

Training Guide: Identifying and Addressing HCV diagnostics and treatment barriers in countries

Purpose

The purpose of these training sessions are to engage with in-country civil society organizations (CSOs) to identify challenges with hepatitis C Virus (HCV) diagnostics, treatment and care in countries, and develop a strategy to prioritize and address some of these challenges.

Content Areas

- Person First Language
- Demand for Treatment
- Commodities Supply
- Systemic Obstacles
- Financing
- Action Planning

Learning Objectives/Goals

1. Identify the global demand for HCV treatment
2. Describe key obstacles for commodities supply chains
3. Explain how systems can create barriers to care
4. Identify different financing mechanisms for HCV care and treatment
5. Define person first language and how it relates to treatment outcomes

Audience

Adapt as Needed for the Audience: Health Care Service Providers, Civil Society Organizations, representatives from Ministries of Health, Funders, other Stakeholders, etc

Agenda

Time	Agenda Item
00:00 00:00	A. Introduction and Community Agreements
00:00 00:00	B. Person First Language
00:00	C. Global and Regional Demand for HCV Treatment

00:00	
00:00 00:00	D. Commodification of Testing and Treatment
00:00 00:00	E. Overcoming Systemic Barriers to Care
00:00 00:00	F. Financing Mechanisms for Treatment Options
00:00 00:00	G. Action Planning
00:00 00:00	H. Closing and Evaluation

Facilitator Resources/Information

Participant Resources:

Handouts:

Content Sources:

Facilitator Resources:

Time	Program Overview	Notes
00:00 00:00	A. Welcome and Introductions <u>Overview</u> <ol style="list-style-type: none"> 1. Welcome participants to the Hep C PACT training program 2. Review the purpose and goals of the Hep C PACT training program 3. Preview the Hep C PACT training program 	<u>Resources:</u> <u>Handouts:</u> <u>Content Sources:</u>

4. Establish the community agreement and community garden
5. Icebreaker/Participant engagement Activity
6. Review the agenda
7. Review the learning objectives

Activity Instructions

1. Welcome participants to the Hep C PACT training program and review the program purpose and goals. (20 mins)
 - Facilitator should begin by introducing themselves with their name and pronouns
 -
 - Invite participants to introduce themselves with their name, pronouns, geographic location, and 1 expectation for this training
 - **HOLD FOR PLATFORM LOGISTICS (Examples)**
 - **Virtual:**
 - **Mute/Unmute**
 - **Video On/Off – Expectations of Video Participation**
 - **In Person**
 - **Breakout Rooms**
 - **Bathroom Locations**
2. Review the Hep C PACT training program purpose by saying to participants
 - “The purpose of the Hep C PACT training sessions is to engage with in-country civil society organizations (CSOs) to identify challenges with hepatitis C Virus (HCV) diagnostics, treatment and care in countries, and develop a strategy to prioritize and address some of these challenges.”

3. Review the learning objectives of the training program by reading aloud each objective
 - Identify the global demand for HCV treatment
 - Describe key obstacles for commodities supply chains
 - Explain how systems can create barriers to care
 - Identify different financing mechanisms for HCV care and treatment
 - Define patient centered care and how it relates to treatment outcomes

4. Establish the Community Agreement and Community Garden by saying to participants “The community agreement is the set of expectations we will have for ourselves while we share space in the training.”
 - Be present
 - Actively participate
 - Ask questions
 - Reflect on your own experience
 - Be respectful of others experiences
 - Seek to maintain a growth mindset
 - Root in respect
 - Chatham House Rules
 - Others?

5. Add any additional items to the community agreement presentation slide.
 - Ask all participants to unmute their lines and verbally state they consent to the community agreement.

6. Community Garden

- The community garden is intended to be the place for questions or ideas to grow. If anyone has a question about an unrelated topic, they can put the question in the community garden or if anyone asks a question that is going to be covered later, the facilitator might put the question in the community garden as well. Also, if anyone has an idea that they want to share which relates to the topic, but they don't want to disrupt the flow, they can put the idea or comment in the garden also.

○

7. Lead participants in a brainstorm to generate hopes and fears about engaging in this work. **(This activity is scheduled with enough time to let most if not all participants to share 1 hope or 1 fear)**

- Say to the participants, "When thinking about engaging in this work, what hopes, or fears do you have?"
- If meeting in person, provide pens and paper for participants to write down one hope and one fear
 - Post Fears and Hopes for the training around the room
 - Review trends with participants
- If virtual, ask participants to unmute themselves and reintroduce themselves with their name and pronouns when responding to the prompt.
 - Fears can also be shared via the chat
 - Review trends with participants
- If participants are not responding, encourage participants individually or ask a facilitator to share a hope or fear.
 - Affirm participant responses.

