



SITUATION ANALYSIS OF VIRAL HEPATITIS IN INDONESIA: A POLICY REPORT

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TABLE OF CONTENTS

Table of contents	2
Executive summary	4
About this report	8
Introduction: viral hepatitis	10
1. Viral hepatitis: the global situation	10
2. Viral hepatitis in Indonesia	12
Methodology	14
Situation analysis	16
1. Policy context	16
1.1. Coordination of the response	16
1.2. The impact of decentralisation	17
2. Awareness and information about hepatitis	19
2.1. Lack of access to information for people infected with HBV or HCV	19
2.2. Lack of expertise and limited professional awareness of viral hepatitis	20
3. Epidemiological data	20
3.1. Overview	20
3.2. Existing prevalence figures	21
3.3. Prevalence among vulnerable groups	22
3.4. Lack of confidence in available data	22
3.5. Factors contributing to inaccuracy of available data	23



4. Prevention	24
4.1. Prevention of hepatitis B	24
4.1.1. <i>Childhood immunisation</i>	24
4.1.2. <i>Mother-to-child transmission</i>	25
4.1.3. <i>Prevention control in healthcare settings</i>	26
4.1.4. <i>Harm reduction strategies for people who inject drugs</i>	26
4.1.5. <i>Harm reduction measures – including nosocomial transmission</i>	27
5. Testing and diagnosis	27
5.1. Underdiagnosis and low levels of testing	28
5.2. Geographic disparities in access to testing	28
5.3. Financial barriers	29
5.4. Limited information given to people being tested	29
6. Treatment	30
6.1. Drug coverage through the National Health Insurance scheme	30
6.2. Access to direct-acting antivirals	30
6.3. Access to hepatitis specialists	31
7. Community engagement	32
8. Social implications of hepatitis	33
Discussion and conclusions	34
1. Discussion	34
2. Conclusion	37
References	38



EXECUTIVE SUMMARY

Indonesia has played a leadership role in the development of global hepatitis policy, having co-sponsored a World Health Organization (WHO) resolution calling for the comprehensive prevention and control of hepatitis by all member states, and by helping to create an annual World Hepatitis Day in 2010. However, this island nation faces unique challenges in attempting to eliminate viral hepatitis: it is the fourth most populous country in the world, with 261 million inhabitants spread over 17,500 islands, covering an area of around 5 million square kilometres. Beyond the physical difficulties of geography, there are hundreds of different ethnic and linguistic cultural groups, which are unevenly spread across the archipelago. Combined with a lack of basic civil infrastructure over much of the country, these factors create significant logistical challenges to undertaking basic health system processes.

The Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) conducted a situation analysis in Indonesia in 2017 to identify and understand a broad range of issues that will either assist or impede the country's capacity to achieve the WHO's goal of eliminating viral hepatitis as a public health threat by 2030. It is CEVHAP's intention to conduct similar studies in other countries across Asia Pacific, guided by the methodologies and findings of this first national situation analysis in Indonesia. This work forms part of CEVHAP's commitment to work with national, regional and global partners to eradicate viral hepatitis in Asia Pacific by 2050, and practically support the WHO's efforts to eliminate viral hepatitis as a public health threat by 2030.

Bringing together data from an extensive literature review and interviews with key stakeholders in Indonesia, this report investigates the country's readiness to meet the WHO's goal by focusing on several key themes, shaped by the WHO's *Global Health Sector Strategy on Viral Hepatitis 2016–2021* and its five 'strategic directions', or areas in which action is required to achieve elimination.

It is our hope that this report will give local stakeholders a tool to advocate for change to eliminate viral hepatitis in Indonesia, aiding in the formulation of practicable goals and targets, the monitoring of progress, and securing adequate funding and resources. The report also has implications for other countries in the region, as many of the challenges it identifies in Indonesia will have relevance to other countries trying to develop an effective national response to viral hepatitis.



