



2014 NYC Hep B Coalition & NYC Hep C Task Force ANNUAL REPORT



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BACKGROUND

100,000 New York City (NYC) residents are estimated to have hepatitis B (Hep B) and at least 150,000 have hepatitis C (Hep C). Approximately a quarter of those infected will progress to end-stage liver disease, which can be fatal. Hep B predominantly affects the immigrant population, and Hep C affects those both immigrants and people with a history of drug use, all of whom face significant health care access barriers.

NYC is rich with resources, including world-renowned health professionals and institutions that focus on viral hepatitis research, prevention, management, and treatment. NYC has a generous public health care system and a multitude of hepatitis care and treatment centers. Despite the existence of these resources, a significant proportion of infected patients remain undiagnosed, experience barriers to optimal care, or are not in care at all.

Multiple strategies are needed to improve health outcomes for people living with Hep B and Hep C. Community coalitions can help to bring stakeholders together to collaborate to meet community needs, as well as to share resources and best practices.

The NYC Hep B Coalition and NYC Hep C Task Force together form a “Network” which brings stakeholders together to communicate, share resources, identify community needs, and collaborate to meet those needs. This report highlights the accomplishments and positive impact of this Network in 2014.

LEADERSHIP

A NYC Health Department staff person has served as the lead organizer of the Network since 2007. In the past, Network partners took a leadership role by managing projects or planning meetings and events as needed in an informal manner. In 2014, the Hep C Task Force and Hep B Coalition (Network) worked towards shared community leadership by forming a Community Chair infrastructure and an Advisory Board. The NYC Health Department's lead organizer recruited the leadership participants during 2014.

Advisory Board

Two separate Advisory Boards were established for the Hep C Task Force and for the Hep B Coalition. The Advisory Board members were selected because they had taken on an informal leadership role in the past, or because they represented key populations affected, regions of NYC, or professional disciplines.

Community Chairs

One citywide Hep B Coalition Community Chair and five Hep C Task Force Community Chairs (one for each borough) were recruited and assumed the Chair position. Chairs were selected because they had taken on an informal leadership role in the region in the past.

Network Administration

In 2012, a Community Organizing Internship was established to assist with the organization and administration of this Network. In 2014, two Master of Public Health students and a Master of Social Work Community Organizing student rotated through the NYC Health Department and served as Network administrators. The interns greatly improved ability to support Network communication and organization, and the internship opportunity supported the professional growth of new leaders.

Leadership Activity

With the input of the leadership participants, the Health Department organizer and interns developed an annual strategic plan, which was implemented and reviewed mid-year. An annual evaluation was conducted and a corollary report was written. The Advisory Board and Community Chairs gathered for one in-person planning meeting, and the NYC Health Department organizer sent quarterly email updates to the leadership group to request feedback on Network activities or plans. Community Chairs co-facilitated each community meeting in their region, and in some cases organized additional hepatitis events.

NYC HEP B COALITION

The NYC Hep B Coalition was founded in 2009 as a citywide network of community-based organizations, health care organizations, service providers, advocates, and others interested in hepatitis B and related issues.

The Coalition meets quarterly in central Manhattan. In addition, Coalition Committees hold separate meetings. Committees include: Team HBV NYC (a student initiative), the Coalition against Hepatitis in People of African Origin (CHIPO)-NYC Chapter, and the Hepatitis Patient Navigator Network.

Mission

To coordinate efforts to prevent, manage, and reduce hepatitis B among all residents of NYC. The coalition seeks to foster an inclusive collaboration among all stakeholders to advance hepatitis B awareness, screening, access to care, and vaccination, through education, outreach, advocacy, and support of research.

MEETINGS

In 2014, the NYC Hep B Coalition convened **4 general meetings** with an average attendance of **28 individuals**. A total of **65 unique participants** attended quarterly meetings, including **33 new participants** in 2014.

