tell us about your role in elimination planning.
- 3 How have you used your story to impact elimination efforts?
- 4 What advice would you offer to people interested in engaging people with lived experience in elimination planning?

## 3 REFERENCES

1. What it Really Takes to Listen to Patients. Harvard Business Review. Published April 4, 2014. Accessed October 15, 2020. <https://hbr.org/2014/04/what-it-really-takes-to-listen-to-patients>.
2. Viral Hepatitis Surveillance – United States, 2018. Centers for Disease Control and Prevention. Published July 2020. Accessed October 13, 2020. <https://www.cdc.gov/hepatitis/statistics/SurveillanceRpts.htm>.
3. Hepatitis. World Health Organization. Accessed October 13, 2020. [https://www.who.int/health-topics/hepatitis#tab=tab\\_1](https://www.who.int/health-topics/hepatitis#tab=tab_1).

## 4 RESULTS



## 5 DISCUSSION

People with lived experience have been engaged in viral hepatitis elimination in various ways such as leadership roles, community navigators, and panelists in community meetings. Clinicians and public health professionals should engage people with lived experience early, frequently, and consistently throughout the planning process. This requires understanding the community-based organizations in their area in order to meet people where they are. It also requires creating a variety of opportunities to amplify their voices. Centering people with lived experience ensures that everyday factors and real-world circumstances meaningfully guide our strategies to eliminate viral hepatitis. Their perspective is critical to developing comprehensive, effective, and practical policies, processes, and programs. It's important that clinicians and public health professional engage diverse communities affected by hepatitis and take ownership of eliminating stigma. People with lived experience help find people who are at risk of contracting or who are living with hepatitis, as well as identify barriers that clinicians and public health professionals may not see. They also provide continuity as clinicians and public health staff turn over. It is important to note that the perspectives captured here are representative of just four people who have lived experience. Additional research is warranted to capture more diverse perspectives, including the experience of people living with hepatitis B.

## 6 CONCLUSION

Successful viral hepatitis elimination efforts require a collaborative approach, including the input of people with lived experience. People with lived experience must be engaged early and often by creating various opportunities to amplify their voices. Only by centering people with lived experience can we achieve viral hepatitis elimination by 2030.

## 7 DISCLOSURES

The National Viral Hepatitis Roundtable receives funding from a diversity of sources, including pharmaceutical companies, insurance companies, governments, foundations and private donations. Study participants received a small honorarium.

## 8 ACKNOWLEDGMENTS

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