Why eliminating viral hepatitis matters

Viral hepatitis is a significant public health issue in Indonesia. Currently around 19 million people are infected with hepatitis B virus (HBV) and 2.5 million are infected with hepatitis C virus (HCV) – and mortality is increasing from both infections. While prevalence of HBV is falling nationally, levels of HCV are predicted to remain stable without focused intervention. Huge variation in the disease burden also exists across provinces and populations.

The national response: policy exists, but its implementation may be hindered

Viral hepatitis has recently transitioned to a national policy concern in Indonesia, with the release of Ministerial Regulation no. 53 on the National Control of Hepatitis, and the formation of a distinct hepatitis sub-directorate within the Ministry of Health. However, effective implementation of the regulations may be hindered by insufficient investment in the health sector, and the logistical challenges of providing healthcare in a large, island-based nation. Government commitment to decentralisation has provided autonomy for provincial and district governments to determine their own health priorities; however, this has limited the national government's ability to implement a cohesive national hepatitis plan.

More information is needed on viral hepatitis

There is an insufficient understanding of the magnitude of viral hepatitis infection in Indonesia due to a lack of reliable epidemiological and other data; such data are critical to guide evidence-based policy development. There is a great need for routine surveillance of HBV and HCV infection as currently there is a lack of standardisation of how and what data are collected. The situation is aggravated by provincial gaps in data, limited data provided by the private healthcare sector, and a lack of training and skills among personnel. When data are collected, they are not always effectively analysed, or widely and transparently disseminated.

As with many other low to middle-income countries in Asia Pacific, there is a lack of publicly available information about viral hepatitis, care pathways and available treatments in Indonesia. This lack of information means that patients do not always understand a diagnosis of viral hepatitis and its potential evolution from a symptomless condition to end-stage liver disease. They may not seek medical care, resulting in late diagnosis and initiation of treatment, and poor outcomes. Knowledge gaps among government and healthcare workers may exacerbate this situation.

Prevention requires parity

Indonesia's recent health spending has principally addressed curative services, to the relative neglect and underfunding of preventive programmes. While high numbers of children receive the full HBV vaccine course, there is large provincial variation in vaccination coverage. Mother-to-child transmission of HBV remains a significant risk, with no national screening programme for pregnant women, and no facility to cover the cost of preventive treatment for infected infants.

A government-funded pilot scheme has commenced to address this issue but is currently limited in scope. Indonesia continues to see new viral hepatitis infections resulting from insufficient infection prevention and control practices in healthcare facilities. Harm reduction services and strategies for people who inject drugs also need to be expanded.

Without testing, treatment cannot occur

Few people in Indonesia who are at risk of viral hepatitis, particularly HBV, are tested for the infection. People do not seek out testing due to a lack of public awareness about HBV and HCV, the asymptomatic nature of the viruses, low levels of health literacy, and the high cost of the tests. These factors are exacerbated by an unequal distribution of testing facilities across the country.

These barriers to testing mean that treatment rates for viral hepatitis are low, despite many viral hepatitis drugs now being available on the National Health Insurance.

However, direct-acting antivirals (DAAs) are not covered by the scheme, although a pilot scheme to provide free treatment to a limited number of patients in a limited number of settings through a Ministry of Health programme is addressing this. The focus on providing clinical management through specialist services, combined with the limited number and geographic spread of hepatitis specialists, also acts as a significant barrier to accessing proper treatment and care.

Community engagement is insufficient

Despite advances in policy and availability of some services, community engagement on hepatitis remains insufficient. While community-based organisations conduct a range of grassroots interventions addressing viral hepatitis, a lack of funding is constraining their impact. Stigma, misconceptions about the condition and its impact, and discrimination of those infected remain important social issues to tackle.