	<ul style="list-style-type: none"> ○ Thank participants for their vulnerability and transparency. ● Ask participants, “Does anyone have any questions related to the logistics for the training or agenda before we begin?” <ul style="list-style-type: none"> ○ Respond to participant questions or feedback 	
<p>00:00 00:00</p>	<p>B. Person First Language</p> <p><u>Overview</u></p> <ul style="list-style-type: none"> ○ Describe how person first language empowers professional interpersonal collaboration ○ Describe how person first language empowers patients to engage and remain in care <p><u>Activity Instructions</u> (00 mins)</p> <p>Person first language has three major goals:</p> <ol style="list-style-type: none"> 1. To acknowledge the inherent and equal value of every individual, before attaching any other descriptors or identities the person may view as secondary or not intrinsic. 2. To build trusting relationships and safe spaces for our colleagues to collaborate, respectfully challenge, and engage in meaningful work 3. To build a relationship with a patient/client such that they feel comfortable sharing their personal information and see you as an ally in their healthcare <p>What do we need to know about person first language:</p>	<p><u>Resources:</u></p> <p>Calling In and Calling Out Guide. (n.d.). Harvard University Office for Equity, Diversity, Inclusion, and Belonging. Retrieved September 25, 2022, from https://edib.harvard.edu/calling-and-calling-out-guide</p> <p>Harvard Diversity Inclusion & Belonging (). Calling In and Calling out Guide. Retrieved September 27, 2022, from https://edib.harvard.edu/files/dib/files/calling_in_and_calling_out_guide_v4.pdf?m=1625683246</p> <p>Intent versus Impact: A Formula for Better Communication. (n.d.). Retrieved September 25, 2022, from https://www.betterup.com/blog/intent-vs-impact</p> <p>Loup Editorial Team. (2022, March 30). Step Up/Step Back: Quick & Thoughtful Tips for Being A Better Collaborator. Medium. Retrieved September 25, 2022, from https://medium.com/the-deep-listen/step-up-step-back-quick-thoughtful-tips-for-being-a-better-collaborator-c4ed03f07d49</p> <p><u>Handouts:</u></p> <p>Person first language handout (.ppt)</p> <p><u>Content Sources:</u></p> <p>Foley, M., & Graff, C. S. (2018, July 20). Getting Started with Person-First Language. EduTopia. Retrieved September 15, 2022, from https://www.edutopia.org/article/getting-started-person-first-language</p>

	<ol style="list-style-type: none"> 1. Communicating using person-first language begins with empathy. 2. The individuals we work with come from various backgrounds, races, ethnicities, geographies, and may have stigmatized identities 3. The majority of our patients/clients, as are many of you, familiar with the isolation created by a lack of person-first language. <p>Ask why is this important?</p> <ol style="list-style-type: none"> 1. It addresses the impact of stigma on those living with HCV 2. Patients/clients who feel seen and valued trust us and are more likely to engage and remain in care 3. Patients/clients are likely to be more forthcoming with the risk factors and treatment concerns 4. The better we are able to align with our patients/clients, the better able we are to work with them and not for or against them <p>Question for the group:</p> <ol style="list-style-type: none"> 1. Today, as a community, what commitment can we make to support using person-first language in our training today? 2. Example: Calling in, not calling out ; intent vs impact, stepping up and stepping back, etc (See Resources Tab) 	<p>Hart, E., VanEpps, E. M., & Schweitzer, M. E. (2021). The (better than expected) consequences of asking sensitive questions. <i>Organizational Behavior and Human Decision Processes</i>, 162, 136-154.</p> <p>Rodgers, J. L., Billy, J. O., & Udry, J. R. (1982). The rescission of behaviors: Inconsistent responses in adolescent sexuality data. <i>Social Science Research</i>, 11(3), 280-296.</p> <p>Näher, A. F., & Krumpal, I. (2012). Asking sensitive questions: the impact of forgiving wording and question context on social desirability bias. <i>Quality & Quantity</i>, 46(5), 1601-1616.</p> <p>Nazione, S., Perrault, E. K., & Keating, D. M. (2019). Finding common ground: Can provider-patient race concordance and self-disclosure bolster patient trust, perceptions, and intentions? <i>Journal of racial and ethnic health dispa</i></p>
<p>00:00 00:00</p>	<p>C. Global and Regional Demand for HCV Treatment</p> <p><u>Overview</u></p>	<p>Resources:</p> <p>MapCrowd.org online global data on hepatitis C. mapCrowd. (n.d.). Retrieved September 25, 2022, from http://www.mapcrowd.org/ http://www.mapcrowd.org/</p>

1. Origins of the Epidemics

- Generalized vs. Population specific epidemics
- Improper Sterilization techniques (Medical malfeasance vs. recreational drug use)
- Understanding goals for HCV elimination
- Clinically-acquired infections and epidemics

