HealthHCV

FOURTH ANNUAL

STATE OF HCV CARE NATIONAL SURVEY™

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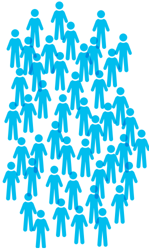
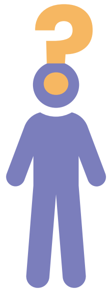
THE EVOLVING HCV LANDSCAPE AND THE NEED FOR THIS NATIONAL SURVEY OF PROVIDERS



2.8 million
infected with HCV in the United States



40%
unaware of their status

3×
increase in HCV rates since 2011

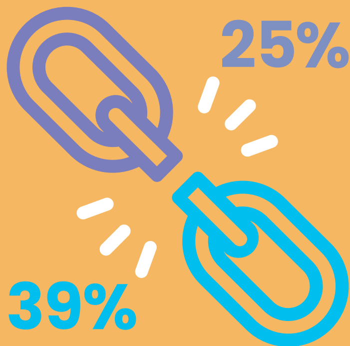
While advances in hepatitis C (HCV) cure therapy have led to improved survival rates for patients with cirrhosis, reduced health care costs, and a reduced need for liver cancer surveillance, a more comprehensive approach to HCV care is needed to curb the epidemic. HCV remains a worldwide epidemic with over 70 million people chronically infected, and as many as **2.8 million infected with HCV in the United States**. Among those living with chronic HCV in the U.S., at least **40% are unaware of their status**. HCV rates nearly **tripled from 2011 to 2018 with two-thirds of cases occurring among persons aged 20–39 years**, the age group most impacted by the opioid crisis. Despite the burden of illness and safe and effective treatments that can cure HCV, this infection remains a "silent epidemic," eliciting limited awareness, resources, and discussion by the public and policymakers.

The Viral Hepatitis National Strategic Plan: A Roadmap to Elimination 2021-2025, released in January 2021, provides a framework to eliminate viral hepatitis as a public health threat in the United States by 2030. The plan asserts the need to: implement universal HCV screening guidelines and linkage to care in a range of settings; expand the capacity of the public health and provider workforce to provide viral hepatitis prevention, testing, care, and treatment services; enhance collaborative, patient-centered models of care; and improve surveillance data collection and analysis to understand opportunities to address viral hepatitis.

In order to evaluate the latest impacts on HCV prevention, screening, treatment, and related support services, HealthHCV released the **HealthHCV Fourth Annual State of HCV Care National Survey™** in May 2021. The survey collected key data points from service providers nationwide regarding the provision of HCV services, including patient populations served, screening and treatment practices, barriers to HCV care, and provider education and training needs.

KEY FINDINGS

One-quarter to one-third of providers* report barriers to HCV prevention, care, and treatment services as: **limited infrastructure** for providing HCV services; **administrative time needed** to process prior authorizations/ pre-approvals; and **treatment utilization policies** impacting coverage by payers.



While nearly a quarter of participants reported that they are seeing HCV reinfection amongst their patient populations—primarily PWID, those experiencing homelessness, and co-infected with HIV and HCV—**39% never screen clients for reinfection**.

Nearly one-third of providers were unable to treat a patient with HCV due to payer/ insurance limitations and restrictions; this is most common for patients with Medicaid and private insurance.

Most providers reported that they provide HCV services through an **onsite co-located model** and identified that this model serves as a **facilitator for both providers and clients**.

The top training needs identified by providers are: current HCV **screening and treatment guidelines**; **simplifying HCV care** and treatment in practice; **enhancing HCV linkage to care strategies** to increase HCV patients on treatment; and discussing substance use with patients with HCV.

Many HCV service providers are not implementing CDC HCV screening recommendations. Fewer than two-thirds implement one-time screening for all adult patients, nearly one-half (44%) do not screen patients diagnosed with HIV, less than half (42%) screen baby boomers (born between 1945 and 1965), and only 14% screen patients pregnant in the third trimester.

To reach people with undiagnosed HCV, providers believe it would be most effective to **increase HCV screening in HIV care and treatment programs**, **substance use centers**, **needle exchange centers**, and **private practice**.

One-third of providers reported that they needed to re-prioritize away from HCV services because of **the COVID-19 pandemic**.

* In this report, providers include clinical and non-clinical providers.