The elimination of viral hepatitis is achievable with concerted action

Indonesia has made significant progress in each of the five 'strategic directions' from the WHO's *Global Health Sector Strategy on Viral Hepatitis 2016–2021*, although further action is required in all of these areas if Indonesia is to eliminate viral hepatitis as a major public health threat by 2030. There are several key gaps:

1. **Information for focused action:** a distinct, evidence-based national hepatitis strategy, paired with a robust strategic information system to analyse and translate up-to-date data on viral hepatitis into usable information.
2. **Interventions for impact:** an essential benefit package of viral hepatitis interventions, services, medicines and commodities clearly defined at the national level.
3. **Delivering for equity:** comprehensive interventions aimed at vulnerable groups, and existing models of service delivery adapted to meet their needs.
4. **Financing for sustainability:** a mechanism to cover the cost of diagnostic tests for the general population.
5. **Innovation for acceleration:** new innovative approaches to improve the efficiency and quality of services and maximise impact.

Despite these gaps, with concerted action and targeted interventions at the national, regional and local level to create a more informed, efficient and coordinated national hepatitis response, the elimination of viral hepatitis in Indonesia is an achievable goal.



ABOUT THIS REPORT

In 2013 and 2016, the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) brought together patient advocates, policy researchers and clinicians to discuss the challenges in addressing the burden of hepatitis in four jurisdictions in North Asia: Hong Kong, Taiwan, South Korea and Japan. This exercise was repeated in 2016, with a forum looking at the same issues as they occur in Bangladesh, Indonesia, India, Malaysia, Pakistan, the Philippines and Thailand. Findings from both these workshops were published and highlighted issues common to all countries, while also underscoring the success stories and contextual factors unique to each country or territory.

The World Health Organization's (WHO's) *Global Health Sector Strategy on Viral Hepatitis 2016–2021*¹ and the *Regional Action Plan for Viral Hepatitis in South-East Asia: 2016–2021*² were published shortly after the latter workshop. These documents offered a blueprint for countries to implement the broad range of activities aiming to support the WHO goal of eliminating viral hepatitis as a public health threat by 2030. In this context, and building on its previous experience, CEVHAP conducted an in-depth situation analysis in Indonesia, to better understand the broad range of issues that will either assist or impede the country's capacity to achieve the WHO's goal. It is CEVHAP's intention to conduct similar studies in other countries across Asia Pacific, guided by the methodologies and findings of this first national situation analysis in Indonesia. This research is critical to identify the key and essential interventions that need to be implemented in the countries in the broader region. This work forms part of CEVHAP's commitment to work with national, regional and global partners to achieve total eradication of viral hepatitis in Asia Pacific by 2050, extending the WHO's efforts to eliminate viral hepatitis as a public health threat by 2030.³

This report is based on data collected through 22 interviews with key stakeholders in Indonesia, and an extensive desk-based literature review. Indonesia is the fourth most populous country in the world, and presents unique challenges to the implementation of prevention, treatment and surveillance efforts for any health condition, given its geographic distribution across more than 17,000 islands covering an area of around 5 million square kilometres. The past decade has seen rising support for addressing viral hepatitis as a global health issue, with Indonesia co-sponsoring a WHO resolution calling for the comprehensive prevention of hepatitis by all member states, and the creation of an annual World Hepatitis Day in 2010.⁴ In 2012, Indonesia officially designated a Hepatitis Control Programme within the Ministry of Health,⁵ with a Ministerial Regulation 'concerning the control of viral hepatitis' released in 2015.



This report was developed and funded by CEVHAP, working in collaboration with The Health Policy Partnership, an independent health policy research consultancy based in London, UK, and Dr Jack Wallace, a researcher from the Burnet Institute, Melbourne, Australia.

It is our hope that this report will give local stakeholders – including members of national and local governments, public health workers, non-governmental organisations, and those affected by viral hepatitis – a tool to advocate for change to eliminate viral hepatitis in Indonesia, aiding in the formulation of practicable goals and targets, the monitoring of progress, and the securing of funding and resources. This report will not only have national benefit for Indonesia but will assist other governments in the region to identify the key elements of an effective and comprehensive response to viral hepatitis within their jurisdiction.

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INTRODUCTION: VIRAL HEPATITIS

Viral hepatitis is increasingly preventable and treatable – yet mortality continues to rise.