2. Demand for Treatment

- Disease awareness (at level of political decision makers, prescribers, communities, as appropriate)
- Diagnosis
 - Screening Tests: (Nucleic Antibody Tests, RIBA, viral load testing, and Blood Serum Antibody (HC Ab) tests
 - Genotyping (not recommended)
 - Cirrhosis Score tests
 - Are there diagnostic performance limitations?
 - Where do patients get diagnosed? How? How many patients?
 - Screening coverage
 - Percent of people diagnosed entering treatment, if known
- Treatment Limitations
 - Storing of materials and controlled access
 - Testing
 - Getting results back to people
 - Poor infrastructure
 - Data tracking
 - Monitoring (Community and Epidemiology/Surveillance)
 - Where do patients get diagnosed? How? How many patients?
 - Screening coverage

The Taskforce for Global Health. (2022, July 28). Coalition for Global Hepatitis Elimination. Retrieved September 15, 2022, from <https://www.globalhep.org/>

American Association for the Study of Liver Diseases & Infectious Diseases Society of America. (2022, July 28). *Recommendations for Testing, Managing, and Treating Hepatitis C*. HCV Guidance. Retrieved September 15, 2022, from <https://www.hcvguidelines.org/>

Handouts:

Simplified HCV Treatment Algorithm for Treatment-Naive Adults Without Cirrhosis. Available at: https://www.hcvguidelines.org/sites/default/files/full-guidance-pdf/AASLD-IDSA_HCV-Guidance_TxN-Simplified-Tx-No-Cirr_e.pdf

Simplified HCV Treatment Algorithm for Treatment-Naive Adults With Compensated Cirrhosis Available at:

https://www.hcvguidelines.org/sites/default/files/full-guidance-pdf/AASLD-IDSA_HCV-Guidance_TxN-Simplified-Tx-Comp-Cirr_e.pdf

Content Sources:

Schillie, S., Wester, C., Osborne, M., Wesolowski, L., & Ryerson, A. B. (2020, April 9). CDC Recommendations for Hepatitis C Screening Among Adults . . . Centers for Disease Control and Prevention. Retrieved September 15, 2022, from <https://www.cdc.gov/mmwr/volumes/69/rr/rr6902a1.htm>

World Health Organization. (2022). Criteria for validation of elimination of viral hepatitis B and C: report of seven country pilots. WHO: Geneva. Available at: <https://apps.who.int/iris/bitstream/handle/10665/362121/9789240055292-eng.pdf?sequence=1> Accessed on September 13, 2022.

Dhiman, R. K., & Premkumar, M. (2020). Hepatitis C virus elimination by 2030: conquering mount improbable. *Clinical Liver Disease*, 16(6), 254.

Dore, G. J., & Bajis, S. (2021). Hepatitis C virus elimination: laying the foundation for achieving 2030 targets. *Nature Reviews Gastroenterology & Hepatology*, 18(2), 91-92.

Waked, I., Esmat, G., Elsharkawy, A., El-Serafy, M., Abdel-Razek, W., Ghalab, R., Elshishiney, G., Salah, A., Abdel Megid, S., Kabil, K., El-Sayed, M. H., Dabbous, H., El Shazly, Y., Abo Sliman, M., Abou Hashem, K., Abdel Gawad, S., El Nahas, N., El Sobky, A., El Sonbaty, S., El Tabakh, H., ... Zaid, H. (2020). Screening and Treatment Program to Eliminate Hepatitis C in Egypt. *The New England journal of medicine*, 382(12), 1166–1174. <https://doi.org/10.1056/NEJMSr1912628>

Shah, R., Agyei-Nkansah, A., Alikah, F., Asamoah-Akuoko, L., Bagou, Y. C. O., Dhiblawe, A., ... & Thomson, E. C. (2021). Hepatitis C virus in sub-Saharan Africa: a long road to elimination. *Lancet Gastroenterology and Hepatology*, 6(9), 693-694.

- Percent of people diagnosed entering treatment, if known
- Treatment guidelines
- Developing a denominator
 - Surveillance data vs. true population size
 - Gaps in data
 - Micro-elimination
 - Developing the HCV Continuum of Care as a tool to conceptualize ending the epidemic
- Treatment adaptation to individual and community needs
 - Key populations
- Prescription
 - Who prescribes treatment, where?
 - Treatment awareness: do prescribers know about the drug and its appropriate usage?
- 3. Adherence to treatment
 - Dropout rates due to side effects
 - Patients lost to follow up along the cascade
 - HCV Ab > RNA
 - RNA > Tx initiation
 - Tx > Tx completion/SVR
 - Perceptions of treatment safety and efficacy in communities
- 4. Key “demand” obstacles
 - This will be regional or country specific

Activity Instructions (00 mins)

1. How have you identified a demand for treatment? What country specific demand obstacles have you identified in your country’s/regions programming?

