

Community Network for Empowerment (CoNE)*

NGO – network of 14 community-based organisations of people who use drugs
Imphal East, India
www.conemanipur.net

SURVEY HIGHLIGHTS

The respondent reviewed 25 items of information that the government of India reported for the 2013 World Health Organization Global Policy Report on the Prevention and Control of Viral Hepatitis in WHO Member States.

✓ The government information was thought to be accurate for **60.0%** of items.

Survey points marked "accurate":
2.1, 2.2, 3.1, 3.2, 3.5, 4.2, 4.3, 4.5, 4.6,
4.8, 4.9, 5.1, 5.2, 5.4 and 5.5.

✗ The government information was thought to not be accurate for **28.0%** of items.

Survey points marked "not accurate":
1.1, 1.2, 1.3, 3.3, 3.4, 4.4 and 5.3.

— The respondent took no position on the government information for **12.0%** of items.

Survey points marked "take no position":
4.1, 4.7 and 4.10.

Survey comments from the Community Network for Empowerment.

Information reported by government (2012–2013)

✓ To our knowledge, this information is accurate.

2.2 The government does not collaborate with in-country civil society groups to develop and implement its viral hepatitis prevention and control programme.

3.1 There is no routine surveillance for viral hepatitis.

3.2 There are standard case definitions for hepatitis. Hepatitis deaths are not reported to a central registry. The percentage of hepatitis cases reported as "undifferentiated" or "unclassified" hepatitis is not known.

4.2 The government has not established the goal of eliminating hepatitis B.

4.9 It is not known whether there is a national policy relating to the prevention of viral hepatitis among people who inject drugs.

5.2 The government does not have national policies relating to screening and referral to care for hepatitis B or hepatitis C.

Civil society respondent comments (2014)

The concerned officials bluntly ignore us when we approach them to initiate a consultation on improving access to hepatitis C treatment.

Even the existing antiretroviral centres do not maintain the data for coinfection.

Government is still yet to realise that mortality among people on antiretroviral therapy is due to hepatitis B and hepatitis C.

Even patients on antiretroviral therapy with hepatitis B coinfection are not encourage with tenofovir.

Whenever we approach the State AIDS Control Society for hepatitis-related issues among people who inject drugs (PWID), they are not concerned. Prevention of hepatitis C among PWID is not on the agenda in national harm reduction strategy.

The referral services provided by targeted Intervention projects for HIV testing to Integrated counselling and testing centres do not include hepatitis.

* World Hepatitis Alliance member.

India

Community Network for Empowerment continued

x *To our knowledge, this information is not accurate.*

Information reported by government (2012–2013)

1.1 There is a written national strategy or plan that focuses exclusively on the prevention and control of viral hepatitis. It includes components for raising awareness, surveillance, vaccination, prevention in general, prevention of transmission via injecting drug use, prevention of transmission in health-care settings, and treatment and care.

1.2 There is a designated governmental unit/department responsible solely for coordinating and/or carrying out viral hepatitis-related activities. It has four staff members. It is not known how many people work full-time on hepatitis-related activities in all government agencies/bodies.

1.3 The government has a viral hepatitis prevention and control programme that includes activities targeting the following specific population: health-care workers, including health-care waste handlers.

3.3 Liver cancer cases and cases with HIV/hepatitis co infection are registered nationally. The government does not publish hepatitis disease reports.

3.4 Hepatitis outbreaks are reported to the government and are further investigated. There is inadequate laboratory capacity nationally to support investigation of viral hepatitis outbreaks and other surveillance activities.

5.3 People testing for both hepatitis B and hepatitis C register by name; the names are kept confidential within the system. Hepatitis B and hepatitis C tests are free of charge for all individuals and are compulsory for blood donors.

— *We take no position regarding this statement.*

4.1 There is no national policy on hepatitis A vaccination.

Civil society respondent comments (2014)

At least the government has started taking the initiative for hepatitis B vaccination for newborn babies.

We have been doing advocacy on improving access to hepatitis C treatment since 2012 with the Government Health Department. However, we do not know of the existence of such teams or units at the state level solely for hepatitis C.

Based on our experience, most health care providers are still lacking adequate information on viral hepatitis.

Cases are not registered nationally and as such the disease report is not applicable.

Hepatitis outbreaks are neither reported to the government nor does the government have any adequate laboratory to support investigations.

We have no such system as of now. Hepatitis B and hepatitis C are among the mandatory tests for antiretroviral initiation. Peoples are paying Rs 300 to the government hospital whereas the fee is Rs 750 at private diagnostic centres.