Meeting Highlights

Below are links to the 2014 Hep B Coalition meeting notes, including presentations, resources provided, needs identified, and attendance records.

- [2-5-14 Meeting Notes](#)
- [4-30-14 Meeting Notes](#)
- [8-27-14 Meeting Notes](#)
- [11-12-14 Meeting Notes](#)

Organizations Represented at Meetings

The following organizations sent a representative to the Hep B Coalition meetings in 2014:

Academic

Columbia University
Cornell University
CUNY Hunter College
NYU Center for the Study of Asian American Health

Association/Foundation

American Cancer Society
American Liver Foundation
Chinese American Medical Society
Hispanic Federation

Community-Based Organizations

African Services Committee
Korean Community Services
Project Heal
Reality House
VOCAL-NY

Government

Centers for Medicaid and Medicare Services
NYC Health Department
NYS Department of Health

Health Business (Pharmaceutical or Communications)

Bristol-Myers Squibb
Evers Pharmacy
Gilead Sciences
GlaxoSmithKline

Health Centers

Bellevue Hospital Hepatitis Clinic
Brooklyn Chinese Family Medical Center
Charles B. Wang Community Health Center
Concorde Medical Group
Maimonides Medical Center
Memorial Sloan-Kettering Cancer Center
New York-Presbyterian Hospital
William F. Ryan Community Health Network



Team HBV NYC, Charles B. Wang Community Health Center, and partners at the 2014 Lunar New Year Parade in New York City

ACHIEVEMENTS



Awareness

The Hep B Coalition's lead organization, Charles B. Wang Community Health Center and the student-focused committee, Team HBV NYC, marched in the **Chinese Lunar New Year Parade** to raise awareness about Hep B. Team HBV NYC also organized the first ever **NYC Hep B Week**, which included: a press conference on the steps of City Hall and an NYC Council Proclamation, a sit-in at Washington Square Park, a film screening, and a medical provider lecture series.



Support of Universal Hep B Birth Dose Coverage

The Hep B Coalition worked in partnership with the NYC Health Department to increase the number of NYC birthing centers on the National Immunization Action Coalition's [Hep B Birth Dose Honor Roll](#). In the first year of establishing this Hep B Birth Dose initiative, 13 of 38 NYC Birthing Centers were added to the National Hep B Birth Dose Honor Roll.

Screening and linkage to care

The Hep B Coalition supported screening and linkage-to-care activities, with a focus on high-risk Asian and African communities. Community screening events, webinars, and at least 10 community health worker-related events in the NYC area were promoted to partners via the Network website and social media.



Advocacy

Hep B Coalition partners organized a hepatitis B briefing with the NYC City Council in April 2014, and testified at a viral hepatitis City Council hearing in May 2014. As a result of this advocacy, in FY 2015 City Council provided funding to establish the Check Hep B Patient Navigation Program at four community health organizations in NYC. More than 250 people enrolled in the first year of service.

NYC HEP C TASK FORCE

The NYC Hep C Task Force was founded in the South Bronx in 2004, and has since grown into a citywide network of service providers and advocates.

The Task Force currently meets in each of the five boroughs of NYC once or twice per year.

Mission

To build community capacity for the effective prevention, screening, management, and treatment of Hepatitis C, by promoting collaboration among key stakeholders and effecting change through participation in policy advancement, initiating innovative projects, and facilitation of enhanced knowledge sharing.

MEETINGS

Six meetings were held in 2014: two in the Bronx and one in each of the other four boroughs. A total of **170 unique individuals, including 136 new participants**, attended Task Force meetings.

Meeting Highlights

Below are links to the 2014 Hep C Task Force meeting notes, including presentations, resources provided, needs identified, and attendance records.