1. VIRAL HEPATITIS: THE GLOBAL SITUATION

In 2015, an estimated 325 million people worldwide were living with chronic hepatitis B (HBV) or hepatitis C (HCV) infection; however, only 11% of those infected are aware of their infection.⁶ These two viruses, which can cause an inflammation of the liver, are now the most common cause of liver cirrhosis and cancer globally⁶ – yet the potential for eliminating HBV and HCV has never been greater. A readily available and effective vaccine exists for HBV, and the number of new HBV infections has been gradually decreasing as a result of the effective implementation of immunisation programmes.⁶ A mostly lifelong treatment programme for HBV also makes the condition entirely treatable for people who are at greater risk of developing liver damage. There is currently no vaccine against HCV; however, treatment of the disease has been revolutionised by the development of direct-acting antivirals (DAAs), which can now cure the disease in most people within a matter of months. Faced with this situation, in 2016 the WHO launched the *Global Health Sector Strategy on Viral Hepatitis 2016–2021*¹ which sets the goal of eliminating viral hepatitis as a major public health threat by 2030.

Even with existing prevention and treatment options, HBV and HCV present unique challenges to governments, health professionals and civil society wishing to achieve the WHO elimination goals.

Major transmission routes differ: in highly endemic areas, HBV is mainly transmitted from mother to child at birth, whereas non-sterile medical practices and unsafe injecting drug use account for the majority of HCV cases (as well as being a frequent mode of transmission for HBV).⁷ The body's reaction to each virus also differs – fewer than 5% of adults who are infected with HBV will develop chronic infection, compared with 80–90% of children infected during their first year of life.⁷ In contrast, 60–80% of people of all ages who contract HCV will develop chronic infection.⁸

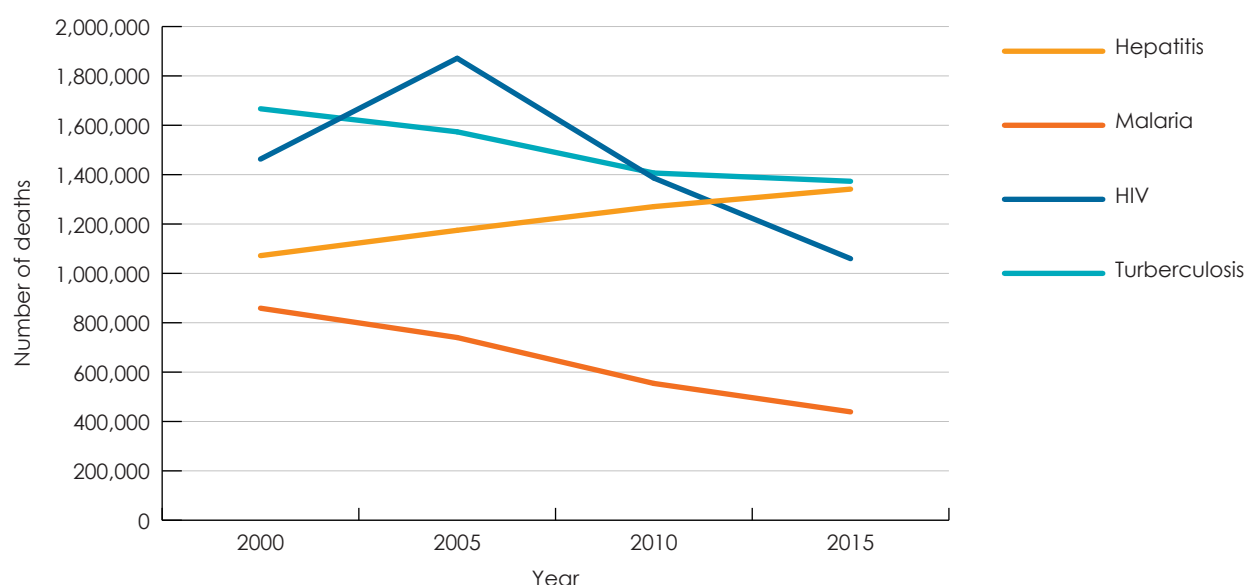


Both viruses continue to be affected by low diagnosis and treatment rates. The WHO estimated that just 9% of all HBV infections and 20% of all HCV infections worldwide were diagnosed in 2015, and only 8% of people diagnosed with HBV infection and 7% of those diagnosed with HCV infection went on to receive treatment.⁶

