Health HCV
An Initiative of HealthHIV

HealthHIV's Report on the State of Hepatitis C Care National Survey

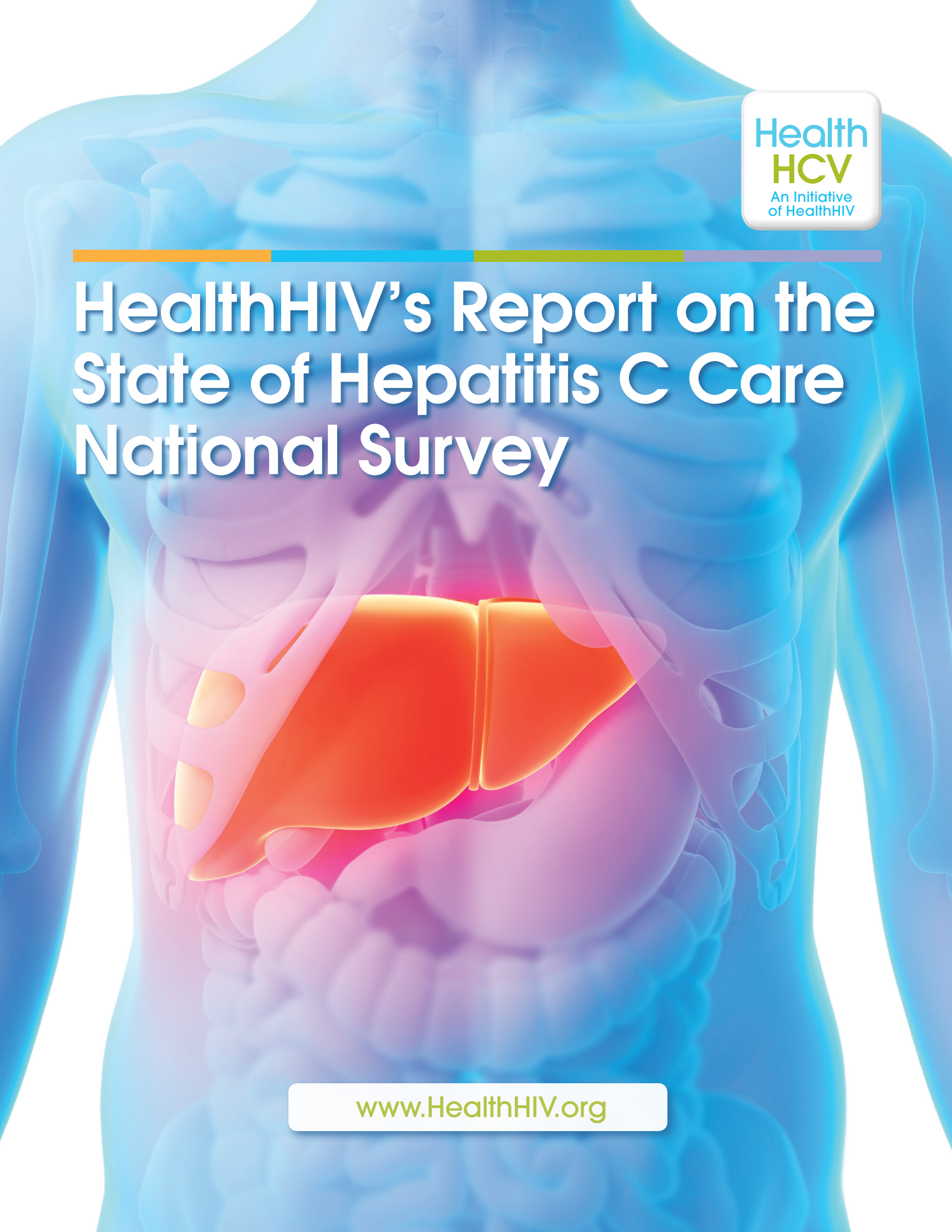

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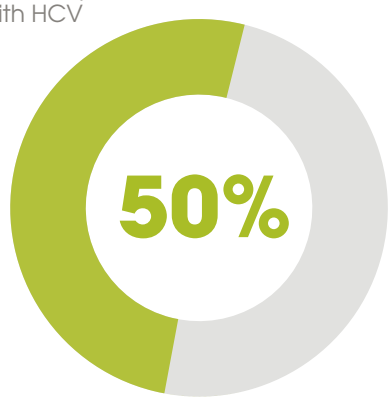
Table of Contents

