Combating the Silent Epidemic of Viral Hepatitis

Action Plan for the Prevention, Care & Treatment of Viral Hepatitis

Increasing Routine Viral Hepatitis Testing: Consultation Report Findings

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Background

Chronic viral hepatitis affects up to 5.3 million Americans and over half of them are unaware of their infection. Accurate blood tests are available however, due to low knowledge, awareness and the reluctance of providers and patients to discuss risk factors; lack of health insurance coverage; conflicting guidelines regarding who should be tested; and limited resources, testing has not been effectively implemented.

As part of its efforts to support implementation of the *Action Plan for the Prevention, Care, and Treatment of Viral Hepatitis* (Action Plan), the Office of HIV/AIDS and Infectious Disease Policy convened a day-long, multi-disciplinary consultation to examine various testing approaches for hepatitis B virus (HBV) and hepatitis C virus (HCV) on February 23, 2012.

Representatives of Federal agencies and other stakeholder groups, including physician associations, State and local health departments (HDs), community health centers (CHCs), community-based organizations (CBOs), and hepatitis advocacy organizations, were invited to describe and discuss approaches to viral hepatitis testing in a variety of public and private settings.

The Challenges of Testing for Viral Hepatitis: A National Perspective

CDC Identified Challenges to Routine Viral Hepatitis Testing

- An estimated 30–70 percent of infected individuals are unaware of their status.
- Providers have low knowledge levels.
- Consumers and patients have low knowledge levels.
- Providers are reluctant to discuss risk factors, especially around past drug use.
- At-risk groups are often culturally and linguistically isolated.
- Individuals at risk often lack insurance.
- Inconsistent Testing Guidelines and Recommendations.
- The public health infrastructure is limited.

Health Care Providers Need:

- More basic information about HBV and HCV;
- Education and outreach to health care providers about the existing HBV testing guidelines;
- Identification of ways to incorporate testing into existing systems; and
- Education addressing the question "Why should I test?" with information about new treatments and the health benefits of behavior change.

Consumers & Individuals in Groups at Risk Have Little Knowledge or Awareness:

- Low knowledge levels, little understanding of different types of hepatitis, and confusion over risk factors;
- Low perceived severity with little to no awareness of the link to liver cancer;
- Belief that infection would be indicated by symptoms (no symptoms would mean no infection);
- Belief that testing had occurred during routine physicals ("They tested me for everything");
- Lack of media attention being equated with lack of importance;
- Stigmatization of the disease; and
- Uncommon, but troubling belief that hepatitis A, B, and C represented stages of severity of the same disease.

Experience from the Department of Veterans Affairs: a Systems Approach to HCV Screening

Barriers	Strategies
▪ Inconsistent recommendations for screening and testing	▪ Initiate the national HCV program (2000)
▪ Competing priorities	▪ Prevalence assessment
▪ Lack of policy or concrete guidance on who to screen for risk and who to test	▪ Implementation planning
▪ Concerns about insufficient funding to test	▪ Improve system-wide communication
▪ Lack of awareness of risk by both the health care team and the patients	▪ Updated algorithm
▪ Confusing testing algorithms, resulting in incomplete testing	▪ System monitoring & feedback
▪ The expectation that doctors be the sole person assessing risk	▪ Conduct systematic screening through clinical reminders
▪ Discomfort in discussing risk	▪ Hold leaders accountable for timely screening and testing
▪ Lack of systematic processes to provide testing to at-risk populations	▪ Commit to linkage to care as well, not just testing
	▪ Health care team responsibility for testing
	▪ Combined risk factor screening
	▪ New lab process for confirmation of viremia

Health Department Perspectives on Viral Hepatitis Testing:

Federal Partners	Target of Testing Program(s)
Centers for Disease Control and Prevention	Communities disproportionately impacted by viral hepatitis, substance users, criminal justice
Community Partners	**Hepatitis Testing Services Provided**
Community based organizations, substance abuse treatment programs, syringe exchange programs, primary care providers, AIDS service organizations, hospitals, and industry partners	▪ HCV screening and linkage to care ▪ HBV screening and linkage to care
Barriers	**Strategies**
▪ Few model programs exist, technical assistance is needed for state health departments ▪ Lack of referral locations for care and treatment ▪ Low/no Medicaid reimbursement (rapid testing) ▪ Confusion between HIV screening and HCV screening ▪ Lack of provider capacity to test ▪ Confusion about what the HCV screening result really means ▪ Lack of adequate or sustained funding, which limits the availability of testing or causes it to vary from year to year ▪ Lack of funds for polymerase chain reaction (PCR) testing for the uninsured ▪ Lack of case management/loss to follow up	▪ Partner with the state primary care associations ▪ Identify potential referral sites for health care and treatment ▪ Work with the state Medicaid program and health insurance office ▪ Train and educate consumers and providers ▪ To address funding barriers, partner with HIV programs and work with industry partners

Community Outreach Models: Education, Awareness, and Testing

Federal Partners	Target of Testing Program(s)
Centers for Disease Control and Prevention	Individuals in groups at risk based on community need and/or program goals
Community Partners	**Hepatitis Services Provided**
▪ Community health centers ▪ Community cancer and/or liver programs ▪ Local health department ▪ Local foundations ▪ Local Medical Associations ▪ Local hospitals, especially liver centers ▪ Academic centers ▪ Department of corrections ▪ AIDS Service Organizations ▪ Other community based organizations	▪ Hepatitis A & B vaccination ▪ Hepatitis B & C screening, testing, counseling, and referral ▪ Hepatitis education ▪ Youth outreach
Barriers	**Strategies**
▪ Funding often covers only equipment not staff or other materials ▪ Lack of follow-up or case management ▪ Lack of familiarity with target group ▪ Low awareness of viral hepatitis among individuals in target groups ▪ Often difficult to follow up with those tested ▪ Communication with nonnative English speakers ▪ Connecting clients organizations that can do confirmatory testing ▪ Program capacity	▪ Provide education to groups/communities at risk ▪ Support integration and collaboration among community groups ▪ Incorporate a health department-community partnership model ▪ Use rapid HCV testing ▪ Provide medical case management ▪ Recruit volunteer nurses ▪ Integrate viral hepatitis into existing funded HIV services ▪ Cross train staff

Jails and State Prisons: Critical Opportunities for Hepatitis Testing and Counseling

Federal Partners	Target of Testing Program(s)
Center for Disease Control and Prevention Bureau of Prisons	▪ Detainees in jails ▪ Incarcerated individuals
Community Partners	**Hepatitis Services Provided**
▪ Community health centers ▪ Tertiary care centers ▪ Community re-entry programs	▪ Viral Hepatitis screenings and testing ▪ Group education sessions ▪ Viral hepatitis treatment (prison only)
Barriers	**Strategies**
▪ Lack of awareness of HCV, HIV, STI status among jail detainees ▪ Short median stay in jails, providing sufficient time for screening but not enough time for initiating treatment ▪ A high rate of patients not completing treatment due to side effects ▪ Patients often under report risk factors ▪ High recidivism and re-infection rates ▪ A high rate of refusals for treatment post-testing ▪ Non-sterile tattooing or piercing ▪ Unprotected sex ▪ Fear of stigma and inadequate confidentiality in jails and prisons ▪ Lack of consistent discharge planning & referral for housing, behavioral health, insurance & medical continuity of care	▪ Offer integrated screening for HCV, HIV, and STIs in jail setting to detect, counsel, and refer for care and treatment ▪ Partner with the community health centers and tertiary care centers to provide follow-up treatment and educational ▪ Develop risk-based screening strategies and provide testing for all high-risk patients in prisons ▪ Conduct multidisciplinary case management ▪ Provide peer support groups and empowerment ▪ Identify patients' support systems

Community Health Center (CHC) Models for Increasing HBV and HCV Testing:

Federal Partners	Target of Testing Program(s)
Health Resources and Services Administration Centers for Disease Control and Prevention	The uninsured, low-income individuals, individuals identified as having elevated liver enzymes, members of high-risk groups, and non-English speakers
Community Partners	**Hepatitis Services Provided**