Benzaken, A. S., Girade, R., Catapan, E., Pereira, G., Almeida, E. C., Vivaldini, S., Fernandes, N., Razavi, H., Schmelzer, J., Ferraz, M. L., Ferreira, P., Pessoa, M. G., Martinelli, A., Souto, F., Walsh, N., & Mendes-Correa, M. C. (2019). Hepatitis C disease burden and strategies for elimination by 2030 in Brazil. A mathematical modeling approach. *The Brazilian journal of infectious diseases : an official publication of the Brazilian Society of Infectious Diseases*, 23(3), 182–190. <https://doi.org/10.1016/j.bjid.2019.04.010>

Thomas, D. L. (2020). State of the hepatitis C virus care cascade. *Clinical Liver Disease*, 16(1), 8.

Huang, C. F., Chiu, Y. W., & Yu, M. L. (2020). Patient-centered outreach treatment toward micro-elimination of hepatitis C virus infection in hemodialysis patients. *Kidney International*, 97(2), 421.

Huang, J. F., Hsieh, M. Y., Wei, Y. J., Hung, J. Y., Huang, H. T., Huang, C. I., ... & Chuang, W. L. (2022). Towards a safe hospital: hepatitis C in-hospital micro-elimination program (HCV-HELP study). *Hepatology International*, 16(1), 59-67

2. Which part of the treatment cascade and adherence measurements do you think best to focus on in your advocacy?

D. Commodification of Testing and Treatment

Overview

1. Commodities Supply

- Drug status
 - Intellectual Property status
 - Regulatory approval status
 - Manufacturing capacity
 - What mechanisms exist to align demand and supply?
 - Supply chains: how is the drug brought to points-of-care?
 - Diagnosis commodities status
 - Intellectual Property status
 - Regulatory approval status
 - Manufacturing capacity
 - What mechanisms exist to align demand and supply?
 - Supply chains: how are diagnostic commodities brought to points-of-care?
 - Key obstacles for commodities supply
2. Breaking patent
 3. Negotiated pricing by government/insurance

Resources:

Handouts:

Content Sources:

World Health Organization. (2018). Progress report on access to hepatitis C treatment. Focus on overcoming barriers in low- and middle-income countries. WHO: Geneva. Available at: <http://apps.who.int/iris/bitstream/10665/260445/1/WHO-CDS-HIV-18.4-eng.pdf?ua=1>. Accessed June 21, 2019.

Cornberg, M., Ahumada, A., Aghemo, A., Andreoni, M., Bhagat, A., Butrymowicz, I., ... & Otano, J. I. U. (2022). Safety and Effectiveness Using 8 Weeks of Glecaprevir/Pibrentasvir in HCV-Infected Treatment-Naïve Patients with Compensated Cirrhosis: The CREST Study. *Advances in Therapy*, 1-13.

Keating, G. M., & Vaidya, A. (2014). Sofosbuvir: first global approval. *Drugs*, 74(2), 273-282.

Li, M., Chen, J., Fang, Z., Li, Y., & Lin, Q. (2019). Sofosbuvir-based regimen is safe and effective for hepatitis C infected patients with stage 4–5 chronic kidney disease: a systematic review and meta-analysis. *Virology journal*, 16(1), 1-10.

Hayes, C. N., Imamura, M., Tanaka, J., & Chayama, K. (2022). Road to elimination of HCV: clinical challenges in HCV management. *Liver International*, 42(9), 1935-1944.

<p>4. Subscription model (pay a flat fee for a limited duration and try to use them before expiration)</p> <p><u>Activity Instructions</u> (00 mins)</p> <ol style="list-style-type: none"> 1. Break into groups and ask participants to think about the commodification of healthcare. What does that mean on a practical level? 2. How can we collectively organize to align demand and supply of HCV medication? Does this require an in-country approach or larger levels of collective organizing? Why? 3. What obstacles to commodities supply can we handle at a local or regional level? What partnerships can we make to improve linkage to care at various points along the continuum? 	
<p>E. Overcoming Systemic Barriers to Care</p> <p>Overview</p> <p>Systemic Obstacles to Access to Care</p> <ol style="list-style-type: none"> 1. List systemic access challenges that may exist based on: <ul style="list-style-type: none"> ○ Law or regulations ○ Sex/gender (including gender identity) ○ Ethnicity ○ Age ○ Sexual orientation ○ Ability ○ Other social or demographic factors 2. Potential role and impact of stigma 3. Special considerations for marginalized communities <ul style="list-style-type: none"> ○ indigeneity/indigenous identity ○ migration/migratory status 	<p>Resources:</p> <p>Faghihi, S. A., Khankeh, H. R., Hosseini, S. J., Arabshahi, S. K. S., Faghih, Z., Parikh, S. V., & Shirazi, M. (2016). Improving continuing medical education by enhancing interactivity: lessons from Iran. <i>Journal of Advances in Medical Education & Professionalism</i>, 4(2), 54.</p> <p>Schwartz, B. (2015). What ‘learning how to think’ really means. <i>The Chronicle of Higher Education</i>, 18. http://www.drдавet.net/uploads/3/1/9/1/31910483/learning_how_to_think_article_chronicle.pdf</p> <p>HIV Stops With Me. (2021, February 19). Homepage. Retrieved September 25, 2022, from https://hivstopswithme.org/</p> <p>Cleveland Clinic. (2013, February 27). Empathy: The Human Connection to Patient Care [Video]. YouTube. Retrieved September 25, 2022, from https://www.youtube.com/watch?v=cDDWvj_q-o8&t=1s</p> <p>Handouts:</p>