- [1-30-14 Bronx Meeting Notes](#)
- [3-5-14 Brooklyn Meeting Notes](#)
- [6-4-14 Harlem Meeting Notes](#)
- [8-6-14 Bronx Meeting Notes](#)
- [10-9-14 Queens Meeting Notes](#)
- [10-28-14 Staten Island Meeting Notes](#)

Organizations Represented at Meetings

The following organizations sent a representative to the Hep C Task Force meetings in 2014:

Academic

CUNY School of Public Health
Hunter School of Social Work
NDRI
Rockefeller University
Touro College of Pharmacy

Association/Foundation

American Liver Foundation
Bronx Reentry Task Force
Peer Network of NY
Russian Hep C Support Group

Community-Based Organization

Argus Community, Inc.
Bridging Access to Care
BronxWorks
Care for the Homeless
Center for Community Alternatives
COPE
Hopes Alive
NBLCA
Palladia
Project Hospitality
Reality House
Safe Space NYC
Tackling Youth Substance Abuse
The Sharing Community

Government

Centers for Medicaid and Medicare Services
NYC Health Department
NYC Housing Authority
NYS Department of Health

Health Business (Pharmaceutical or Communications)

AbbVie
Bristol-Myers Squibb
CVS Caremark
Echo Pharmacy
Evers Pharmacy
Gilead Sciences
GlaxoSmithKline
Johnson & Johnson
LeMed Pharmacy
Merck & Co.
Onyx Pharmaceuticals
OraSure Technologies
Vertex Pharmaceuticals

Harm Reduction/Substance Abuse

After Hours Project
BOOM! Health
Community Health Action of Staten Island
Harm Reduction Coalition
VOCAL-NY
Washington Heights Corner Project

Health Centers

AIDS Healthcare Foundation
Damian Family Health Center
Harlem United
HELP/PSI
Housing Works
Kingsbridge Heights Home Care
Port Morris Wellness Center
Rockaways Free Clinic

Hospitals

Montefiore Medical Center
Bronx-Lebanon Hospital
Lincoln Hospital
Mount Sinai Hospital
North Shore-LIJ Health System
NYU Langone Medical Center
Queens Hospital
Staten Island University Hospital

ACHIEVEMENTS



Advocacy

Hep C Task Force partners testified at a viral hepatitis City Council hearing in May 2014. As a result of this advocacy, City Council provided funding to support the continuation of the NYC Health Department's Check Hep C Patient Navigation Program, and to establish the Injection Drug Users Health Alliance (IDUHA) Hep C Peer Navigation Program in FY 2015.



[Check Hep C Patient Navigation Program](#) supported free Hep C patient navigation services at four community health organizations. Navigators provided linkage to care and care coordination services for individuals chronically infected with Hep C. More than 600 people enrolled.



[IDUHA Hep C Peer Navigation Program](#) supported peer navigators at 14 NYC syringe exchange programs to provide Hep C prevention services, health coaching, linkage to testing, and linkage to medical care. More than 1600 people at risk for or currently living with Hep C enrolled.



Raising Awareness to Prevent a New Epidemic of Hep C among Youth

In 2014, an increase in Hep C infections among youth became a growing national concern. To alert and prepare NYC partners, the NYC Health Department presented enhanced surveillance data, and the National Drug Research Institute (NDRI) presented research findings and intervention ideas at Task Force meetings. The Task Force established a [resource page](#) on the Network website, including prevention interventions, resources, and referral information, and began to recruit youth-focused organizations (such as Tackling Youth Substance Abuse and Safe Horizon Street Works) to participate in the Hep C Task Force.



Preparing Partners for the Future of Hep C Treatment

2013 and 2014 were groundbreaking years for Hep C treatment. Highly effective oral medications with few side effects became available to treat and cure Hep C. To inform partners of new and upcoming treatments, the Task Force organized the second annual [Hep C Clinical Trials and Pharmaceutical Pipeline Training](#) with Tracy Swan of Treatment Action Group. Forty participants attended, and over 200 reviewed the online training materials and report.