METHODOLOGY

51
quantitative and qualitative questions

HealthHCV developed the fourth annual survey instrument to include questions that define survey respondents, identify trends, and gather information on the state of HCV in specialty and primary care, including the latest impacts on HCV screening practices, treatment access and reimbursement, barriers to care, and integration and coordination of HCV services with behavioral health and substance use treatment. The survey instrument consisted of 51 quantitative and qualitative questions. HealthHCV distributed the survey nationally using Research Electronic Data Capture (REDCap). Respondents were recruited through open invitations using targeted email lists and social media postings. Data was collected from May to June 2021. The survey was a convenience sample, and no incentive was provided for participation.

The survey included a diverse set of topics to explore the latest impacts on HCV screening, treatment and related support services.

A diverse set of topics

- Demographics
- Organizational and Provider Information
- HCV Practices and Services
- Patient Populations/Communities Served
- COVID-19 Implications on HCV Services
- HCV Facilitators, Barriers, and Future Implications
- HCV Treatment Costs
- Community Partnerships and Resources

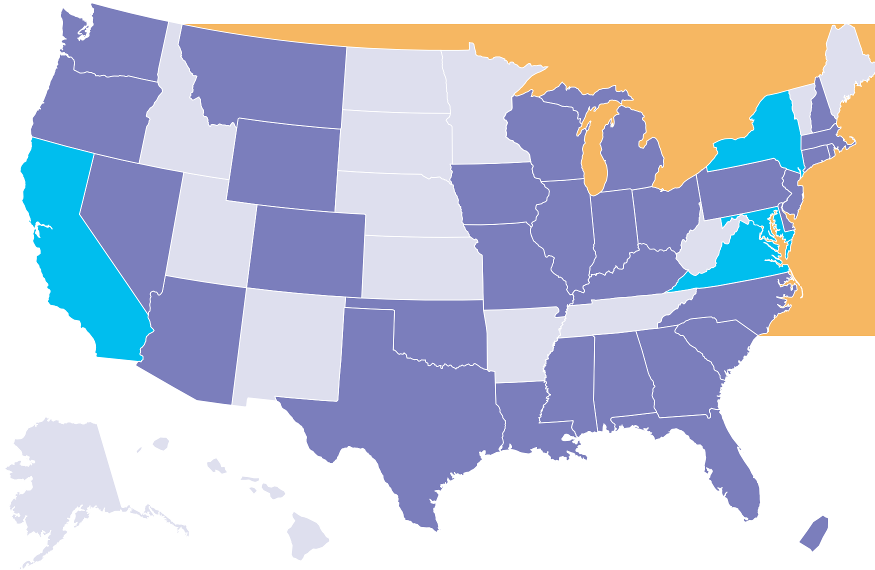
DATA ANALYSIS

Data was analyzed using SAS (Statistical Analysis Software 9.4, SAS Institute Inc, Cary, North Carolina, USA).

ELIGIBILITY REQUIREMENTS

To be eligible to take the survey, participants had to indicate that they either provided or worked for an organization that provided services to people with or at risk for HCV.

DEMOGRAPHICS



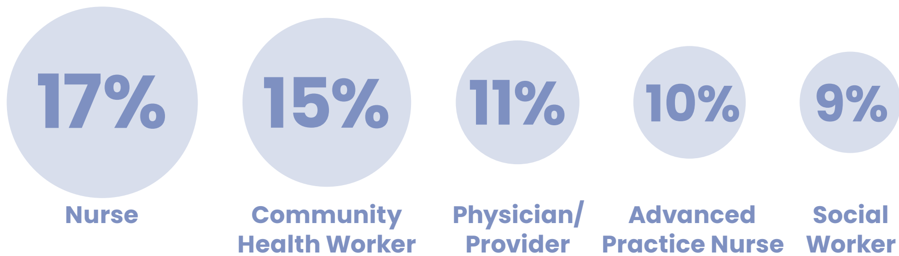
444 respondents engaged in the survey from across the country; including **35 states**, **Washington DC**, and **Puerto Rico**.

HIGHEST RESPONSE RATES

Maryland (9%)
New York (8%)
Virginia (8%)
California (7%)

COMMON PROFESSIONS

The majority of respondents **practice in urban areas (58%)**, followed by **rural areas (26%)**, then **suburban (15%)** and **tribal (1%)**.