4. Mental health considerations (e.g. impact of disease diagnosis on patients' mental health)

Activity Instructions (00 mins)

1. How do we define Access to Health Care?

Share that the World Health Organization defines health and wellness

- World Health Organization (WHO) defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” WHO defines wellness as “the optimal state of health of individuals and groups,” and wellness is expressed as “a positive approach to living.”

The UN has also declared health care as a human right.

- Access to care has no basis on merit or requirement other than being alive. Access to care based on pure humanity helps our patients achieve a state of complete physical, mental and social well-being.

The US based Agency for Healthcare Research and Quality (AHRQ) defines access to health care as “the timely use of personal health services to achieve the best health outcomes”

It goes further to state Access to Care consists of 4 components:

1. Coverage: facilitates entry into the healthcare system. (public or private insurance)
2. Services: Having a usual source of care and a usual provider
3. Timeliness: ability to provide health care when the need is recognized.

Content Sources:

Agency for Healthcare Research and Quality [(AHRQ)]. (2018, June). *Elements of Access to Health Care*. Retrieved September 18, 2022, from <https://www.ahrq.gov/research/findings/nhqdr/chartbooks/access/elements.html>

Shukla, N., Pradhan, B., Dikshit, A., Chakraborty, S., & Alamri, A. M. (2020). A Review of Models Used for Investigating Barriers to Healthcare Access in Australia. *International journal of environmental research and public health*, 17(11), 4087. <https://doi.org/10.3390/ijerph17114087>

Ma, L., Luo, N., Wan, T., Hu, C., & Peng, M. (2018). An Improved Healthcare Accessibility Measure Considering the Temporal Dimension and Population Demand of Different Ages. *International journal of environmental research and public health*, 15(11), 2421. <https://doi.org/10.3390/ijerph15112421>

World Health Organization. (2020, March 11). Hepatitis. Health Topics. Retrieved September 25, 2022, from https://www.who.int/health-topics/hepatitis#tab=tab_1

Londeix, P. (2014). New Treatments for Hepatitis C Virus: Strategies for Achieving Universal Access. Hep C Coalition. Retrieved September 25, 2022, from https://hepccoalition.org/IMG/pdf/web_daas_strategies_for_achieving_universal_access_en.pdf

Tang, W., Tao, Y., Fajardo, E., Reipold, E. I., Chou, R., Tucker, J. D., & Easterbrook, P. (2022). Diagnostic Accuracy of Point-of-Care HCV Viral Load Assays for HCV Diagnosis: A Systematic Review and Meta-Analysis. *Diagnostics*, 12(5), 1255. <https://doi.org/10.3390/diagnostics12051255>

Lazarus, J. V., Safreed-Harmon, K., Thursz, M. R., Dillon, J. F., El-Sayed, M. H., Elsharkawy, A. M., ... & Colombo, M. (2018, August). The micro-elimination approach to eliminating hepatitis C: strategic and operational considerations. In *Seminars in liver disease* (Vol. 38, No. 03, pp. 181-192). Thieme Medical Publishers.

Lazarus, J. V., Picchio, C. A., Byrne, C., Crespo, J., Colombo, M., Cooke, G., ... & Dillon, J. (2022, February). A global systematic review of hepatitis C elimination efforts through micro-elimination. In *Seminars in Liver Disease* (No. AAM). Thieme Medical Publishers, Inc..

Hollande, C., Parlati, L., & Pol, S. (2020). Micro-elimination of hepatitis C virus. *Liver International*, 40, 67-71.

Lozano-Sepulveda, S., Bryan-Marrugo, O., Merino-Mascorro, J., & Rivas-Estilla, A. M. (2016). Approachability to the new anti-HCV direct acting antiviral agents in the Latin American context. *Future Virology*, 11(1), 39-46.