JOINT HEP B COALITION AND HEP C TASK FORCE ACHIEVEMENTS

Several initiatives in 2014 involved both the Hep B Coalition and the Hep C Task Force.



National Hepatitis Testing Day

Over 100 Network partners gathered on the steps of City Hall on May 19 to commemorate National Hepatitis Testing Day. Speakers included representatives from Health and Human Services, NYC Health Department, Latino Commission on AIDS, Chinese American Medical Society, and patient advocates.



World Hepatitis Day

On July 28, Network partners gathered together in City Hall Park to commemorate World Hepatitis Day in concert with the World Hepatitis Alliance global awareness campaign.



Coalition Against Hepatitis in People of African Origin (CHIPO) – NYC Chapter

The Network held the third annual forum on [Viral Hepatitis in the African Community in NYC](#) at African Services Committee. Forty people were in attendance, and presentation topics included: raising awareness about Hep B by collaborating with African Radio stations, data on the risk for liver cancer in the African-born population, Hep B and C screening and outreach efforts in the past year, and the national CHIPO initiative.



Fifth Annual Hep Health Care Access Training

In 2014, the fifth annual [Hep Health Care Access Training](#) was held in partnership with the Centers for Medicaid and Medicare Services, and was attended by over 70 participants. Topics covered included national health care access advocacy, Hep B and C patient navigation best practices, Hep C medication coverage, and [Project INSPIRE](#), which aims to develop a payment system to allow for Medicaid and Medicare reimbursement of Hep C care coordination services.



Alcohol Screening and Brief Intervention Training

In response to Network partner requests, the NYC Health Department developed and piloted [Hep-SBIRT](#), a tailored version of the Substance Abuse Brief Intervention and Referral to Treatment (SBIRT) intervention, which provides a standard protocol for alcohol screening and counseling of hepatitis patients. In 2014, the training was piloted four times with over 100 Network participants.

Hep Free NYC Patient Navigator Network

The [Hepatitis Patient Navigator Network](#), a committee of the Hep B Coalition and Hep C Task Force, was established in 2014 in response to ongoing requests for professional support for the role of patient navigator. This committee met to conduct tours of leading NYC hepatitis medical centers to facilitate referral to care. In 2014, there were three tours, attended by 10-25 navigators each, at the Bellevue Hospital Hepatitis Clinic, Mount Sinai Hep C Primary Care Program, and the Montefiore Medical Center HIV/Hep C Clinic.

2014 NETWORK EVALUATION FINDINGS

In 2014, the NYC Health Department, with input from the Leadership group, developed and conducted the second annual Network evaluation. An online survey was disseminated to Network participants via email to assess participant characteristics, recommendations, and coalition impact. In addition, meeting and communication records were reviewed and analyzed.