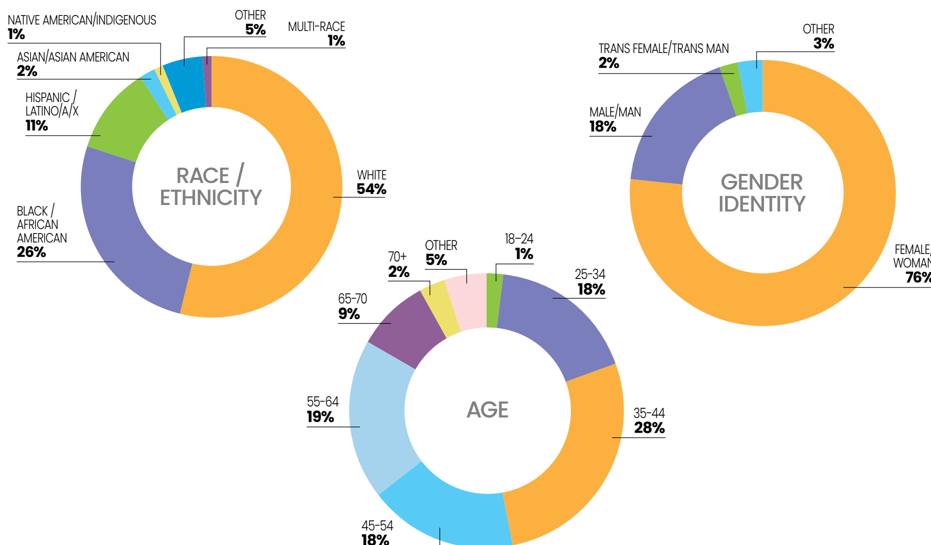
389 respondents provide HCV services and/or work at organizations that provide services directly to people with or at risk for HCV.

45% of respondents provide clinical services.

The majority of respondents have provided HCV prevention, care and treatment services from less than one year to four years (51%).

RESPONDENTS CHARACTERISTICS

Majority of respondents identified primarily as women (76%), white (54%), and between the ages of 25-54 (64%).



HCV SCREENING, CARE, AND TREATMENT PRACTICES

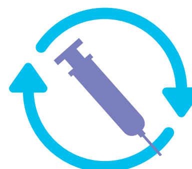
PATIENT POPULATIONS THAT RECEIVE HCV SCREENING

%	Patient population
65%	Patients who present with a risk factor for HCV
63%	Persons who inject drugs (PWID)
61%	All adult patients
59%	Patients who request screening
56%	Patients who are diagnosed with HIV
45%	Men who have sex with men (MSM)
42%	All patients born between 1945 and 1965
14%	**Only 14% screen patients who are pregnant in the third trimester**

Participants reported that the following settings are the most effective environments to increase HCV screening in order to reach people with undiagnosed HCV:

HIV care and treatment programs

Substance use centers



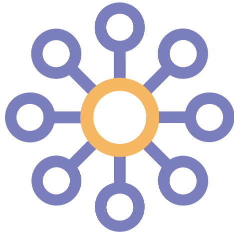
Needle exchange centers

Private practice

HCV SERVICE DELIVERY

SERVICE DELIVERY OPTIONS*

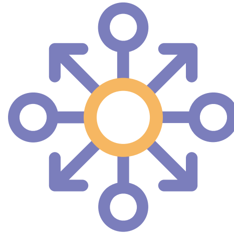
The data shows that respondents provide different HCV service delivery models.



Co-Located Onsite Model

The majority—**56%**—indicated that clients receive HCV prevention and treatment services onsite

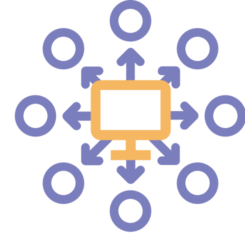
Of those that provide prevention and treatment services onsite, **73% treat patients onsite** by primary care providers



Distributed Onsite and Referral Model

42% of respondents indicated that they screen for HCV onsite, but patients are treated offsite

Within this model, **75%** of respondents referred patients to hepatitis specialists for care after diagnosis



Telehealth-based Collaborative Management Model

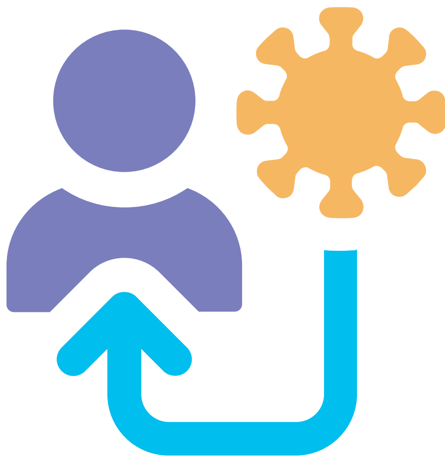
13% are treated via telehealth-based collaborative management mode

Participants who provided clinical services were asked how frequently they provided HCV services. The majority of participants reported that they discussed managing side effects, determined the appropriate course of treatment, discussed alcohol and drug use, described the use of Direct Acting Antivirals, and referred patients for support services on a monthly basis. They are less likely to have counseled patients on risk factors, evaluated for signs of acute HCV and advanced liver disease, and monitored patients not on treatment on a monthly basis.