▪ Local viral hepatitis advocates & coalitions
▪ Local health departments
▪ Local foundations
  ▪ CBOs Treatment programs
  ▪ Needle exchanges
  ▪ Faith-based organizations
  ▪ Schools
▪ Tertiary care centers
▪ Other CHCs
▪ Industry partners
	▪ HAV and HBV vaccination
	▪ HBV testing
	▪ HBV care, treatment and liver cancer surveillance
	▪ HCV testing
	▪ HCV care, treatment and liver cancer surveillance

Barriers	**Strategies**
▪ Cost to sustain free tests and vaccines ▪ Inconsistent screening guidelines ▪ Limited access to secondary prevention services ▪ Limited vaccination and prevention education ▪ Limited access to treatment, care, support, and medications ▪ Difficult to abstract data from electronic health records ▪ Primary care physicians not testing or providing care for patients with viral hepatitis ▪ Systems in place do not facilitate testing ▪ Lack of community awareness ▪ Lack of appealing patient education materials in Spanish and English	▪ Seek funding via local grants ▪ Meet with key community and provider stakeholders to set goals ▪ Adopt screening guidelines for organization ▪ Hire a patient coordinator for chronically infected patients ▪ Increase access to treatment on site and through referral to tertiary care center ▪ Negotiate for better pricing with lab ▪ Partner with CBOs on referrals and counter referrals for HCV ▪ Develop patient registries ▪ EHR investments & improved processes ▪ Provide regular feedback to medical staff via quarterly physician report cards. ▪ Collaborate with other organizations to increase community awareness via press conference, media, and advertisement

Substance Abuse Treatment and Hepatitis Testing: Successes, Challenges, and Key Elements

Federal Partners	Target of Testing Program(s)
Substance Abuse and Mental Health Services Administration, National Institutes of Health, Centers for Disease Control and Prevention	Patients admitted to Methadone Maintenance Treatment Programs (MMTP)
Community Partners	**Hepatitis Services Provided**
▪ Health departments ▪ Community Health Centers	▪ Routine screening and testing for hepatitis A, B and C ▪ Hepatitis A & B vaccination
Barriers	**Strategies**
▪ Difficulty informing patients of their results ▪ Lack of care and treatment providers ▪ Patients failing to follow-up on appointments for confirmatory testing ▪ Patients failing to follow up on referrals to the specialty clinic evaluation and possible treatment ▪ Limited funding for viral hepatitis activities ▪ Staff retention	▪ Link preliminary screening test to follow-up steps ▪ Provide education, case management, and other services on site to improve adherence to recommended offsite care ▪ Provide confirmation testing on site ▪ Provide HCV home test kits ▪ Incorporate a holistic approach to both recovery and hepatitis services ▪ Create internship opportunities to help support staffing needs ▪ Secure sufficient funding ▪ Partner with the state/local health department to offer free testing/vaccination ▪ Refer patients to community health centers ▪ Develop partnerships with liver specialty centers

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Consultation Summary: Barriers, Strategies, and the Role of HHS

Many individuals infected with viral hepatitis do not know their status and work must be done with and within the organizations that provide health services to them in order to address the problem. Organizations working on viral hepatitis must move ahead with the resources at hand. Information gathered from the consultation will be used to inform ongoing and future federal and non-federal efforts regarding useful information, materials, and strategies to implement routine viral hepatitis testing.

Barriers and Needs Identified

- **CREATE AND DISSEMINATE BEST PRACTICES AND GUIDELINES.** Conflicting and complicated guidelines regarding viral hepatitis testing recommendations lead to confusion and missed opportunities. There is a need to create and disseminate guidelines and best practices that meet the needs of providers from multiple sectors.
- **EDUCATE PROVIDERS.** Primary care providers do not always have the information they need to conduct testing and follow-up. A national standard curriculum and provider outreach could help address this need.
- **CREATE CLINICAL MEASURES.** The development of clinical measures can be used as indicators for efficacy, looking at the time of diagnosis to the onset of demonstrable disease, a measure similar to testing positive for HIV and the onset of AIDS.
- **ADDRESS LABORATORY CHALLENGES.** There are a number of challenges with laboratories including the costs of tests and the lab capacity to process tests often due to funding and/or staffing constraints.
- **OVERCOME FUNDING CHALLENGES.** Lack of funding on federal, state and local levels is a barrier to implementing routine testing. However, even with existing resources, viral hepatitis testing practices could improve. When HIV testing was initiated, similar reservations were voiced about testing people when treatment might not be available or accessible to everyone. Although the importance of treatment cannot be minimized, much more can be done to increase awareness of the disease and help people to stay healthy with chronic viral hepatitis, in addition to referral for therapy.