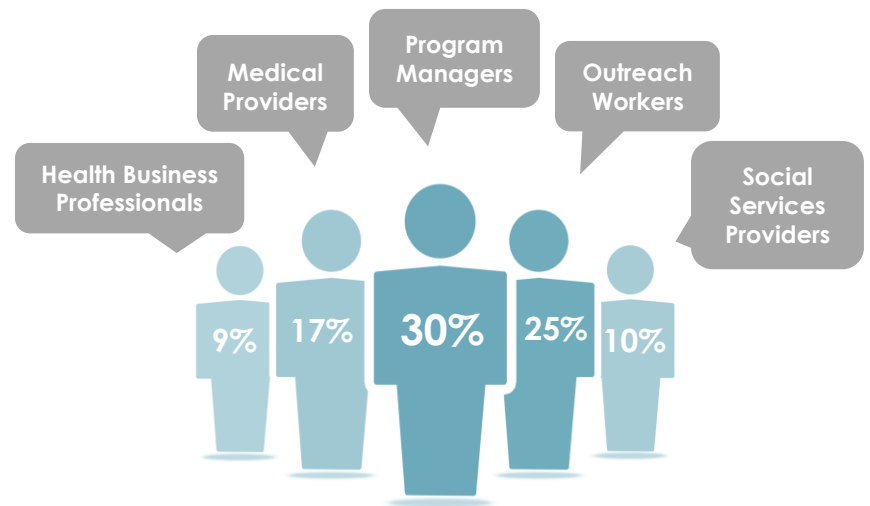
PARTICIPANT CHARACTERISTICS

- 142 survey respondents
- 31 participated in the NYC Hep B Coalition only
- 68 participated in the NYC Hep C Task Force only
- 33 participated in both the NYC Hep B Coalition and NYC Hep C Task Force
- 19 participated in the Hep Free NYC Patient Navigator Network
- 9 were members of Team HBV NYC (Student Initiative)

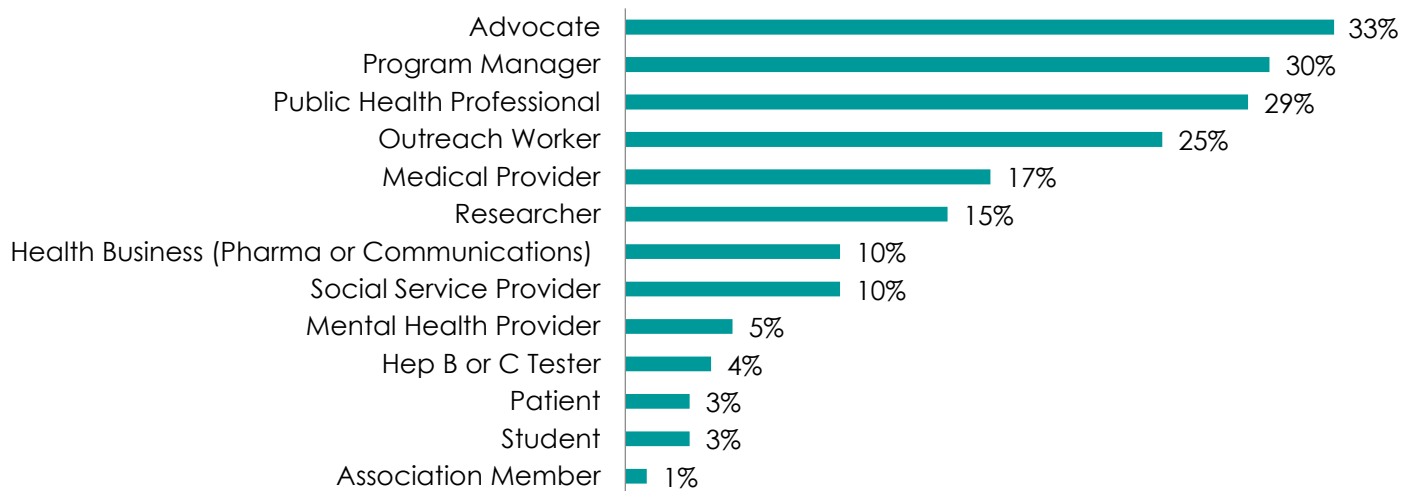
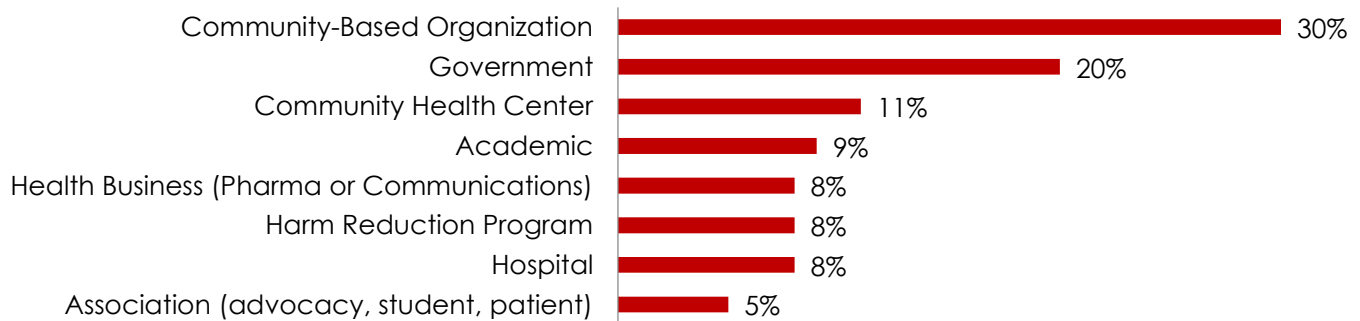
Participant Role

