

# HOW TO MEANINGFULLY INVOLVE PEOPLE WITH LIVED EXPERIENCE IN HEPATITIS ELIMINATION STRATEGIC PLANNING

Well-informed hepatitis elimination planning and programming requires meaningful involvement of people and communities with lived experience of hepatitis. Experience of and capacity for engagement of people with lived experience varies among Health Departments and jurisdictions, but it is important to conceptualize this work as iterative and ongoing. This section of the toolkit is intended to provide some tips for where and how to identify community members to engage, as well as to describe practices to implement and practices to avoid in doing this work.

**Q: WHERE AND HOW DO I FIND FOLKS WITH LIVED EXPERIENCE OF HEPATITIS?**

**A: IT'S HELPFUL TO SEEK OUT PROGRAMS WHERE THE POPULATION MAY ALREADY BE CONNECTED. EXAMPLES OF THESE INCLUDE:**

- Harm reduction programs
- Opiate treatment programs and other drug treatment programs
- HIV service organizations
- Clinical practices specializing in infectious diseases, gastroenterology, or hepatology
- Organizations that serve people experiencing homelessness



**TIP:** If you're looking for people specifically with lived experience of hepatitis B, it may be helpful to connect with Hep B United's local partners.

**TIP:** Offer periodic hepatitis update trainings for staff or clients of organizations serving the target population to help develop relationships and get a sense of hepatitis-related knowledge and access to hepatitis treatment. (This can also help provide clarification of the health department's role and what information they can and cannot share with clients.)

## BEST PRACTICES IN ENGAGING PEOPLE WITH LIVED EXPERIENCE IN HEPATITIS ELIMINATION PLANNING AND WORK.

### Involve community members with lived experience in hepatitis elimination planning work:

- Go beyond surveys—try using casual conversations, focus groups, advisory boards, and/or hiring folks from impacted communities to obtain deeper and ongoing involvement.
- Compensate folks for their time and expertise.
- Where possible, direct financial compensation is generally preferred over gift cards. If health department policies impede timely processing of payment, in some cases, it may be useful to facilitate compensation through a community-based organization.
- Provide food if meeting with folks in person (food can be to-go if concerned about COVID-19 exposure)
- Make involvement meaningful and iterative.

### Involve community members with lived experience in hepatitis program planning (e.g., community-based testing or linkage programs for vulnerable populations):

- Get feedback from people with lived experience prior to launching a new program (ask questions such as: What would be the best locations for services? What time of day is best? How do we best get the word out?)
- Collect and use data creatively to monitor program effectiveness and learn more about who are benefitting from existing services, and who may be unintentionally left out.



### AVOID THE FOLLOWING PRACTICES:

- Tokenizing or assuming a single person with lived experience can speak for an entire population.
- Assuming that the privilege of being involved is sufficient motivation for participation—it's up to you to make it meaningful and enjoyable.
- Creating hoops for folks to jump through before they can be involved.
- Making assumptions about what folks want and need.
- Substituting voices in recovery for voices of people who are currently using drugs—both are crucial populations with important insights, but they bring different perspectives.