Executive Summary	4-7
Methodology	7
Demographics of Survey Respondents	8-9
Hepatitis C Screening and Treatment Practices	10
Barriers to Providing Care	11
Treatment Funding Challenges	11
Other Barriers to HCV Treatment and Adherence	11
Educational needs	12
Current Practices & Anticipated Increased Need	12
Funding	14
Patient Barriers	15
Policy Awareness	15
Implications	16-17
Appendix: Demographic Characteristics of SurveyMonkey™ Respondents	18-19

*Estimated

Population that does not know that they are infected with HCV



Executive Summary

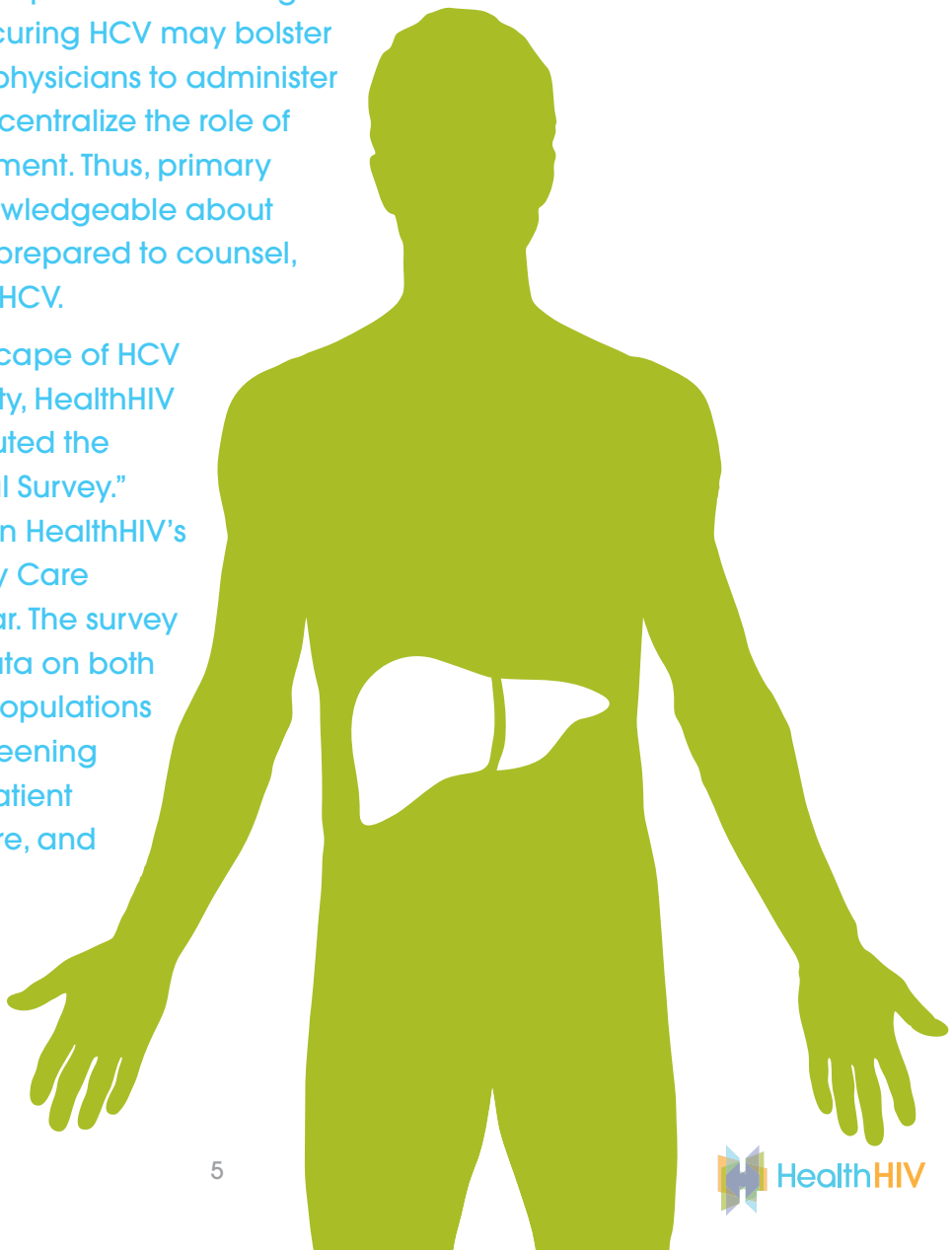
The prevalence of hepatitis C (HCV) presents a complex and urgent situation for healthcare providers and the healthcare system. An estimated 3 million people a re living with HCV in the United States, and at least 50% of this population does not know that they are infected. From 1999 to 2007, HCV-associated deaths increased 50% in the United States, eventually eclipsing the number of deaths attributable to HIV. HCV also is the leading cause of liver cancer and the number one cause of liver transplants. Despite the increasing burden of illness, HCV remains a "silent epidemic," eliciting only limited awareness and discussion by the public, policymakers, and even healthcare providers.

