

## **Executive summary**

**Background:** For the elimination of visceral leishmaniasis (VL) in the Indian subcontinent it is essential to evaluate and fully understand today's actual burden of the disease in endemic countries such as Nepal and India. As India and Nepal just entered the "consolidation phase" of the VL elimination strategy, it is important to determine the current state of VL reporting, VL response and VL treatment to successfully continue the path taken. Recent data indicate that VL cases are still underreported in these countries, as there is no regular active case detection system in place at the community level. In addition, patients of both countries still face long delays when seeking treatment: A patient delay by not being able to seek health care despite feeling sick, a diagnosis delay when entering the health system and a treatment delay after receiving a diagnosis. Moreover, it is likely that information of passively detected VL cases does not reach the higher authorities of the VL reporting systems of both countries in a timely manner.

**Objective:** To determine patient, diagnosis and treatment delays caused by the health system and patient behavior.

To determine and compare delays/ problems of VL reporting from the district to the state/ national VL authorities of the Indian state of Bihar and Nepal.

**Methods:** Cross-sectional study using different type of interviews (structured, semi-structured and in-depth). Study was conducted in 12 districts of Nepal and 9 districts of Bihar in the summer of 2012. To identify patient delay, diagnosis delay and treatment delay, 92 VL patients having experienced 103 VL episodes were interviewed in hospitals or at their home using a structured questionnaire. To identify VL reporting delay, 49 district health managers were interviewed at their workplace using a semi-structured questionnaire. In-depth interviews were conducted with central level health managers of state and national authorities concerned with VL. On-site collected VL reporting documents were evaluated. Data was analyzed using non-parametric tests of statistical significance.

**Results:** Diagnosis delay of Bihar was identified to be 3.6 times higher as compared to Nepal (90 compared to 25 days). This could be attributed to increased utilization of the private sector in Bihar. In Nepal, patient delay was identified to be 3.75 times higher than in Bihar (30 compared to 8 days). For both countries, treatment delay was found to be low (6 days in Bihar and 3 days in Nepal).

VL reporting delay to central level health managers was identified to be 2.7 weeks for “Early Warning and Reporting System” (EWARS) sentinel reporting sites of Nepal, 4.0 weeks for “District Malaria Offices” (DMOs) of Bihar and 10.8 weeks for “District (Public) Health Offices” (D[P]HOs) of Nepal. Sentinel reporting was found to be established in Nepal but not in Bihar. In Nepal, 73% of health managers were found to use computers to file VL cases, whereas in Bihar only 16% are able to do so due to the unavailability of computers in DMO offices. District health managers of both countries do not use standardized reporting formats and mainly rely on paper-based reporting.

**Conclusions:** In Bihar, diagnosis delay is the most prominent drawback for patients whereas patient delay is the main concern in Nepal. Both delays need to be addressed as soon as possible, to be able to achieve the VL elimination goal by 2015. To reduce the diagnosis delay in Bihar, the utilization of public service providers by VL patients needs to be increased. Furthermore, private service providers need to be trained to be able to refer patients immediately to public hospitals when suspecting VL. In Nepal, VL patients need to be encouraged and supported to visit public hospitals immediately when feeling sick. Therefore, patients need to be informed about VL symptoms and VL-related services and incentives offered by the public service providers.

The VL reporting system of both countries still needs to be substantially improved to achieve VL reporting as outlined in the VL elimination guidelines. In Bihar, VL sentinel reporting has not been established yet, and thus has to be a primary goal in the near future. In Nepal, VL reporting from D(P)HOs could be reorganized, as reporting speed was slow. It could also be considered to expand VL sentinel reporting and establish EWARS reporting sites in D(P)HOs of VL endemic districts. An imperative improvement required for the VL reporting system of both countries is to establish standardized reporting formats. At the same time, it should be strongly considered not only to introduce novel standardized paper-based reporting formats, but instead move forward and establish an electronic reporting system.