Participants serve many roles in their organizations. Survey respondents reported working primarily as program managers (n=38), outreach workers (i.e., peer workers, patient navigators, and support group leaders) (n=32), and medical providers (n=22).

Many respondents identified their role in the hepatitis field or current organization as an advocate (n=42), a public health professional (n=37), or a researcher (n=19) (see Figure 3).



Almost 33% (n=36) of respondents work in community-based organizations, while close to 20% (n=23) work in government, and 10% (n=13) work at community health centers (see Figure 4).

Figure 3. Participant Role (more than one role could be selected)**Figure 4. Organization Characteristics**

MAJOR FINDINGS

Mixed Participation Methods



80% participate in person at:

1. Meetings
2. Awareness events
3. Trainings



95% participate online by:

1. Reading emails
2. Using the website
3. Following on social media

Participant Activity

Participants were active in the Network in many ways. Sixty percent of respondents read and then forward or share Network information, such as emails and job opportunities, and over half report that they use Network resources to make hepatitis program improvements at their organization. Nearly 40% reported that they respond to action alerts on policy issues and nearly 33% take part in a Network committee or project. Twenty percent of respondents were in leadership roles, including Advisory Board members and initiative leaders.

Online Engagement

The shared website for the Hep B Coalition and the Hep C Task Force, now located at www.hepfree.nyc, is maintained by several Network partners, both at the Health Department and at community-based organizations. The website underwent a major update in 2014 to improve user experience, navigation, and enable mobile readiness. The website serves as the main

communications hub of the Network. Contributors published over 200 posts and 155 events over the course of the year, and there were almost 13,000 unique visitors to the Network website.

In 2014, 62 Network email campaigns were sent to over 2,000 subscribers, including 550 new subscribers. There were **41,427 email opens** and **7,845 clicks on links in emails** for an average open rate (16.3%) and click rate (3.2%) that were comparable to industry averages. A complete breakdown of online engagement, including social media, is shown in Figure 5.