In 2015, the U.S. Department of Health and Human Services released its updated **Action Plan for the Prevention, Care, and Treatment of Viral Hepatitis**, which asserted the need to improve community awareness and provider education, improve testing, care, and treatment, strengthen public health surveillance, improve HCV preventive services for injection drug users, develop a HCV vaccine, and prevent HCV transmission in healthcare settings. The action of healthcare providers is crucial for the success of these strategies.

In conjunction, ongoing health system transformation and medical advances will likely shift the onus of HCV care largely onto primary care. The Patient Protection and Affordable Care Act (PPACA) is streamlining and strengthening primary care practice by establishing

an integrated, collaborative, and patient-centered primary care service delivery model. As a result, patients are more likely to turn to their primary care providers for the management of a wider spectrum of care, including the treatment of HCV infection. In addition, development of simplistic medical regimens that are highly effective in curing HCV may bolster the ability of primary care physicians to administer HCV medical care and decentralize the role of specialists in HCV management. Thus, primary care providers must be knowledgeable about populations at risk and be prepared to counsel, test, and treat patients with HCV.

In order to assess the landscape of HCV care practices and capacity, HealthHIV and Medscape, LLC distributed the "State of HCV Care National Survey." This survey was modeled on HealthHIV's annual "State of HIV Primary Care Survey," now in its fourth year. The survey collected demographic data on both providers and the patient populations they serve, gaps in HCV screening and treatment practices, patient and provider barriers to care, and provider education needs.



Key Survey Findings

- Providers anticipate that their HCV caseloads will increase in the coming years, and that they will need to scale up HCV care and treatment in their practice in the next three years to accommodate the increasing demand.
- Many primary care providers have begun treating HCV patients only recently, however most PCPs are currently conducting some form of HCV screening based on risk factors.
- Most providers also offer HIV care in their practice.
- The most frequently cited barriers to providing HCV care to patients are: treatment utilization policies impacting coverage by payers, limited infrastructure for proving hepatitis C screening and treatment, and limited clinical knowledge about screening and/or treatment.
- Providers have experienced significant restrictions on coverage for HCV treatment with both private and public insurance payers -- most significantly with Medicaid and private payers. Denial of coverage, as well as extensive and confusing paperwork, disrupts providers' ability to treat HCV-infected patients.
- Severity of liver damage, current drug use, and current alcohol use are the most frequently cited reasons payers deny coverage for HCV treatment.
- Insurance restrictions have not decreased most providers' willingness to screen patients for HCV.
- More providers are needed to treat the growing number of patients entering care.