4. Workforce: capable, qualified, culturally competent providers.

Activity Instructions

Within your breakout groups, at your tables or online, think about the 4 AHRQ components that facilitate access to care.

1. What are some of the strengths and weaknesses of the current policies on access to care for those living with Hepatitis C in your region? How can you utilize the strengths of current policies to build capacity within your program?
2. If your organization chose to focus on one driver to improve access to care, where would you focus your attention? Why?

A shared vision for true access to care would be the unfettered entry into quality health care services when and where they are needed to obtain optimal treatment outcomes

Acknowledge: We have a long way to go to meet this ambitious vision, but we are closer than ever before to making this a reality for people living with HCV because HCV can be cured.

Barriers to accessibility are varied and are often dependent on location, disease state and patient characteristics

Barriers to accessibility drive epidemics and result in disparate treatment outcomes. Here we will explore how barriers to care are impacted by the following:

- Law or regulations
- World Health Organizations HCV working policies
- HCV Diagnostic and Treatment Guidelines

Dunn, R., Musabaev, E., Razavi, H., Sadirova, S., Bakieva, S., Razavi-Shearer, K., ... & Nasrullah, M. (2020). Progress Toward Hepatitis B and Hepatitis C Elimination Using a Catalytic Funding Model—Tashkent, Uzbekistan, December 6, 2019–March 15, 2020. *Morbidity and Mortality Weekly Report*, 69(34), 1161.

Carrillo, J. E., Carrillo, V. A., Perez, H. R., Salas-Lopez, D., Natale-Pereira, A., & Byron, A. T. (2011). Defining and targeting health care access barriers. *Journal of health care for the poor and underserved*, 22(2), 562-575. <https://muse.jhu.edu/article/430672/summary>

- a. Presenters will update this section with relevant legislation and political structure for their region
 - i. Look for relevant legislation currently under review and encourage participants to discuss how they might use their advocacy skills
 - ii. If there is no current legislation, look for an example utilizing the treatment guidelines and working policies

Activity Instructions

Break your participants into groups and give them one of the following categories:

- **Sex/Gender**
- **Ethnicity**
- **Age**
- **Ability**

Have them use the concepts below the words to drive a conversation about how that element may incur or address obstacles to accessing care

- Sex/gender
 - a. Gender Identity
 - b. Right to Privacy
 - c. Personal Safety/Interpersonal Violence
 - d. Social and Family Roles
 - e. Systemic Discrimination/Criminalization
- Ethnicity
 - a. National Identity
 - b. Regional Identity
 - i. Indigeneity/indigenous identity
 - ii. Migration/migratory status
 - c. Language Access
- Age

- a . Specific concerns across the lifecycle
- b . Length of infection
- Ability
 - a . Are the services provided in a variety of ways that allows those of differing ability an easy entry point
 - b . Considerations vary depending upon the disability classification

Bring the groups back together to have a report out on what their conversations yielded. Commend them on their responses. Add any elements that may have been missed or that would add to the conversation.

Now that we have touched on those, we are going to discuss how access can be further complicated in regards to sexual orientation and other social and demographic factors. Review the following areas together. **Be mindful that this may be the time that we have to revisit Person First Language and calling in versus calling out.**

- Sexual orientation
 - a . Condom distribution laws
 - b . LGBTQIA+ protections or lack thereof
 - c . Harm/Risk Reduction Messaging to prevent sexual transmission of HCV
- Other social or demographic factors
 - a . Stigma
 - i. Social stigma of having HCV
 - ii. Internalized stigma of having HCV
 - iii. Social stigma of having to go to a treatment facility known for treating those with HCV
 - b . Mental Health
 - i. Mental health as a risk factor for substance use

	<ul style="list-style-type: none"> ii. Impact of an HCV diagnosis on an individual’s mental health c. Substance Use <ul style="list-style-type: none"> i. Connecting a patient/client to any available harm reduction service ii. Harm/Risk Reduction Messaging to prevent transmission from shared equipment and syringes d. Literacy <ul style="list-style-type: none"> i. Is information being presented in a way that is understandable? ii. Are we “teaching back” to insure understanding of information being provided e. Access to basic resources (shelter, food, water, safety, etc) <ul style="list-style-type: none"> i. Maslow’s Hierarchy of Needs: Individuals may delay care if their basic needs are not met or if they do not feel safe. 	
	<p>F. Financing Mechanisms for Treatment Options</p> <p>Financing continues to place external barriers on our ability to diagnose, treat, and cure Hepatitis C.</p> <p>Conversations surrounding funding will be largely country based and may be varied depending on the location of the participants.</p> <p>In general we know that:</p> <ol style="list-style-type: none"> 1. Funding for disease in countries is not constant <ol style="list-style-type: none"> a. Global and national funding is often dependent on national interest in disease elimination b. There are competing public health priorities (i.e. COVID-19, HIV, disaster relief, etc) 	<p><u>Resources:</u></p> <p><u>Handouts:</u></p> <p><u>Content Sources:</u></p> <p>Schaffer, S. K., Messner, D., Mestre-Ferrandiz, J., Tambor, E., & Towse, A. (2018). Paying for perspectives on solutions to the “affordability issue”. <i>Value in Health, 21</i>(3), 276-279.</p> <p>Hatzakis, A., Lazarus, J. V., Cholongitas, E., Baptista-Leite, R., Boucher, C., Busoi, C. S., ... & Manns, M. P. (2020). Securing sustainable funding for viral hepatitis elimination plans. <i>Liver International, 40</i>(2), 260-270.</p>

