

Hepatitis C Positive: Stigma and Drug Use Challenges

Andrea Lombard RN, BSN, MPH, CIC¹, Ronni Marks²

¹ Connecticut Department of Public Health (DPH), ² The Hepatitis C Mentor and Support Group (HCMSG)



BACKGROUND

Stigma is experienced among hepatitis C (HCV) patients, especially with co-existing drug use behaviors. HCV is curable; yet, treatment uptake rates are low. Drug use, addictions, and the notion of “breaching societal rules” contributes to HCV stigma. Stigma can be a barrier to care and adverse health outcomes. Internal sources of stigma can be manifested as “SILENCE”, feelings of unworthiness, social isolation, not getting treated, and depression. External social and structural sources of stigma can be manifested as “labeling”, exclusion, discrimination, negative judgments, and lack of access to care or treatment. Healthy support systems, education, harm reduction, trust, and positive relationships with providers can help to ameliorate stigma and improve health outcomes.

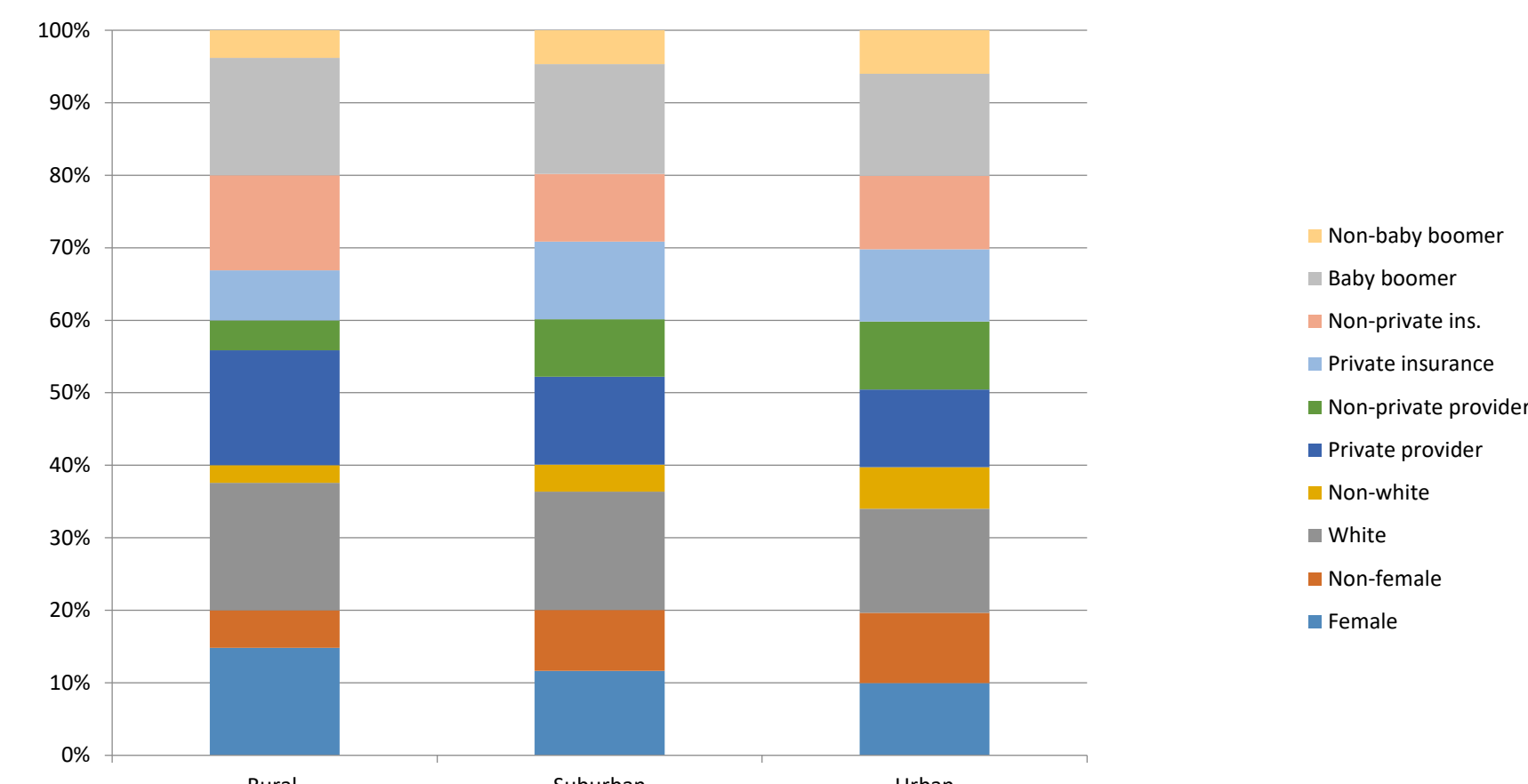
METHODS

Description of intervention:

A survey was developed using a multidisciplinary approach and distributed to persons with past or present HCV. Psycho-social factors related to stigma, drug use, education, support systems, care and treatment were explored. The 28 item instrument included quantitative and qualitative responses. The survey was HIPPA compliant and confidentially administered March to December 2015 via Survey Monkey. The distribution was facilitated by over 500 national/global networks, partners and providers yielding the recruitment of 281 unique respondents. The respondents lived in rural(21%), suburban(31%) and urban(49%) communities. Respondents ranged from 18-80 years old; however, 74% were between the ages of 51-71 (baby boomers). Other characteristics of the respondents were: Native American Indian(1%), Asian(2%), Other(3%), Black(8%), Hispanic(8%), and White(78%); Transgender/other(5%), Male(38%), Female(57%). People received their care at: private provider(61%), hospital clinic(20%), community health center(13%), or VA(4%); 4% did not have a provider. Respondents' care was supported by: Medicare(27%), Medicaid (13%), private/commercial insurance(48%), or uninsured -100% out of pocket(10%); 4% were unknown. The survey was completed in 10 minutes or less by 86% of the respondents. Data was analyzed using Microsoft Office Excel and SPSS, Inc. (PASW statistical data editor).

METHODS

Characteristics of the survey respondents:



There was a wide distribution and variations in the respondents' characteristics and demographics.

RESULTS

Question: I believe there is a stigma with being HCV positive and I feel unworthy - statistically significant. (X² (2,N=164)=12.64,p <.0001)