Reasons behind low diagnosis and treatment rates differ between countries; however, they include low public awareness of the condition, inadequate linkages between testing and treatment, limited capacity and funding for testing and treatment, an asymptomatic illness, and a high degree of stigma linked to the condition.⁹

The outcome of this situation is that, unlike HIV, malaria and tuberculosis, deaths from viral hepatitis have continued to increase worldwide – accounting for 1.34 million deaths in 2015 (see Figure 1). This startling reality has led experts to suggest that global public health priorities be adapted to focus on the ‘big four’ (including viral hepatitis) as opposed to the ‘big three’ triad of malaria, tuberculosis and HIV.¹⁰

Figure 1. Global deaths from malaria, TB, HIV and viral hepatitis, 2000–2015¹¹



Source: WHO (2016). Global health estimates 2015 summary tables: global deaths by cause, age and sex, 2000–2015

2. VIRAL HEPATITIS IN INDONESIA



High prevalence, compounded by geographical and logistical challenges, makes viral hepatitis a significant public health concern in Indonesia.

Viral hepatitis is a significant public health problem in Indonesia: currently, around 19 million people are infected with HBV, while 2.5 million are infected with HCV.ⁱ National prevalence of HBV infection has gradually reduced, moving the country from having a high to a moderate endemicity,¹² but the prevalence of HCV has remained stable and is predicted to remain at its current level without focused intervention.¹³ There is huge variation in the disease burden, with infection prevalence rates in some provinces found to be two to three times higher than the national average,¹⁴ and vulnerable populations sometimes experiencing rates 80 times higher than the national average.¹⁵

There are significant logistical challenges to undertaking basic health system processes, such as data collection, and access to health services. Much of Indonesia lacks basic civil and health infrastructure. For example, in 2015 it was estimated that 3,650 km of roads, 15 airports, 24 seaports, 3,258 km of railway network and 35,000 megawatt power plants would be needed to bring Indonesia up to international benchmarks suitable for a middle-income country.¹⁶ Significant provincial variation in development also exists, with provinces located in the east of the archipelago often at an economic and developmental disadvantage.¹⁷⁻¹⁹

ⁱ Based on current population levels and the results of Riskesdas 2013.

The geographical layout of Indonesia poses specific challenges to the prevention, treatment and elimination of viral hepatitis. Its 261 million inhabitants²⁰ are spread out along an archipelago of around 17,500 islands²⁰ covering around 5 million square kilometres. Many of the provinces have population sizes larger than many independent nations, including a population of over 43 million people in West Java, and 37 million in East Java. Beyond the physical challenges of geography, there are hundreds of different ethnic and linguistic cultural groups, which are unevenly spread across the country.

Given Indonesia's geography, the administration of healthcare and other government responsibilities is heavily decentralised. The administration and provision of health services is conducted through 34 provincial governments, which are further separated into districts and villages, all of which have health-related responsibilities. The Indonesian health system includes a mix of public and private providers, including networks of hospitals and clinics managed by not-for-profit and charitable organisations, for-profit providers, and individual doctors and midwives who engage in dual practice.

The distribution of responsibilities among respective levels of government is described in *Table 1*.

Table 1. Distribution of responsibility for healthcare among national, regional and local levels in Indonesia

Level of administration	Responsibility
Central Ministry of Health	Manages some national-level tertiary and specialist hospitals, provides strategic direction, the setting of standards, regulation, and ensuring availability of financial and human resources
Provincial governments (34 in total)	Manage provincial-level hospitals, provide technical oversight and monitoring of district health services, and coordinate cross-district health issues within each province
District/municipal governments	Manage district/city hospitals and the district public health network of community health centres (puskesmas) and associated subdistrict facilities