Figure 5. Breakdown of Online Engagement in 2014

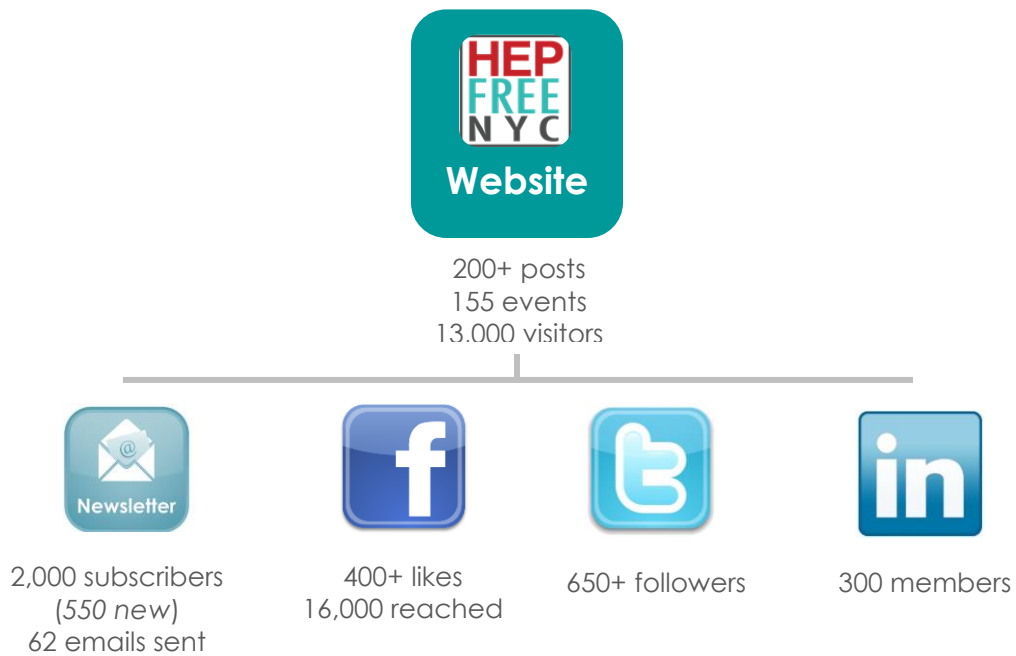
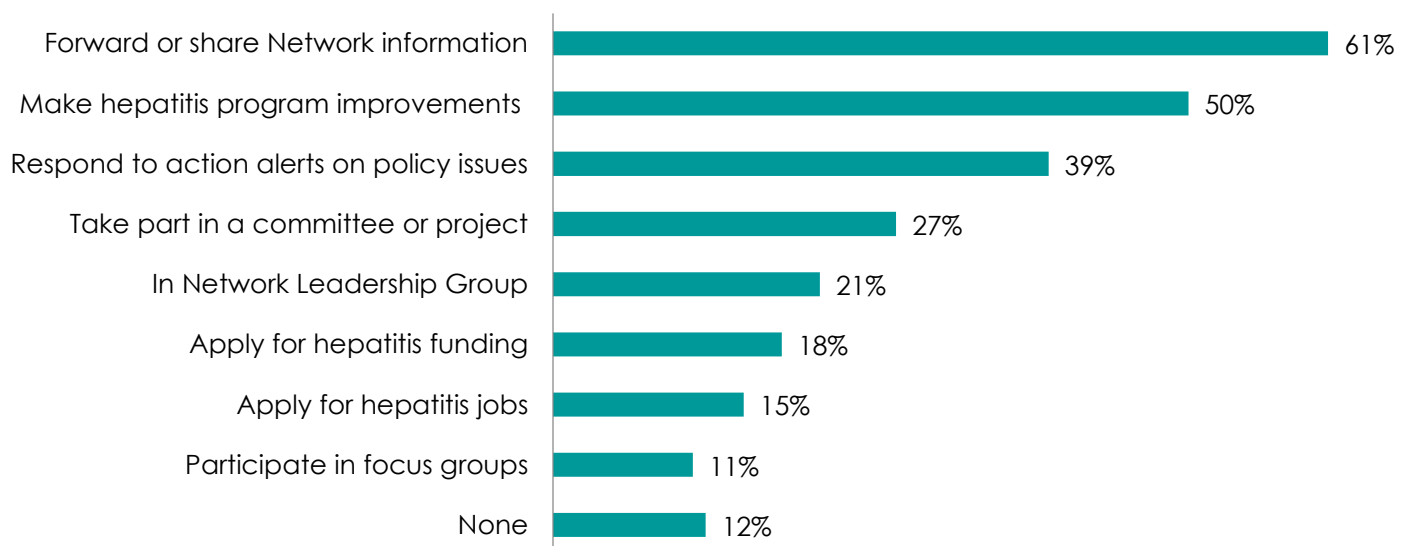