2. Funding often comes with “strings attached” that limit how diagnosis and treatment is funded
3. The cost of treatment and cure is often higher than the amount of money being allocated towards it resulting in scarcity
4. Financing mechanisms are normally an amalgamation of international programs, national insurance programs, private insurance, and out of pocket costs

Activity Instructions

Break out to discuss what funding looks like in your country/region for diagnosis, care, and treatment. Answer the following questions:

1. Does your system of care include...
 - Funding for treatment and diagnostics?
 - International funding programs (such as PEPFAR)?
 - Public system and private sector payment methods?
 - Any out of pocket costs or exclusions within the public sector?
 - Restrictions on vulnerable populations such as those who use drugs or engage in other higher risk behaviors
 - Provide for any indirect costs such as transportation, lodging, or nutrition?

Within these conversations, it may also arise that there is a need for policy change to meet the national demand. Bring back to the larger group:

1. What policies need to be addressed to remove key funding obstacles?
2. What happens when people “opt out” of the public system?

Han, R., Liang, S., François, C., Aballea, S., Clay, E., & Toumi, M. (2021). Allocating treatment resources for hepatitis C in the UK: a constrained optimization modeling approach. *Journal of market access & health policy*, 9(1), 1887664.

Kondili, L. A., Aghemo, A., Andreoni, M., Galli, M., Rossi, A., Babudieri, S., ... & Russo, F. P. (2022). Milestones to reach Hepatitis C Virus (HCV) elimination in Italy: From free-of-charge screening to regional roadmaps for an HCV-free nation. *Digestive and Liver Disease*, 54(2), 237-242.

Campillo-Artero, C., Garcia-Armesto, S., & Bernal-Delgado, E. (2016). The merry-go-round of approval, pricing and reimbursement of drugs against the Hepatitis C virus infection in Spain. *Health Policy*, 120(9), 975-981.

Angelotta, C., McKoy, J. M., Fisher, M. J., Buffie, C. G., Barfi, K., Ramsey, G., ... & Bennett, C. L. (2007). Legal, financial, and public health consequences of transfusion-transmitted hepatitis C virus in persons with haemophilia. *Vox sanguinis*, 93(2), 159-165.

Massard da Fonseca, E., Shadlen, K. C., & Inácio Bastos, F. (2019). Brazil’s fight against Hepatitis C: universalism, local production, and patents. *New England Journal of Medicine*, 380(7), 605-607.

- a. Use of personal resources which can result in a tiered healthcare system?
- b. Giving up because the public system is too onerous and problematic?
- c. Both?

Action Planning Activity Instructions:

Break your participants out into groups to discuss the following scenario:

- I only have \$X resources for HCV treatment through my ministry of health.
 - How do we prioritize when we have limited resources?
 - Where on the cascade would you prioritize your intervention?
 - How is this rolled out on the “front lines”?

How do we address funding restrictions placed on my country by external funders and country specific policy?

- Addressing scarcity
- Policy limitations on specific populations (i.e. justice involved individuals)

G. Action Planning

Overview:

Action Planning

Activity Instructions (00 mins)

Resources:

Médecins du Monde & Treatment Action Group. (n.d.). Online global data on Hepatitis C. mapCrowd. Retrieved September 25, 2022, from <https://www.mapcrowd.org/en/>

Médecins du Monde & Treatment Action Group. (2022, August 9). Policy Statements. hepCoalition. Retrieved September 25, 2022, from <https://www.hepcoalition.org/en/advocate/policy-statements/>

Médecins du Monde & Treatment Action Group. (n.d.-a). Main page. Hep C Coalition. <https://hepcoalition.org/en/>

1. Action planning for HCV treatment and elimination must consider distinct and tailored intervention for different communities:

- Populations include individuals who use drugs, those infected through interventional medical procedures (blood transfusions, vaccination, nonsterile technique, etc), and community acquired infections (i.e. sexual contact between MSM)
- Addressing limited treatment options that must be considered for people of child bearing potential
- Addressing limited pediatric treatment options
- Rural communities-moving from diagnostics to treatment
- Who to test and treat first? Triaging in a time of limited access to DAAs and diagnostic equipment
- Peer led interventions have consistently shown success in supporting individuals in treatment for HCV.
- “Nonspecialist” treatment (moving beyond a hepatologist) as excellent approaches to care provision

2. Have groups break out and brainstorm for 5-7 minutes on:

- How can we best use community health workers to improve treatment options?
- How do we best use nontraditional providers to improve treatment and cure rates?
- How do we work with hospitals to promote sterile technique in an environment with limited resources and use of best practices? (e.g dialysis)
- How do we promote sterile techniques as a harm reduction practice for higher risk individuals?
- How does your institution address limited supplies of diagnostic tools and DAAs? Are there priority populations

Coalition for Global Hepatitis Elimination. (2022, January 25). Hep C Elimination Tool. Coalition for Global Hepatitis Elimination Resources. <https://analytics-tools.shinyapps.io/hep-c-elimination-tool/>

International Network of People who use Drugs. (2022, January 27). Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs -. The IDUIT. Retrieved September 25, 2022, from <https://inpud.net/iduit-implementing-comprehensive-hiv-and-hcv-programmes-with-people-who-inject-drugs/>

WHO. (2021, June). Interim guidance for country validation of viral hepatitis elimination. Geneva: World Health Organization;. License: CC BY-NC-SA 3.0 IGO.

Handouts:

Content Sources:

Admin. (2021, August 27). Key Populations’ Values and Preferences for HIV, Hepatitis and STI services: A Qualitative Study.. INPUD Community Blog. Retrieved September 25, 2022, from <https://inpud.net/key-populations-values-and-preferences-for-hiv-hepatitis-and-sti-services-a-qualitative-study/>

or is it first-come-first-serve? How does this look in practice?

3. CQM Models for HCV Treatment (Listed Under Resources)

- INDUIT: “People who inject drugs want immediate, fast and affordable access to DAA HCV treatment with minimal barriers including: funding for DAA treatments, a ‘Test to Treat’ approach, multiple low-threshold access points, peer-based Point of Care (PoC) PCR testing, diagnosis and DAA treatment service models, removal of discriminatory barriers such as cessation/abstinence from drug use as a treatment criterion and recognition of harm reduction as an integral part of HCV treatment services.”
- The IDUIT – Implementing Comprehensive HIV and HCV Programmes with People Who Inject Drugs

4. WHO Resources

- Coalition for Global Hepatitis Elimination
- As a group, walk participants through an in-county example using the interactive tool

5. Next Steps in Action Planning

- 1. What will you do in your CSOs and as a group in the short (next 2-4 weeks) and long-term to ensure the obstacles to demand for treatment identified above are addressed?
- 2. What will you do in your CSOs and as a group in short (next 2-4 weeks) and long-term to address the obstacles to commodities supply identified above?

	<ul style="list-style-type: none"> ● 3. How would your CSO and the group work to advance the one driver to improve access to care identified above? ● 4. What will you do in the short (next 2-4 weeks) and long-term to ensure the centering of key populations in funding programs in your country? ● 5. What can you do collectively in the short (next 2-4 weeks) and long-term to address the weaknesses in access to diagnosis and treatment policies? ● 6. Which other stakeholders do we need to involve in this process? ● 7. What timelines and follow-up actions work best for the group? 	
<p>00:00 00:00</p>	<p>Closing & Evaluation</p> <p><u>Overview</u></p> <ul style="list-style-type: none"> ○ Reflect on key topics and concepts that left an impression on participants ○ Receive feedback from day’s agenda, content, and activities ○ Identify any corrections or additional information needed for the future <p><u>Activity Instructions</u> (20 mins)</p> <ul style="list-style-type: none"> ● Closing Activity (05 mins) ○ Keep or Change (10 mins) <ul style="list-style-type: none"> ○ Say to participants <ul style="list-style-type: none"> ● Reflect on today’s training – the content, the logistics, the staff, the preparation – was there anything about today’s training that would recommend we keep in the future or anything that you think we should 	<p><u>Resources:</u></p> <p><u>Handouts:</u></p> <p><u>Content Sources:</u></p>

change tomorrow? In the next training?
What would you keep and what would you change?

- Document participant responses
- Respond to any participant feedback as needed
 - Take note of any recommendations which can be implemented immediately
- Closing Evaluation Reminder (5-10 mins)
 - Review the “community garden” and consult with faculty to identify and address any additional questions, comments, or feedback provided throughout the day
 - Ask participants, “Are there any remaining questions or feedback about the training or material covered today?”
 - Respond to any participant questions, comments, or feedback
 - Provide a reminder for the evaluation which will be e-mailed to them