LINKAGE TO CARE

Linkage to HCV care after diagnosis is key to expanding access to HCV cure therapy and is often where most patients with HCV drop out of care. Many respondents actively link patients to care by scheduling appointments and/or providing transportation to appointments (38%); 32% provide the referral contact information, and 30% refer out for HCV treatment solely.

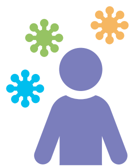
* Results are not mutually exclusive; therefore percentages do not equal 100%.



24%
report reinfection in their patient populations

95%
are injection drug users

39%
are experiencing homelessness



34%
are co-infected with HIV and HCV

REINFECTION

While rates of HCV reinfection remain small, reinfection in certain populations such as PWID and HIV-diagnosed MSM threatens HCV elimination. Nearly a quarter (24%) of participants reported that they are seeing HCV reinfection amongst their patient populations. Populations experiencing reinfections according to the survey respondents:

- Persons who inject drugs (95%)
- Persons who are experiencing homelessness (39%)
- Persons who are co-infected with HIV and HCV (34%)

35% of respondents who provide clinical services screen for reinfection once per month, and **39% never screen for reinfection**. To address reinfections, participants explained that they provide a range of services from counseling on HCV transmission and reinfection risk to HIV testing to drug treatment delivery. The diverse portfolio of services is necessary to address the complexities for persons at risk for HCV.

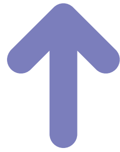
Addressing Acute Needs to Prevent Reinfection

- Counseling on HCV transmission and reinfection risk (89%)
- HIV testing (75%)
- Offsite syringe exchange program referral (30%)
- Onsite syringe exchange program (27%)

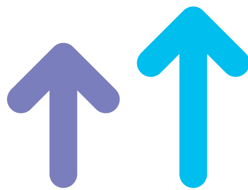
Addressing Upstream Needs to Prevent Reinfection

- Mental health services (54%)
- Case management services for wraparound services (41%)
- Drug treatment services (40%)
- Housing services (19%)

2020: COVID IMPACT ON HCV



28% experienced an increase in patients diagnosed with HCV



48% predict they will scale up care within two years

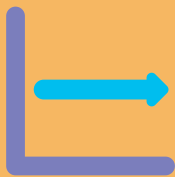
With HCV screening rates decreasing and opioid use and overdoses increasing through the COVID-19 pandemic, respondents noted the following impacts on their patients and services.

THE EFFECT OF COVID-19 ON PATIENTS

- In the past 12 months, **28% of respondents experienced an increase** in the number of patients diagnosed with HCV.
- As a result of this increase, challenges persist including **insurance barriers** (51%), **administrative time** involved in processing claims (35%), and **lack of trained providers** in the service area (35%) and onsite (31%).
- 48% of respondents predict that **they will scale up HCV care** and treatment within the next two years.

THE EFFECT OF COVID-19 ON SERVICES

- 39% reported that HCV services have remained the same during the pandemic.
- 32% have incorporated telemedicine into their practices.
- 21% indicated that HCV services have been halted completely or partially.
- 31% reported that they needed to re-prioritize away from HCV services because of COVID-19 pandemic.



39% reported services remained the same

32% incorporated telemedicine

21% halted HCV services

31% re-prioritized away from HCV services

FACILITATORS AND BARRIERS TO PROVIDING SERVICES

PROVIDER LEVEL

Providers indicated that the following were facilitators and barriers in providing HCV services.

Provider-level **facilitators** to providing HCV services included:

- Co-location of wraparound services (53%)
- HCV training and resources (46%)
- Co-location of HCV prevention and care services (46%)
- Simplicity of Direct-Acting Antiviral regimens (44%)

Provider-level **barriers** to providing HCV services included:

- Limited infrastructure for providing HCV services (32%)
- Administrative time needed to process prior authorizations/pre-approvals (28%)
- Treatment utilization policies impacting coverage by payers (26%)
- Lack of consensus about screening and treatment guidelines (23%)

CLIENT LEVEL

Respondents were asked about the facilitators and barriers that clients face when accessing HCV services.

