Consensus Statement on Hepatitis C Elimination in NYS

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Background

• In the spring of 2016, VOCAL-NY and other community organizations active in the HCV response partnered with the NYS DOH and NYC DOHMH to consider and build consensus on the opportunity for statewide HCV elimination.

• Between September and mid-December, a broad committee of 94 stakeholders came together to develop recommendations to inform a statewide plan to eliminate HCV infection.

• Work groups were established in five areas of focus: prevention; testing and linkage; care and treatment access; data, surveillance and metrics; and social determinants of health.
Five Community Pillars of HCV Elimination

1. Enhance HCV prevention, testing and linkage to care services for people who inject drugs, people who are incarcerated, men who have sex with men, and other populations disproportionately impacted by HCV infection.

2. Expand HCV screening and testing to identify people living with HCV who are unaware of their status and link them to care.

3. Provide access to clinically appropriate medical care and affordable HCV treatment without restrictions, and ensure the availability of necessary supportive services for all New Yorkers living with HCV infection.

4. Enhance NYS HCV surveillance, set and track HCV elimination targets and make this information available to the public.

5. Commit NYS government and elected officials, public health professionals, HCV experts, and industry partners to leadership and ownership of the NYS Plan to Eliminate HCV alongside community members living with and affected by HCV.
Call to Action

New York State (NYS) faces a growing hepatitis C epidemic with a rising death toll. Given the availability of new highly effective, well-tolerated curative treatments, we can no longer settle for a low cure rate that perpetuates the high fiscal and human costs of inaction. The committee that organized the NYS Hepatitis C Elimination Summit, along with the other providers, community-based organizations and individuals living with and affected by hepatitis C that sign this consensus statement, call on Governor Andrew Cuomo, the NYS Legislature, and industry partners to make a joint commitment to hepatitis C elimination, and for appointment of a formal NYS Hepatitis C Elimination Task Force.
Defining Targets for Elimination of Hepatitis C (HCV) in New York State

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New York City Department of Health and Mental Hygiene

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What is a target?

### Goal
- Time-bounded realization of a vision/end-state
- Collectively accountable
- Ex: Eliminating HCV in New York State by 2030

### Target
- Specific, quantitative indicators by which to measure progress towards realizing the goal
- Specific organizations/strategies are accountable as part of a larger whole
- Ex: 50% reduction in new cases by 2020; 15,000 treated per year by 2021

### Metric
- Measures that monitor the activities performed and resources used to meet the target
- Used after target is set
- Ex: # of HCV Medicaid-approved practitioners / prescribers
Why have a target?

• Identifies the overall financial investment needed to support all elimination activities
• Assists in the development of metrics that gauge annual progress leading up to the elimination year
• Facilitates economic evaluations that quantify effects of new therapies on broader population health

Setting a target = Quantifying the outcome we seek by a set date
How to set a target for HCV elimination?

- **Cherokee Nation**: 85% cured by 2020
- **Country of Georgia**: 95% treated & cured by 2020
- **World Health Organization**: 70% reduction in new cases with 60% reduction in HCV-associated deaths by 2030
- **State of Rhode Island**: 90% reduction in chronic cases by 2030
New York State (NYS) Elimination target

- 90% reduction in chronic cases by 2030
- Number to treat annually in NYS starting in 2020
Partners

• New York City (NYC) Department of Health and Mental Hygiene
• New York State (NYS) Department of Health AIDS Institute
• Center for Disease Analysis (CDA)
Estimating HCV burden

• NYS (w/ NYC) 2008 Prevalence 1.95% with 286,262 cases

• NYC 2010 Prevalence 2.37% with 146,500 cases

Will update HCV burden through 2015
Identify all individuals with hepatitis C in NYS from 2000-2015

Modify case list for deaths & out-migration from NYS

Adjust for individuals no longer infected & under-diagnosis to get proportion with HCV
Clinical Consequences of HCV Infection

