The State of Hepatitis B: Role of civil society & communities in driving elimination

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ELIMINATION
will not be achieved without involving
PEOPLE WHO ARE AFFECTED
by viral hepatitis
Harnessing the power of people

STEP 1

Identify

Energise

The power of the millions

People living with viral hepatitis

STEP 2

Combat Stigma & Discrimination

Increase awareness
Demand access,
Drive advocacy

Partner with scientists,
researchers & policymakers

Improve programme delivery

Worldwide, people living with:

Hepatitis B - 296 million
Hepatitis C - 58 million
(HIV - 38 million)
Find The Missing Millions.

Overcoming the barriers to diagnosis: The Role of Civil Society and the Affected Community in the viral hepatitis response.

The Importance of Involving Civil Society and the Affected Community in the Response

People living with viral hepatitis and the affected community should be at the heart of every effort to eliminate viral hepatitis. Aside from fulfilling the need for trusted entities that consistently disseminate reliable information, civil society organisations bring fundamentally important perspectives and experiences which greatly enhance the effectiveness of strategies and programmes.
6.4.4 Community engagement

The meaningful participation of people living with hepatitis B and C and their families and communities is of critical importance in determining and developing national and subnational policies for affected communities, and should be actively promoted. Community engagement is also important and highly relevant for supporting and implementing service delivery.

Community engagement can be assessed through evidence of formal and active national-level participation of affected persons in the development, implementation and evaluation of the national hepatitis responses.

Assessment of community engagement supporting elimination during the validation process includes the following:

1. evidence of affected community representatives in the national hepatitis task force;
2. national hepatitis policy documents explicitly state the active participation of the affected community in hepatitis prevention, diagnosis and treatment services;
3. evidence of peer-led or peer navigation interventions for hard-to-reach, rural and marginalized populations;
4. government funding for representative groups of the hepatitis-affected community.
## ANNEX 2. CHECKLIST FOR SUPPORTING EVIDENCE OF IMPLEMENTATION CONSIDERATIONS FOR VALIDATION OF ELIMINATION

Note: This checklist is provided to facilitate the writing and documentation of the implementation considerations in the national hepatitis elimination report; it is suggested that the full checklist be filled in and used as an annex to the main national elimination report. Depending on the option that is chosen for validation of elimination or path to elimination, not all items of the checklist apply (e.g. when applying for validation of elimination of HCV as public health problem only, the items limited to HBV do not apply).

<table>
<thead>
<tr>
<th>Implementation component</th>
<th>Present (Y/N)</th>
<th>Detailed information on component (e.g. when developed/updated, etc.)</th>
<th>Evidence of statement and references</th>
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<tr>
<td>4. Human rights</td>
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<td>4.1 Evidence of voluntary viral hepatitis B and C testing and treatment</td>
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<td>4.2 Evidence of confidentiality and privacy of hepatitis B and C status and treatment</td>
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<td>4.3 Evidence of absence of legal discrimination (for employment status, access to education, housing, social benefits)</td>
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<td>4.4 Evidence of stigma-free access to health care and treatment for those with HBV and HCV</td>
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<td>4.5 Evidence that people living with hepatitis are informed of their status and provided adequate counselling</td>
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<td>4.6 Evidence of the absence of drug use, sexual orientation status, incarceration experience, immigration status or profession as a criterion for exclusion from hepatitis treatment</td>
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<td>5. Equity</td>
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<td>5.1 Evidence of testing and treatment service decentralization and integration</td>
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<td>5.2 Evidence of disaggregation of programme and epidemiological data by gender and other equity stratifiers</td>
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<td>6. Gender equality</td>
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<td>6.1 Evidence of the presence of national policy that includes specific reference to addressing the gender needs of those living with or at risk for viral hepatitis, including access and stigma/discrimination</td>
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<td>6.2 Evidence of efforts to address stigma/discrimination of men and women living with hepatitis</td>
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<td>7. Community engagement</td>
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<td>7.1 Evidence of affected community representatives in the national hepatitis task force</td>
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<td>7.2 National hepatitis policy documents explicitly state the active participation of affected community in hepatitis prevention, diagnosis and treatment services</td>
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<td>7.3 Evidence of peer-led navigation in hepatitis service delivery for hard-to-reach, rural and marginalized populations</td>
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<tr>
<td>7.4 Evidence of government support or funding for representative groups of the hepatitis-affected community</td>
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Find the Missing Millions with HBV

Only 10% have been diagnosed globally

Impact of US national screening strategies: HIV vs HBV Care Cascade

1,200,000 in US with HIV

Routine Screening
One time for all adults, as of 2006

Risk-Based Screening

1,250,000 in US with Chronic HBV (low estimate)

168,000 Unaware & Not in Care

480,000 Aware of Infection & In Care

552,000 Aware & Not in Care

35,000 Aware of Infection & In Care

990,000 Unaware & Not in Care

225,000 Aware & Not in Care

Student & Healthcare worker discrimination in the US

- **2011** Two medical students lose acceptances over HBV diagnosis, DOJ brought in
- **2012** CDC updates guidelines for health care students & professionals with hepatitis B
- **2013** People w hepatitis B officially protected under the American Disabilities Act
- **2013** Letter sent from DOJ, Dept of Education, Heath & Human Services to healthcare schools

Yet, the Hepatitis B Foundation has received 20-30 cases/year of students or professionals facing discrimination

Nurses, physicians, x-ray technicians, physical therapists, dentists, ultrasonographers
It’s time to raise awareness that “Hep Can’t Wait”

**30s**
Every 30 seconds someone loses their life to a hepatitis related illness.

**People in prison**
can’t wait

**7%**
of people living with TB also live with hepatitis C.

**INDIGENOUS PEOPLE CAN’T WAIT**

**2.7m**
2.7 million people live with HIV and hepatitis B.

**NEWBORN BABIES CAN’T WAIT**

**43%**
Only 43% of children receive the hepatitis B birth dose vaccine.

**1.1m**
more than 1.1 million lives are lost each year to hepatitis B and hepatitis C.

**Policymakers can’t wait to act**

**2.3m**
2.3 million people live with HIV and hepatitis C.

**People who inject drugs can’t wait**

**REFUGEES CAN’T WAIT**
“Hep Can’t Wait” & World Hepatitis Day July 28, 2021 around the world
Launched in 2016 to hold governments accountable to the promise to eliminate hepatitis by 2030.

**What is NOhep?**

NOhep unites people around the world behind a shared goal: the elimination of viral hepatitis. With one voice we demand action, we demand change and we demand that millions of people around the world are given a chance to live a life free of this disease!
Raise your voice!

Join our campaign and make sure no child gets left behind!

Sign our open letter to Gavi, the Vaccine Alliance, urging them to accelerate plans to provide the hepatitis B birth dose vaccine to low- and middle-income countries.

Sign the open letter
The first **NOhep Village** was held in 2018 in Toronto bridging the gap between medical professionals and civil society organisations.

**NOhep Medical Professionals** are a global network of leading medical professionals using their expertise to drive action to meet the 2030 targets.