These findings indicate the need for:

- Increased capacity, linkages, resources and education to support the provider workforce
- Increased financial support, either through changes in insurance policies or outside resources, to impact providers' continued ability to effectively treat patients
- Incorporating substance abuse behavioral interventions into care may provide another avenue for securing coverage of HCV treatments for many patients
- Recruitment of specialists into HCV care and strengthening referral networks between primary care and specialists
- Engagement of allied health professional to support patients and address co-morbidities and other social determinants experienced by HCV patients
- Provider training on current practice guidelines and treatment of co-infections and co-morbidities

Methodology

HealthHIV developed the survey instrument. National advocacy groups, industry partners, and providers provided input into the final version. Questions were developed to define provider types, identify trends and gather information on current prevention and treatment strategies and challenges. The survey instrument, consisting of 4 7 questions (5 qualitative, 42 quantitative), was posted by HealthHIV using SurveyMonkey™. An abbreviated version was posted via Medscape, LLC. HealthHIV and Medscape, LLC recruited respondents through open invitations using targeted email lists, monthly newsletters, and website postings. Data were collected between April 23, 2015 and June 11, 2015. The survey was convenience sampled and no incentive was provided for participation.

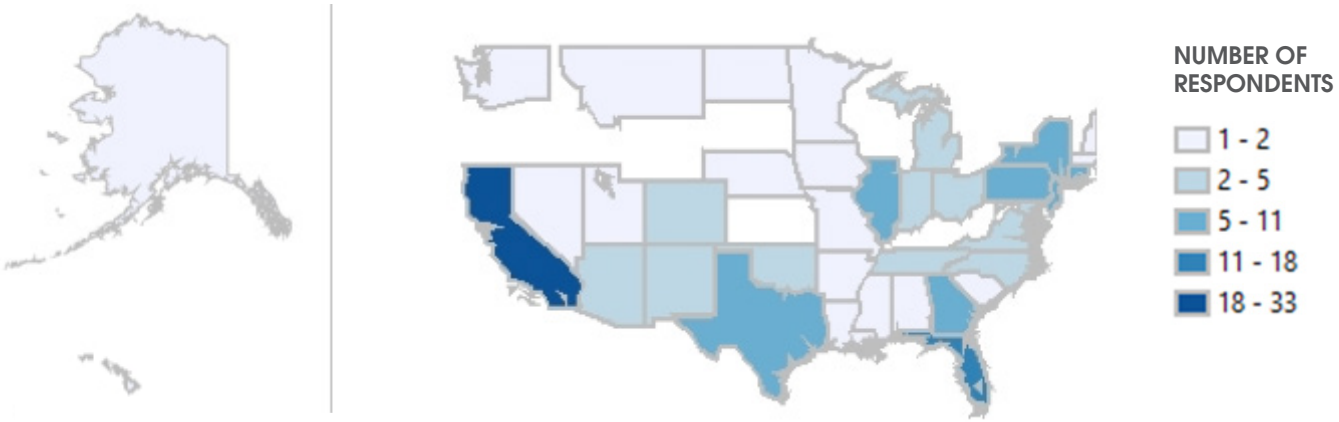
Demographics of Survey Respondents

418 respondents from 41 states participated in the survey. Participants who were not licensed to prescribe medication were excluded from the analysis. Analysis focused on 194 prescribing providers (physicians, physician assistants, and pharmacists).

A total of 59 prescribing providers took the complete survey available via SurveyMonkey™. Additional findings from this sub-sample are provided at the end of the report.