- Normal Liver
- Chronic Hepatitis
- Cirrhosis
- HCC ESLD

- HCV Infection: 75-85%
- Cirrhosis: 20-30%
- HCC: 2-7% per year

Time:
- 20-25 years
- 25-30 years
Rhode Island Elimination Scenario

DIFFERENCE IN HCV BURDEN
Take-home message

1. Update HCV prevalence for NYS

2. Confirm elimination target: by 2030, achieve at least 90% reduction in number of chronic cases from 2015

3. Calculate number to treat annually (starting in 2020) in NYS that meets the 90% target
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• Homie Razavi, Sarah Robbins
NYS Hepatitis C Elimination

Prevention Work Group

John Barry
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Background

Hepatitis C kills more Americans annually than HIV.
Recent studies indicate that this disease that was most prevalent among baby boomers has grown exponentially among twenty somethings in the last decade, primarily due to injection drug use.
We are fortunate to live at a moment in history when effective treatments are available. Available but expensive.
Much like HIV, we know that both treatment costs and human suffering can be avoided if the initial infection never happens.
The good news in New York is that we know that we already have the political will and the public health infrastructure to prevent Hepatitis C infections, because we have been successful in preventing HIV infections.
Prevention Recommendations:

• Develop and implement a public health education campaign to raise awareness, inform, and educate the public, health care providers and social service providers.

• Expand Syringe Exchange Programming.

• Increase availability of Medication Assisted Treatment for those addicted to heroin/opiates.

• Prevent youth who are using drugs from transitioning to injecting.

• Increase prevention, testing and treatment in correctional facilities.

• Provide targeted prevention to men who have sex with men and the transgender community.
Prevention Work Group Members:

- Co-chair: Holly Hagan, NYU College of Nursing
- Co-chair: John Barry, Southern Tier AIDS Program
- Diana Aguglia, Alliance for Positive Health
- Gail Brown, COPE
- Gale Burstein, Erie County Department of Health
- Allan Clear, NYSDOH AIDS Institute
- Don DesJarlais, Beth Israel
- Emma Fabian, Evergreen Health Services
- Tino Fuentes, SACHR
- Pedro Mateu-Gelabert, NDRI
Prevention Work Group Members:

- Shantay Owens, LESHRC
- Sharon Stancliff, Harm Reduction Coalition
- Marlene Taylor-Ponterotto, Montefiore Center
- Tina Wolf, Community Action for Social Justice
- Angie Woody, Independent Consultant
- Monique Wright, DOHMH Bureau of Alcohol & Drug Use Prevention, Control and Treatment
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Testing & Linkage to Care Work Group

Recommendations to Promote Opportunities for Care and Cure

Joelle Toal, RN, MUP, Director of Testing Services, Evergreen Health, Buffalo
Background

To maximize the effectiveness of new HCV treatments that can cure up to 90% of chronic infections, individuals must be engaged and retained in care. It is estimated that 45-85% of adults with chronic HCV are unaware of their infection. Additionally, many who are diagnosed do not receive recommended medical evaluation and care once their HCV infection has been confirmed.

The public and personal health burdens of undiagnosed and untreated disease are significant and highlight the need for public health interventions that expedite movement along the HCV care continuum. Implementing policies and best practices to improve the frequency, availability, and acceptability of viral hepatitis testing, and linking patients to care and treatment are critical components of any HCV elimination plan.
Testing & Linkage Recommendations:

• Create processes and systems that facilitate and/or ensure diagnostic testing
• Expand Patient and Peer Navigation Programs
• Expand training and other educational opportunities for medical providers, testing and linkage to care staff, and the Public
• Design screening, linkage to care, and treatment delivery models and processes that better engage complex patient populations (active drug users, including youth and women of childbearing age, homeless, mentally ill, etc.) in settings serving groups at high-risk for hepatitis C infection
• Develop better, more flexible HCV tests
• Increase provider capacity for HCV care and treatment
• Remove financial barriers to testing, care, and treatment
• Create tools to improve surveillance and outbreak detection so that testing can be offered to those at risk and follow up provided to those diagnosed with HCV
Testing & Linkage Work Group Members:

- Co-chair: Beth Weir, Assistant Director, Bureau of Hepatitis Health Care, NYS DOH AIDS Institute
- Co-chair: Jocelyn Camacho, Outreach Coordinator, HEALS Program, Division of General Internal Medicine, Mt. Sinai
- Marie Bresnahan, NYC DOHMH
- Nirah Johnson, NYC DOHMH
- Monica Parker, NYS DOH, Wadsworth Laboratory
- Vinh Pham, NYU/Bellevue
- Emma Roberts, Harm Reduction Coalition
- Marilyn Scales, New York Harm Reduction Educators
- James Tomarken, Suffolk County Department of Health Services
- Joelle Toal, Evergreen Health, Buffalo
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Care & Treatment Access
Work Group

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Background

Despite the existence of curative life-saving medications for Hepatitis C, significant barriers to access care exist for New Yorkers including access to medical providers and support services that ensure retention in care and successful treatment outcomes. These barriers particularly affect the most marginalized communities: people living with HIV, transgender persons, minors, people with mental health and substance abuse disorders, and incarcerated persons.

Even those who have access to providers are often unable to obtain the medications due to insurance payers’ restrictions that are not based on clinical guidelines or evidence based research. Payers restrict medication access because of the high costs of these life-saving drugs and they are unable to effectively negotiate prices. Concerns about reinfection affect payer restrictions as well, but there is often not enough support for patients after treatment to address this issue.
Care & Treatment Access Recommendations:

- Increase resources and support for providers regarding Hepatitis C management and treatment, particularly for providers in settings with high prevalence and/or limited Hepatitis C provider access. Maximize opportunities for supportive services for patients to achieve retention in care and successful treatment completion.

- There should be increased resources and attention for high risk populations: HIV+ patients, transgender persons, patients with substance abuse disorders, and minors.

- All payer formulary restrictions for Hepatitis C medication authorization that is not based on AASLD guidelines should be eliminated. Payers should always approve medications per evidence based guidelines.

- Payers should expect a clear and consistent policy and full payment for Hepatitis C medications. There should be increased transparency about negotiated drug costs for payers.

- Special attention should be given to the intersection between incarceration and Hepatitis C.

- Resources should be given to post-treatment health issues with Hepatitis C.
Care & Treatment Access Work Group Members:

• Co-chair: Shuchin Shukla, Montefiore Medical Center
• Co-chair: Corinne Miga, Erie County Medical Center
• Reed Vreeland, Housing Works
• Ronni Marks, Hepatitis C Mentor & Support Group
• Jeff Weiss, Mt. Sinai Medical Center
• Michael Selick, Harm Reduction Coalition
• Alain Litwin, Montefiore Medical Center
• Ponni Perumalswami, Mt. Sinai Medical Center
• Terry Leach, Amida Care
• Freddy Molano, CHN/CHCANYS
• Luis Santiago, Act Up New York
• Andy Talal, University of Buffalo
• Trang Vu, Mt. Sinai Medical Center
• Acxel Barboza, New York Harm Reduction Educators
• Abraham Bisrat, NYC DOHMH
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Surveillance, Data & Metrics Work Group

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City University of New York
Any large-scale initiative on HCV elimination requires an evaluation plan and associated metrics to track progress towards goals.

Data needed to develop a core set of metrics for a large scale HCV initiative exist in many forms and locations, and include:

- Population-based surveillance systems
  - New HCV diagnoses
    - Not the same as HCV incidence
  - Laboratory reporting of antibody and PCR test results
    - Not the same as HCV prevalence
  - Potential to estimate and monitor treatment, cure, reinfection

- Vital statistics
  - Deaths due to HCV-related causes

- Missing
  - Population-based estimates of HCV incidence
  - Population-based estimates of HCV prevalence (undiagnosed+diagnosed)
  - Population-based data on morbidity

Arguably, there is a need for implementation and process measures as well.