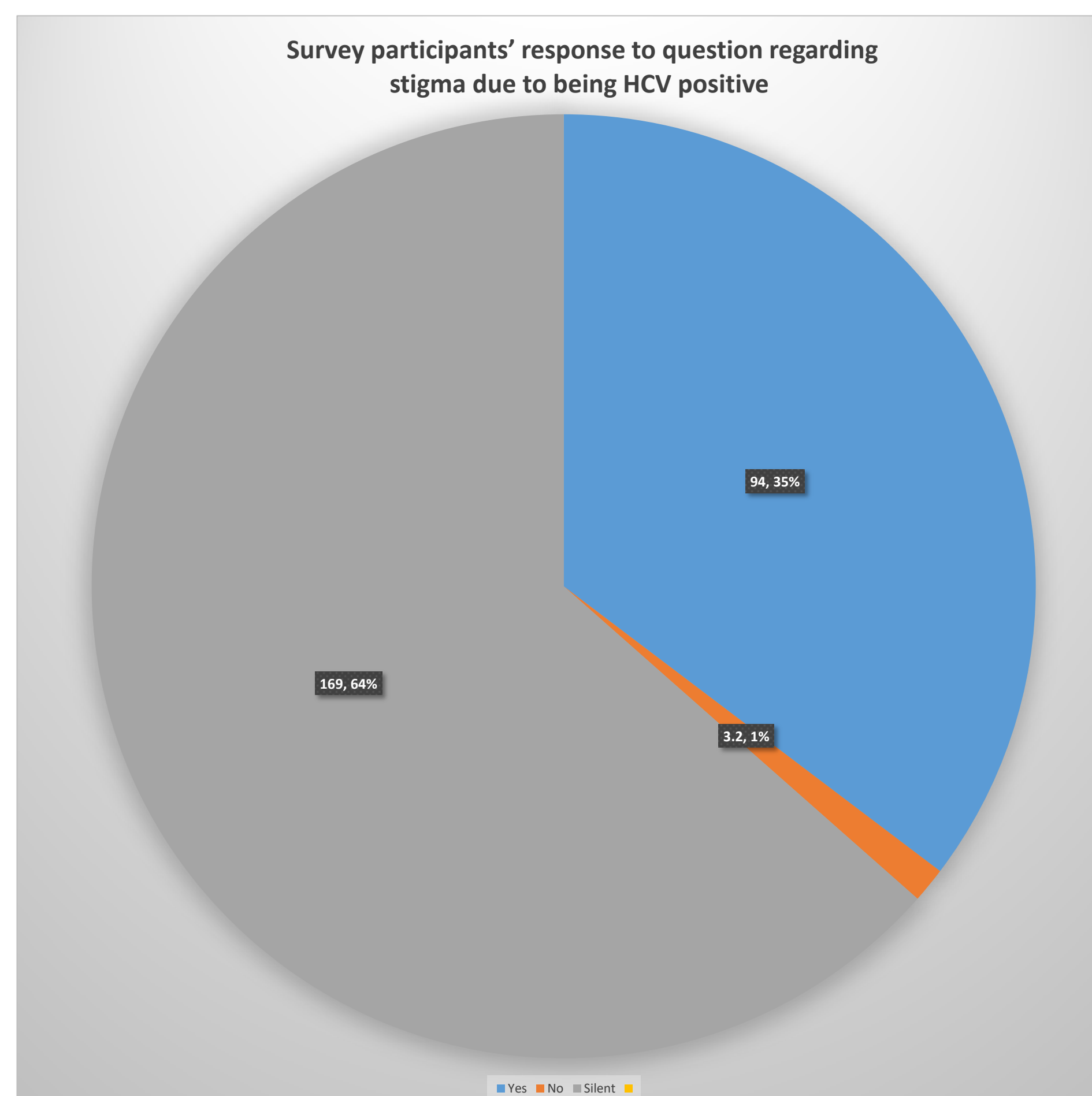
“...it (HCV) made me feel dirty and disgusting”
Anonymous

Question: I believe that there is a stigma with being HCV positive.

N=124 (76%) of those responded answered YES. Of those, statistical analysis revealed that there was no difference in stigma for the following variables: drug use; gender; race and ethnicity; age/ birth cohorts; insurance status; place of care; provider. **ALL experienced stigma.**

SILENCE:

The majority of respondents were **SILENT** about stigma and drug use. **SILENCE** is an indicator of internal stigma.



“The stigma and ignorance of people was horrible. I was afraid to say anything to anyone, and if I told anyone I was afraid they would say something”
- Anonymous

RESULTS

Question: Drug use (ever).

Drug use was prevalent across all variables, except for in one cohort - 21% of the respondents who live in rural communities. This cohort was Female (74%), White(88%), and Baby boomer (81% - born 1945-1965). It was statistically significant that this cohort was less likely to use drugs than were people who lived in urban or suburban areas [(X² (3, N = 198) = 10.098, p <.006)].

Question: Drug use (daily).

60% responded to the question, of those 97(35%) reported that drug and alcohol use was a significant part of their daily lives; 70 (72%) were Baby boomer - birth cohort 1945-1965.

Question: HCV treatment.