Professional Characteristics	
Profession	
Physician (MD,DO)	**93%**
Pharmacist (PharmD, RPh)	4%
Physician Assistant (PA)	3%
Organization	
Academic Health Center	**22%**
Hospital	20%
Clinic (Urgent Care)	15%
Private Practice	15%
Hospice	13%
Community Health Center	11%
HIV Clinic	11%
Government Agency	9%
Federally Qualified Health Center	8%
Community-based Organization	7%
Public Health Department	7%
Infectious Disease Clinic	6%
AIDS Service Organization	5%
College or University	5%
Military/Department of Veterans Affairs	5%
Prison-based Clinic	5%
Long-term Nursing Facility	4%
Sexually Transmitted Infection Clinic	3%
Family Planning Clinic	3%
Jail-based Clinic	3%
Pharmacy	3%
HMO/Managed Care Organization	2%
Substance Abuse Treatment Facility	2%
Rural Health Clinic	1%
School based Health Center	1%

Distribution of Survey Respondants in 41 States Across the U.S.



Professional Characteristics	
Specialty	
Internal Medicine	**29%**
Family Medicine	23%
Infectious Diseases	19%
HIV/AIDS	8%
Gastroenterology	5%
Public/Community Health	2%
Pediatrics	2%
Cardiology	2%
Population Served	
Racial or Ethnic Minorities	**69%**
People Who Use Drugs	62%
Lesbian, Gay, Bisexual, Transgender	60%
Medicare Beneficiaries	59%
Medicaid Beneficiaries	57%
Youth (under 24)	52%
People with Mental Health Issues	52%
People with Limited English Proficiency	48%
Documented Immigrants	46%
Homeless Populations	45%
Veterans	40%
Undocumented Immigrants	39%
Recently Incarcerated Populations	36%
Incarcerated Individuals	21%
Migrant workers	20%

Demographic Characteristics	
Region	
Northeast	19%
Midwest	16%
South	35%
West	30%
Gender	
Male	**63%**
Female	36%
Transgender	1%

Hepatitis C Screening and Treatment Practices

Provision of HCV care is a new practice for many primary care providers who participated in the survey. Four in ten respondents (41%) who practice HCV care have been practicing for five years or fewer, with almost one in ten of these (9%) practicing HCV care for less than one year. Three in ten respondents (30%) do not provide any type of HCV care.

Most respondents reported conducting some form of HCV screening of their patients in-house. 24% screen based on identified risk factors, 14% screen all individuals born between 1945 and 1965, and 29% follow the current guidelines set by the Centers for Disease Control and Prevention and screen based on both factors. Only 6% reported not screening, or referring patients out for screening.

One-third of participants (33%) treat HCV patients directly. One in five participants (20%) refer patients to an offsite specialist for treatment; one in ten (10%) provide collaborative management with specialist consultation; and one in ten (9%) refer to an onsite specialist. 15% reported providing no HCV services within their practice.

Barriers to Providing Care

Providers face a variety of challenges in attempting to support patients. The largest barriers to providing HCV care to patients were treatment utilization policies impacting coverage by payers, limited infrastructure for proving HCV screening and treatment, and limited clinical knowledge about screening and/or treatment.

Treatment Funding Challenges

Many providers reported encountering challenges with third-party payers while trying to provide treatment to patients. Over one-third (36%) of respondents reported being unable to treat a patient's infection due to payer restrictions. Respondents cited patients' denial of insurance coverage for treatment and patients being unable to pay out-of-pocket, as well as the cumbersome and inconsistent application process for providers as reasons for denial of treatment.

The most frequently reported payers who presented barriers to treatment were private insurance (36%), Medicaid (31%), and Medicare (19%).

Severity of liver damage (27%), current drug use (21%), current alcohol use (20%) were the most frequently cited payer reasons for denying coverage for HCV treatment.

Despite these challenges, 83% of respondents report that these restrictions have not made them less likely to screen patients for HCV.