Our network mainly focuses on hepatitis B and hepatitis C. We have no information on hepatitis A.

Statement from the Community Network for Empowerment regarding key hepatitis policy issues in India:

India does not have a surveillance system for hepatitis C and the burden of the disease is unknown. However, the graveness of the situation is documented through data and information from independent studies. Recent studies conducted by the World Health Organization have reported that among people who inject drugs the national prevalence rate of HIV/hepatitis C coinfection is 92%¹ while individual sites have also reported a prevalence range of 26% to 93%.²

In the context of Manipur, the prevalence of the coinfection has been reported as 92%³ and 90.2% in Churachandpur district.⁴

In spite of having such rich data for more than a decade now, and in spite of India being a signatory to the World Health Assembly's 2010 viral hepatitis resolution, nothing substantial has been done to improve services, prevention measures or provide treatment as a government response.

Considering the seriousness of the hepatitis issue in India, particularly hepatitis C, the government should develop a national strategy to respond to this public health issue including resource allocation at the earliest. An exclusive programme for prevention of hepatitis should be implemented in collaboration with different key stakeholders.

Civil society should be provided a greater role in curbing viral hepatitis in terms of planning, implementation and monitoring. Community-based groups and networks of hepatitis C-infected and -affected people should be involved in all decision-making, planning and implementation of hepatitis programming.

1. Walsh Nick, July 2009, Scoping document: A review of viral hepatitis in Injecting Drug Users and assessment of priorities for future activities, Prepared for WHO Geneva. P/8.
2. Ibid p/16.
3. Saha, MK, et al, February 2000, Prevalence of HCV and HBV infection amongst HIV seropositive intravenous drug users and their non-injecting wives in Manipur, Indian J Medical Research.
4. Devi KhS et al, March 2009, Coinfection by human immunodeficiency virus, hepatitis B virus and hepatitis C virus in injecting drug users, Indian J Medical Research.

India

Liver Foundation, West Bengal*

NGO – direct service provider

Kolkata, India

www.liverfoundation.in

SURVEY HIGHLIGHTS

The respondent reviewed 25 items of information that the government of India reported for the 2013 World Health Organization Global Policy Report on the Prevention and Control of Viral Hepatitis in WHO Member States.

✓ The government information was thought to be accurate for **80.0%** of items.

Survey points marked "accurate":
1.3, 2.1, 2.2, 3.1, 3.2, 3.3, 3.4, 3.5, 4.1, 4.2, 4.3, 4.5, 4.6, 4.7, 4.8, 4.9, 5.1, 5.2, 5.4 and 5.5.

✗ The government information was thought to not be accurate for **4.0%** of items.

Survey points marked "not accurate":
1.1.

– The respondent took no position on the government information for **16.0%** of items.

Survey points marked "take no position":
1.2, 4.4, 4.10 and 5.3.

The Liver Foundation, West Bengal did not provide any comments about survey items.

Statement from the Liver Foundation, West Bengal regarding key hepatitis policy issues in India:

Chronic hepatitis, as a term, is exclusionary for insurance coverage by most insurance providers.

No national hepatitis control programme exists that can provide support to infected and diseased people for their health care expenditures through government funding.

No guidelines or standard protocol for the management of hepatitis exist. This lays bare the situation even further and creates a freestyle situation in patient care strategies. In the absence of any system for monitoring of clinical and hospital practice, this often turns out to be an absolutely "zero protection" scenario for patient

interest. Indiscriminate and unnecessary hospitalisations, unnecessary drug use and unnecessary therapeutic procedures are some of the examples of imperfect practice of relevance in hepatitis care that are in vogue.

There is a perception even in government circles that hepatitis B and hepatitis C are not priorities in India which is besieged with so many other conditions. Lack of data on the disease burden and economic impact of hepatitis are the primary reasons for this.

National coordination for necessary regulations for supporting patient's interest including health care-related travel subsidies treatment subsidies, other social security benefits that are available to people with chronic diseases such as HIV

and cancer should be initiated. There are multiple stakeholders with different roles that can be knit together to create a proactive hepatitis supportive ambience.

Liver Foundation, West Bengal, is a voluntary organisation focused on different health issues. Initiated by a handful of professionals and socially committed scientists having an interest and focus on liver disease awareness as well as public health issues facing the country. So this view is based on our own experience as well as different reports and statistics.

* World Hepatitis Alliance member.