Client-level **facilitators** to HCV services include:

- Accessing a trustworthy and experienced HCV medical provider (57%)
- Receiving culturally competent care (49%)
- Receiving wraparound services (38%)
- Accessing prevention and treatment through a co-located model (36%)
- Receiving insurance and payment navigation services (31%)
- Ability to pay for HCV services (31%)

Client-level **barriers** to HCV services include:

- Social barriers (66%)
- Lack of knowledge of HCV (34%)
- Costs associated with services (31%)
- Absence of symptoms (28%)
- Insurance restrictions (27%)
- Substance use-associated comorbid conditions (22%)

WRAPAROUND SERVICES

The survey data indicates that wraparound services are essential in providing effective HCV prevention and care services. The table below outlines the wraparound services provided in conjunction with HCV services. Most respondents offer insurance navigation, mental health, substance use services, and transportation either onsite or provide an offsite referral. While there are clear gaps in providing more upstream focused services such as case management, employment, legal services, childcare/parenting services, and transportation.

SERVICE	ONSITE	OFFSITE REFERRAL	NO/NOT OFFERING
Insurance Navigation	63%	30%	10%
Mental Health	52%	42%	10%
Substance use services	46%	47%	10%
Transportation	39%	39%	24%
Case Management	25%	50%	28%
Employment	12%	48%	40%
Childcare/Parenting services	8%	43%	49%
Legal Services	6%	52%	43%

* Results are not mutually exclusive; therefore percentages do not equal 100%.

67%
of acute HCV cases are among injection drug users

The CDC's 2019 Viral Hepatitis Surveillance Report showed that injection drug use was the most commonly reported risk factor (67%) for acute HCV cases.[1] Therefore, harm reduction services are essential in preventing initial HCV infections and reinfections. Almost half of providers indicated that there is adequate access to sterile syringes, and 59% expressed that they have adequate referrals to opioid and substance use disorder treatment facilities.

1 Centers for Disease Control and Prevention. Viral Hepatitis Surveillance Report – United States, 2019. https://www.cdc.gov/hepatitis/statistics/2019surveillance/index.htm. Published May 2021. Accessed July 20th, 2021.

PAYERS AND INSURANCE

Insurance coverage is a challenging barrier to accessing care

When asked about barriers to accessing care, respondents indicated that **insurance coverage is a challenge at the provider and client levels**. 29% reported that they were unable to treat a patient with HCV due to payer/insurance restrictions. The payers that present the most challenges are: **Medicaid** (49%), **Private Insurance** (36%), and **Medicare** (20%).

In an effort to address these challenges, providers, staff, and clients utilize a varied set of services including:

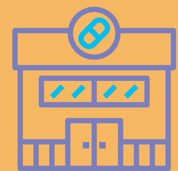
- Insurance navigation services (54%)
- Information on patient assistance programs (46%)
- Directly contacting patient assistance programs on behalf of patient (44%)
- Prior authorization and/or pre-approval processing (53%)
- Provider appeals [when initially denied] (40%)
- Collaboration with pharmacy to facilitate prior authorizations (46%)
- Designated staff member to facilitate prior authorizations/pre-approvals (33%)

CHALLENGING THE BARRIERS

54% used insurance navigation services

53% use prior authorization or pre-approval processing

46% used info on patient assistance programs



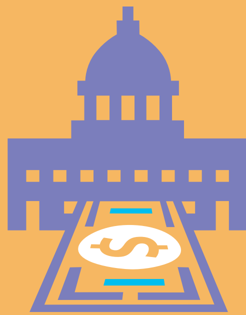
46% work with pharmacies for prior authorization

HCV FUNDING

HCV is notoriously underfunded and treatment services are costly; therefore a diverse funding portfolio is imperative in comprehensively addressing HCV prevention and care. Participants indicated that their primary sources of HCV funding are primarily **grants** (44%), then **insurance carriers** (32%), and lastly **patient self-pay** (10%).

Participants further shared that they utilize a variety of patient assistance programs such as pharmaceutical programs to assist with HCV service costs. However, 35% said they do not use any of these programs.

PRIMARY SOURCES OF HCV FUNDING



44%
Grants

32%
Insurance Carriers

10%
Patient Self-Pay

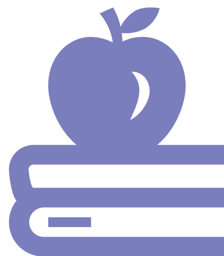
35%
do not use patient assistance programs to assist with HCV service costs

HCV RESOURCES, EDUCATION, AND TRAINING NEEDS

Funding

Coverage

Staffing



Training & Education

Respondents indicated that they need a wide breadth of resources to provide HCV prevention and care services.