Other Barriers to HCV Treatment and Adherence

Multiple respondents identified a lack of specialists for referral, as well as provider treatment education as missing resources in their area. Some went so far as to identify the complexity of care as a disincentive to providers:

"Inadequate providers due to poor compensation for complexity of care and barriers placed by insurers in acquiring FDA approved therapy for patient. Unreimbursed hours spent applying for approvals has most GI specialists refusing to treat the disorder."

Providers were asked to identify important factors in their experience that could increase client retention. A number of respondents believe that a medical home model is an effective approach, as well as close monitoring and/or frequent contact with patients. Multiple respondents also mentioned patient education about HCV infection and treatment and funding support as key factors in retention.

Educational Needs

Education and training interests were diverse overall. Respondents were most interested in receiving education regarding CDC's current HCV screening guidelines (41%), followed by determining the appropriateness of treatment for HCV/HIV co-infected patients (28%), monitoring HCV patients not on treatment (28%), determining when to initiate treatment for HCV infection (27%), describing the virologic markers for treatment success in HCV treatment (27%), and describing the USPSTF's current HCV screening guidelines (26%).

The remaining findings refer to questions only asked to SurveyMonkeyTM respondents, and thus only reflect the experiences of those 59 providers. Demographics of this sample are provided in the appendix.

Current Clinical Practices in HCV

Respondents were largely comfortable with HCV screening and clinical tasks. Respondents reported the least comfort with ordering and interpreting IL28-b genetic testing (18%), ordering and interpreting liver biopsies to determine the stage of hepatic fibrosis (15%), discussing the risks and benefits of ribavirin for women of child bearing age and those who are pregnant (12%), and monitoring hepatitis C patients not on treatment (12%).

Nearly all respondents (89%) also provide HIV care in their practice.

Respondents were asked to describe how they anticipated their need for HCV services would change in the coming years. 78% anticipate that their hepatitis C caseload will increase, and 82% anticipate scaling up hepatitis C care and treatment in their practice within the next three years.

Funding

Providers receive funding for HCV related services from a variety of sources. Over half receive funding from public funding sources—largely Medicaid and Medicare—and four in ten receive funding form private insurance payers. Only a small number of providers receive funding support from government programs, such as Centers for Disease Control and Prevention (CDC) counseling and testing funds and Substance Abuse and Mental Health Services Administration (SAMHSA)

Sources of Funding	
Medicaid	63%
Medicare	56%
Private Insurance	40%
Pharmaceutical Patient Assistance Program	38%
Other Public Insurance	27%
Ryan White Program Funding	25%
AIDS Drug Assistance Program (ADAP)	25%
Patient Self-pay	17%
Centers for Disease Control and Prevention (CDC) Counseling and Testing Funds	15%
Section 340B Drug Discount Program	13%
Substance Abuse and Mental Health Services Administration (SAMHSA) Grants	8%
Housing Opportunities for People with AIDS (HOPWA)	6%
Section 330 of the Public Health Service Act	4%
Health Care for the Homeless Grant	4%
Disproportionate Share Hospital (DSH) Adjustment Payments	4%
Indian Health Services	2%
Title X family planning grants	2%

Additionally, over half (54%) of respondents reported the number of hepatitis C patients utilizing reimbursement sources for services at their practice increased in the past year.

Patient Challenges

In addition to provider barriers, respondents were asked to identify challenges they witness within their patient population. Based on provider perspective, patients experience significant challenges with covering the cost of treatment. The top identified barriers were impaired access due to health insurance (79%), insurance restrictions and/or prior authorization requirements (74%), and associated costs (68%). Other significant barriers include social barriers, such as unemployment, unstable housing, lack of transportation (56%), poor knowledge or inaccurate perceptions of hepatitis C (56%), substance use-associated comorbid conditions (47%), and absence of symptoms (47%).