Need to be able to track metrics by sociodemographic and epidemiologic groups, as well as by geography.

Data should be timely and relate directly to initiative goals.
Surveillance, Data & Metrics Recommendations:

• Systematically estimate baseline status for key outcomes and set realistic but ambitious targets for these outcomes as part of NYS's HCV Elimination initiative.

• Strengthen surveillance systems to improve the timeliness and accuracy of key outcome-related metrics related to HCV elimination.

• Systematically track information on: implementation strategies, efforts and policies that are expected to result in achieving the initiative's goals; and on key outcomes in order to measure baseline status and progress towards achieving the goals of the initiative.

• Disseminate actionable information on progress towards achieving the HCV elimination initiative’s goals to all who need to know in a timely fashion.

• Establish sentinel surveillance programs to track HCV prevalence and incidence in populations where estimates based on reported cases are inadequate.
Surveillance, Data & Metrics Work Group Members:

• Co-chair: Denis Nash, Institute for Implementation Science in Population Health, City University of New York
• Co-chair: Bruce Schackman, Weill Cornell Medical School
• Angelica Bocour, NYC DOHMH
• Kyle Fluegge, NYC DOHMH
• Mary Ford, NYC DOHMH
• Annette Gaudino, Treatment Action Group
• Charles King, Housing Works
• Wendy Levey, NYS DOH, AIDS Institute
• Angie Maxted, NYS DOH, Bureau of Communicable Diseases
• Daniel Raymond, Harm Reduction Coalition
• Larissa Wilberschied, NYS DOH, AIDS Institute
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Social Determinants Work Group

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Background

In order to eliminate HCV epidemic in NYS it will be critical to address the needs of people living with, cured of, and at risk for HCV. First and foremost, people living with and at risk for HCV must be treated as people (not just patients) and must be meaningfully included in the planning and implementation of the State’s HCV elimination plan.

For many people living with hepatitis C, diagnosis, linkage to care, and engagement and retention in curative treatment will require addressing a cluster of interrelated issues, including co-occurring health and mental health conditions, substance use, poverty, housing instability, food insecurity and lack of transportation. Homelessness, hunger and other unmet subsistence needs are powerful barriers to HCV screening, engagement in treatment and medication adherence.

It is also important to take concrete actions to reduce and eliminate HCV stigma and end the criminalization of injection equipment and people who use drugs.
Social Determinants Recommendations:

- Identify and address social and structural barriers to linkage and retention in effective HCV treatment.
  - Assess barriers to HCV care using standardized measures.
  - Enhance services to support the non-medical needs of all persons with HCV infection.
  - Invest in affordable and supportive housing programs to eliminate mass homelessness statewide.
  - Employ referrals to the full range of existing care coordination systems to enhance and streamline access to services to meet the non-medical needs of low-income persons with HCV infection in New York State (including Health Home eligibility for HCV mono-infected).
  - Support development and evaluation of new models for improving HCV service delivery, to promote testing, engagement in care and treatment adherence.

- Eliminate Legal Barriers to HCV Prevention Services for People Who Inject Drugs.
  - Fully legalize syringe possession.
  - Legalize possession of non-syringe injection equipment, including with regard to drug residue.
  - Authorize supervised drug consumption services.
  - Reduce criminal justice involvement of PWID at risk of HCV infection.

- Give proper attention to and implement culturally appropriate messaging to the multiple populations with higher HCV risk or prevalence.

- Improve HCV prevention, screening and care for people with HCV who are incarcerated and increase funding for discharge planning and care coordination services following release from correctional settings.
Social Determinants Work Group Members:

- Co-chair: Matt Curtis, VOCAL-NY
- Co-chair: Matthew Akiyama, Montefiore Medical Center
- Co-Chair: Reed Vreeland, Housing Works
- Erin Bortel, ACR Health
- Gloria Searson, COPE
- Heidi Bramson, Legal Aid Society
- Hiawatha Collins, Harm Reduction Coalition
- Matt Scherer, New York Presbyterian
- Virginia Shubert, Housing Works