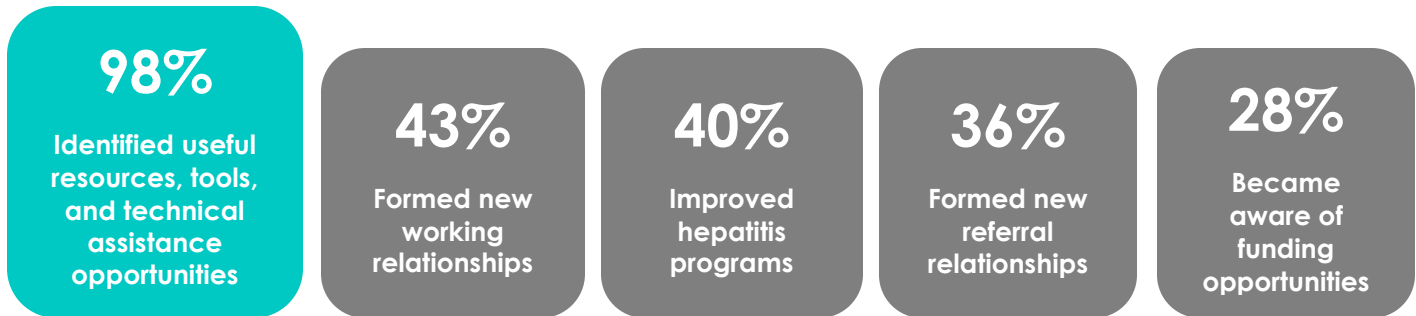
Figure 6. Type of Participant Engagement with the Network



Benefits to Individuals

Participants reported that through Network participation they **gained knowledge** about hepatitis (80%, n=103) and **skills** to better assist hepatitis clients/patients (63%, n=81). Over half (57%, n=73) of respondents also found **inspiration** from their participation with the coalition and nearly one third (32%, n=41) reported that the Network provided them with **professional development opportunities**.

Benefits to Organizations



Both individual participants and the organizations they work with benefit from being involved with the Network. Half of respondents collaborated on a project with a person or organization they connected with through the Network, including organizing awareness events, making linkages to care with specialty pharmacies and providers, and setting up referral networks.

Members agree that the Network helps the community. The vast majority of survey respondents (93%) agree that the Network helps identify and respond to community hepatitis needs.

Unmet Needs: Underserved Areas and Access to Hep C Treatment

Participants of the Hep C Task Force reported key areas of unmet needs, including the need for outreach in underserved areas, such as Staten Island, and the need for greater provider awareness, patient education, and advocacy for insurance coverage of the new Hep C treatments.

FUTURE PLANNING

Respondents prioritized the following areas of focus for the Network in 2015:

1. Increase public awareness about hepatitis
2. Advocate for funding
3. Increase medical provider awareness
4. Increase hepatitis knowledge and skills of Network partners
5. Advance health policy

SUMMARY

2014 was a great year for the NYC Hep B Coalition & NYC Hep C Task Force! A total of **13** general meetings and citywide trainings were held and had more than **450** total participants. We sent **62** emails resulting in **41,427** opens and **7,845** clicks, we had over **1,400** followers on social media, and we had almost **13,000** unique visitors to our coalition website. The [Team HBV NYC](#) (Student Initiative), [Coalition Against Hepatitis in People of African Origin \(CHIPO\) NYC](#), and the [Hep Free NYC Patient Navigator Network](#) raised awareness and supported referrals to care. Thirteen NYC Birthing Centers achieved [National Hep B Birth Dose Honor Roll](#) status. We came together to raise awareness at the Chinese Lunar New Year Parade, National Hepatitis Testing Day, the first NYC Hep B Week, African American Hep C Action Day, and World Hepatitis Day!

HEP FREE NYC

The NYC Hep B Coalition and NYC Hep C Task Force share many goals, partners, and resources, and both seek to raise awareness and build community capacity to prevent, manage, and treat Hep B and Hep C in NYC. At the end of 2014, NYC Hep B Coalition and NYC Hep C Task Force united under the shared vision of a new overarching Network title: **Hep Free NYC**.