Policy Awareness

Overall, respondents reported a high level of awareness around most HCV policy issues. Approximately a quarter of providers were unaware of the following policies and documents: the Department of Health and Human Services Action Plan for the Prevention, Care and Treatment of Viral Hepatitis (29%), Institute of Medicine's National Strategy for Prevention and Control of Hepatitis B and C (29%), and Healthy People 2020 goals related to viral hepatitis (26%).

Implications

- More HCV-infected individuals are entering care. Providers will need **increased capacity**, including fiscal and training support, **to adequately address** the needs of this **growing patient population**.
- Strengthening **connections, collaborative management**, and **referral networks** between primary care providers and specialists could increase workforce capacity for HCV treatment and patient retention in care and leverage limited resources.
- **Payer restrictions** impede providers' ability to provide care to their clients and patients' ability to access care. Without changes to insurance policies supporting coverage of HCV treatment and/or access to additional resources, providers will likely continue to be unable to provide effective HCV care to their clients, even if they are willing and capable of doing so.
- The incorporation of **substance use behavioral interventions** into healthcare response to HCV may **increase accessibility** of insurance coverage for patients.

- Many HCV patients have complex **social and medical conditions** that **impede** their ability to **access** and establish care. Allied health professional are needed to support patients and address co-morbidities and other social determinants experienced by HCV patients.
- Despite availability of robust screening policies, **confusion** still persists **around** current **screening recommendations**. Providers should receive training on CDC screening guidelines, USPSTF recommendations, and other clinical guidelines.
- A large proportion of the HCV-infected population — in particular **injection drug users** — are **co-infected with HIV.** Most providers managing HCV patients also provide HIV care. Thus, providers should receive training on treatment for HCV/HIV co-infected patients.
- Providers also require training on **HCV-related policies**, specifically on official national action plans, strategies and goals.

Appendix: Demographic Characteristics of SurveyMonkey™ Respondents

Additional demographic information was obtained from SurveyMonkeyTM respondents (n=59). Full demographic information of the sub-sample is provided below.

Professional Characteristics	
Profession	
Physician (MD,DO)	**79%**
Physician Assistant (PA)	12%
Pharmacist (PharmD, RPh)	9%
Organization	
Community Health Center	**28%**
HIV Clinic	20%
Academic Health Center	19%
Federally Qualified Health Center	19%
Hospital	17%
Clinic	13%
Infectious Disease Clinic	13%
Private Practice	11%
Community-based Organization	9%
College or University	7%
Jail-based Clinic	7%
Government Agency	6%
Sexually Transmitted Infection Clinic	6%
Pharmacy	6%
Family Planning Clinic	4%
Military/Department of Veterans Affairs	2%
Long-term Nursing Facility	2%
HMO/Managed Care Organization	2%
Substance Abuse Treatment Facility	2%
Rural Health Clinic	2%
Specialty	
Infectious Diseases	**25%**
HIV/AIDS	25%
Internal Medicine	20%
Family Medicine	20%
Hepatology	4%
Public/Community Health	2%
Emergency Medicine	2%

Professional Characteristics	
Population Served	
Women	**94%**
Racial or Ethnic Minorities	91%
People who Use Drugs	91%
Lesbian, Gay, Bisexual, Transgender	91%
People with Mental Health Issues	81%
Youth (under 24)	80%
Medicare Beneficiaries	78%
Documented Immigrants	74%
People with Limited English Proficiency	72%
Homeless Populations	72%
Recently Incarcerated Populations	65%
Undocumented Immigrants	57%
Veterans	44%
Medicaid Beneficiaries	41%
Migrant workers	35%
Incarcerated Individuals	33%

Demographic Characteristics	
Region	
Northeast	21%
Midwest	13%
South	32%
West	34%
Gender	
Male	**56%**
Female	42%
Transgender	2%
Age	
20-29	5%
30-39	20%
40-49	24%
50-59	29%
60-69	11%
70 or older	4%
Hispanic/Latino	
Yes	15%
No	85%
Race	
White or Caucasian	84%
Black or African American	14%
Asian	2%

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