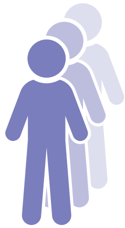
- Funding for HCV
- Insurance coverage
  - Focused on comprehensive HCV screening and treatment services
- Staffing
  - More medical providers trained to provide HCV prevention, care, and treatment services
  - Support staff to provide wraparound services to HCV clients
- Program Support
  - Dedicated navigation services to help clients cover the costs of HCV services
  - Syringe service programs and services
  - Marketing resources to educate the public about HCV
- Trainings
  - HCV focused trainings for medical providers
- Educational Resources
  - Outlining new HCV treatment regimens
  - Outlining evolution of HCV treatments

Top five training needs identified:

- Current HCV screening guidelines
- Current HCV treatment guidelines
- Simplifying HCV care and treatment in practice
- Enhancing HCV linkage to care strategies to increase HCV clients on treatment
- Discussing substance use with patients with HCV

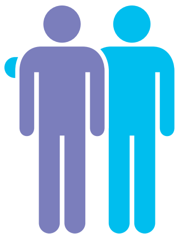
Participants would like to receive this training primarily through a CME course, in-person intensive training, and/or at a national conference/meeting.

IMPLICATIONS



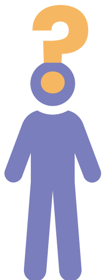
More HCV patients are expected to enter care as a result of delayed services and increased opioid use during the past 12 months of the COVID-19 pandemic. Thus, more providers will be needed to treat the growing number of patients needing HCV treatment.

Primary care providers and other non-specialists can be trained to implement the **simplified treatment algorithm** for treatment-naive adults and scale up their HCV care and treatment to accommodate the increasing demand.



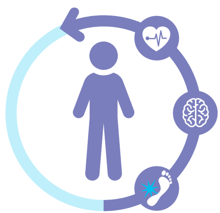
Collaborative HCV care management for treatment-experienced patients is an effective way for primary care providers and specialists to work together to expand workforce capacity for HCV treatment, increase patient retention in care, and leverage limited resources.

Providers need increased capacity to facilitate linkage to and retention in HCV treatment, including administrative support to navigate prior-authorizations and payer restrictions.



There are still more than 40% of people infected with HCV that **don't know their status**. HCV screening must increase in settings most likely to reach the undiagnosed, such as substance use centers, HIV care and treatment programs, needle exchange centers, and private practice.

Increasing integration of **substance use interventions and harm reduction services** with HCV care and treatment can improve retention and reduce reinfection opportunities.



Many HCV patients have complex social and medical conditions that impede their ability to access and establish care. **Comprehensive wraparound services are needed** to address co-morbidities and other social determinants experienced by HCV patients.

Payer restrictions and authorizations limit providers' ability to efficiently engage patients in HCV treatment. Providers need access to additional education and resources to support their patients so that they do not fall out of care and also need additional staff support such as patient navigators to help guide patients through the system. Providers also should be engaged in advocating for changes to insurance policies supporting coverage of HCV treatment.

ABOUT HEALTHHCV

HealthHCV Advocacy

- Advocating for the development of sound public health policy responsive to the shifting landscape of HCV and health care.
- Increase the Number of Individuals Aware of HCV Infection
- Improve Care Options for Individuals Living with Chronic Hepatitis C
- Build Surveillance and Research Capacity

HealthHCV Education and Training

Providing relevant and comprehensive medical and consumer education on HCV screening, testing, and treatment remains a core focus. HealthHCV will focus on education and training to address HCV in HIV care and primary care settings. Initiatives include:

- HealthHCV's HCV 20/20 Project: A Clear Vision for HCV Testing and Linkage to Care
- HealthHCV's HCV Primary Care Training & Certificate Program™
- Addressing the Evolving Opioid and HCV Epidemics Through Community Engagement and Education: Curriculum-Based Live and Online Activities

HealthHCV Research and Evaluation

Lack of comprehensive HCV data on a national level has impacted education and capacity building efforts, as well as funding for HCV prevention, care and treatment activities and research. HealthHCV conducts an annual State of HCV Care National Survey™ among HIV and primary care providers, and develops infographics to visualize trends in HCV and the broader healthcare landscapes.

HealthHCV

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