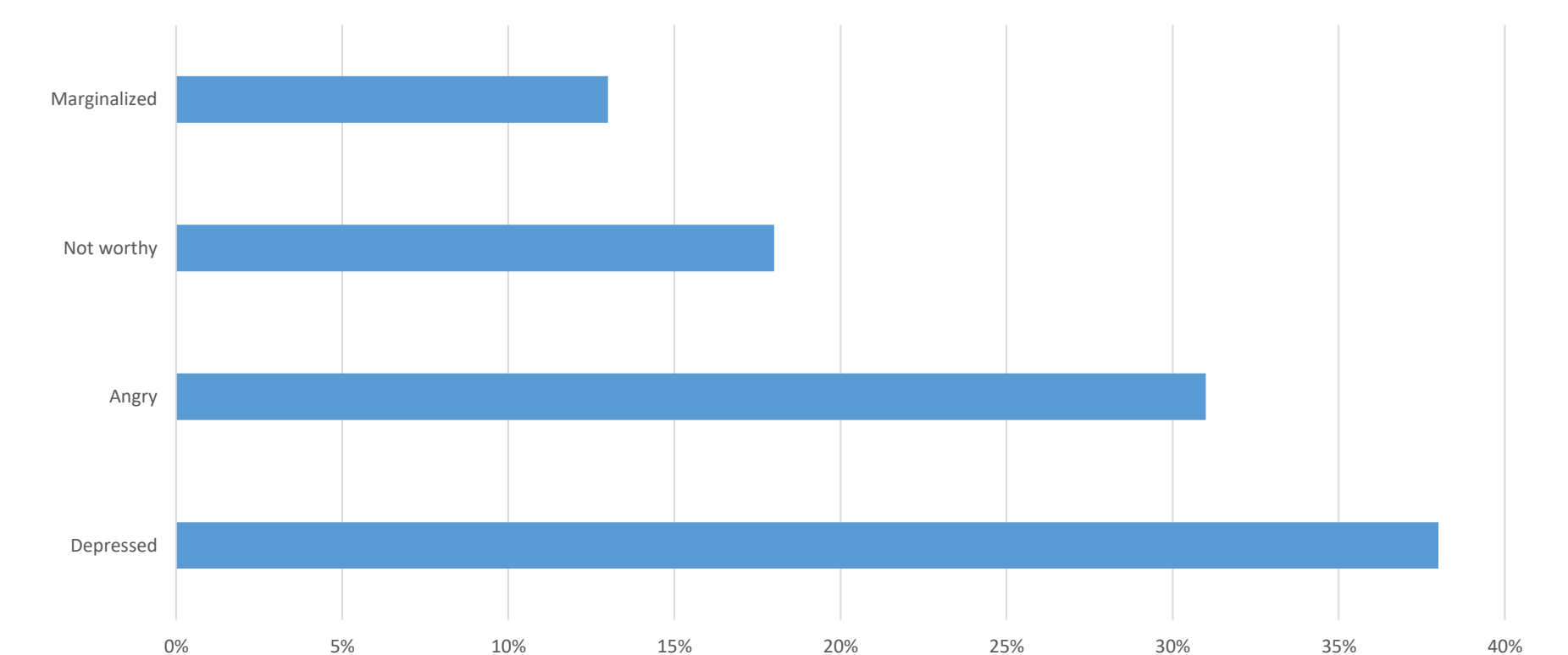
After HCV diagnosis, 226 (80%) indicated that they wanted to be treated. 166 (59%) received treatment “ever” and of those, 59% had to wait more than six months.

“Being cured of hepatitis C is like a second chance at life”
Anonymous

Questions: HCV treatment barriers.

Of the 166 who received treatment, the two most common HCV treatment barriers (indicators of structural social stigma) reported were: wait times for insurance approval (41%), and wait times for seeing a specialist (23%).

Question: How I felt about HCV treatment barrier.



CONCLUSIONS/ NEXT STEPS

Stigma is a common experience for HCV positive persons. Further study is needed to explore: HCV social, structural, and internal individual stigma; the syndemic impact with the opioid epidemic; and, educational support groups for patients and providers. Surveying a wider demographic will provide more insights that are needed to inform HCV models of care.

SUPPORT

Disclosure of Interest Statement: HCMSG received Gilead Sciences Inc. unrestricted funding to support initial survey. The primary author participated as a volunteer and did not receive any form of compensation.