Strategies Identified

Best Practices and Models for Testing

- **LINK TO CONFIRMATORY TESTING AND CARE.** Testing for viral hepatitis must be closely linked with testing to confirm infection and care and treatment options. Strong linkages to existing resources and systems of care for confirmatory testing and medical management is a critical best practice – particularly in light of the low proportion of people who return for confirmatory PCR testing or primary care appointments.
- **LEVERAGE ESTABLISHED HIV SYSTEMS.** Utilizing established HIV outreach systems and resources such as trained HIV staff to conduct routine viral hepatitis testing is one common platform upon which to build viral hepatitis testing activities.
- **UTILIZE ELECTRONIC HEALTH RECORDS.** EHRs are an essential component to access information on an individual and population level. EHRs can be used as a best practice to support viral hepatitis testing by reminding, providers about HBV and HCV testing, vaccination, and recommended follow up and documenting and tracking patients.
- **NON-PHYSICIAN CENTERED MODELS.** Non-physician centered models such as team-based approaches, nurses, physician assistants, etc. effectively extend the provision of viral hepatitis testing in various health care settings.
- **EDUCATE AND SUPPORT PATIENTS.** Patients often feel hopeless when diagnosed with chronic viral hepatitis and become even more discouraged if they cannot immediately get into treatment. Therefore, patients need to be educated about the meaning of their diagnosis and what actions they can take to improve their health, such as exercise, nutrition, and reduction of alcohol intake.

Best Practices and Models for Working with Specific Populations

- **PROVIDE CULTURALLY COMPETENT SERVICES.** Screening and testing should be done by providers who are culturally and linguistically competent to work with the targeted population. This is of particular importance because of the diverse communities at risk for viral hepatitis (e.g., AAPIs, African Americans, immigrants, Veterans, substance users).
  - **PEOPLE WHO ARE INCARCERATED.** Opt-out consent for viral hepatitis testing is very effective for reaching people who are incarcerated. Testing all prisoners is not necessary, but testing should be regularly offered viral hepatitis testing to all and test those who do not opt out. This will both routinize testing and target testing to those with identified risk behaviors and/or who request to be tested.
  - **SUBSTANCE USERS.** Testing people initiating long-term residential treatment as a way to reach substance users. It is important to provide active drug users and young people with hepatitis prevention messages and resources.
  - **AFRICAN AMERICANS.** Utilizing faith based organizations can be an entry point for screening in African-American communities. Public service announcements and health literacy efforts specifically targeting African Americans may be effective strategies.
  - **YOUTH.** Lessons learned from HIV and intravenous drug users (IDU) should be used when working with youth. Although older IDUs are aware of hepatitis risks, younger users are not.
  - **VETERANS.** Screening in VHA substance use clinics proved a good opportunity for screening for hepatitis A, B, and C and then vaccinating for A and B. Research findings indicate that a positive HCV result is a motivator for substance use treatment. Taking blood samples during the first visit and then conducting a confirmatory test, if needed, was a successful model for following up and linking veterans to follow-up services
  - **AAPIS.** The use of public media outlets is a useful strategy to reach AAPIs. Media messaging needs to take into account the diversity of the AAPI community, including first-generation, second-generation and 1.5-generation (people who moved to the United States as children) immigrants.

Role of HHS

- **COMPILE AND DISSEMINATE BEST PRACTICES.** Many community health centers, substance use programs, and jails have best practices and lessons learned; these could be compiled and made available publicly. An additional recommendation was that HHS develop an inventory of resources in the form of a searchable database, in particular for Viral Hepatitis Testing Day.
- **INCORPORATE VIRAL HEPATITIS** in grant announcements. Hepatitis best practices should be incorporated into grant announcements, where appropriate, to ensure that grant-funded efforts are coordinated and based on previous experience of effective activities.