Since decentralisation, health development has been a political priority at the national level, second only to the national education programme.²¹ The current government has positioned the health sector as a vital national interest through its 'nine pillars of national development' agenda, a key vision of the new National Health Insurance programme. Political commitment to health development continued through the 2015–2019 midterm planning, which gave rise to the Healthy Indonesia Program, whose aim is to improve health status through financial protection, continuing the focus on the health insurance mechanism.²¹

These plans form part of a hierarchy of interrelated long-term, medium-term and annual health plans, from central to provincial and district level, with the planning process being made up of top-down direction and bottom-up participation from communities and local agencies.²¹ However, political commitment to health development has not been matched by commitment in funding, with health spending remaining low.²²



METHODOLOGY

A literature review was conducted to build up a detailed, evidence-based picture of Indonesia's readiness to eliminate viral hepatitis as a public health threat by 2030, and also to identify key stakeholders for interview. A research template was first developed based around the five areas, or 'strategic directions', that require action to achieve the elimination of viral hepatitis according to the WHO *Global Health Sector Strategy on Viral Hepatitis 2016–2021*:

1. **Information for focused action**
2. **Interventions for impact**
3. **Delivering for equity**
4. **Financing for sustainability**
5. **Innovation for acceleration**

An extensive desk-based literature review was then undertaken using the template, covering both academic and grey literature. Key stakeholders for the interview stage of the research project were identified during analysis of the documents.



Twenty-two interviews were then held with key stakeholders in Indonesia. The stakeholders were identified after an initial consultation with Indonesian CEVHAP members, and through the personal contacts of the investigators. This initial list was expanded as a result of the literature review. Professional categories of people interviewed included: health economists; clinical specialists including hepatologists, gastroenterologists and infectious disease physicians; individuals from organisations representing people who inject drugs and people living with viral hepatitis; government policy officers; and academics.

While the interview schedule was adapted to reflect the perspective of each of the interviewees, its focus was to identify and document the participant's perspective of Indonesia's capacity to achieve the WHO goal of eliminating viral hepatitis as a public health threat by 2030. Interviews were conducted in English, electronically recorded with the verbal consent of the participant, and lasted for between 30 and 75 minutes. Interviews were transcribed by the researchers, and notes were taken during the interviews.

The key issues arising from the interviews are described in eight sections that include a discussion of: the policy context in which hepatitis efforts are occurring; the contextual issues affecting the delivery of health services to the community in Indonesia, including people with viral hepatitis; the infrastructure available to lead the government response to viral hepatitis; issues related to the prevention, testing and treatment of viral hepatitis in Indonesia; and the social implications of viral hepatitis.



SITUATION ANALYSIS

1. POLICY CONTEXT

1.1. Coordination of the response



The Indonesian government has launched a plan to eliminate viral hepatitis, but its implementation may be hindered by inadequate funding and a lack of healthcare resources.

Ministerial Regulation no. 53 on the National Control of Hepatitis (2015) has been implemented to direct central and regional governments to implement national hepatitis control with community participation.²³ A distinct sub-directorate for hepatitis was created within the Ministry of Health to provide leadership and direction related to hepatitis policy, along with a national expert committee on viral hepatitis – consisting of 16 members from universities, health research institutions and major hospitals – which was tasked with providing technical support for the new sub-directorate in the formulation and implementation of the viral hepatitis programme.²⁴ The sub-directorate's initial focus has been on reducing mother-to-child transmission of HBV,²⁵ and providing access for 6,000 people to free DAA treatment for HCV through 13 different specialist hospitals.²⁶

While the growth of national policy on viral hepatitis is encouraging, resource restrictions resulting from broader governmental health policy may constrain its effective implementation. Health spending in Indonesia remains low, with the proportion of health spending to GDP being below average among low-to-middle-income countries.²² Policies aimed at increasing healthcare worker numbers to WHO-recommended levels by 2019 have not been as effective as planned, with staff-to-patient ratios well below safe levels.²⁷ This underinvestment in the health sector is likely to be exacerbated by a reduction in aid, as Indonesia's recent economic growth has resulted in it graduating out of international funding schemes.²⁸ Simultaneously, the launch of a compulsory National Health Insurance System (Jaminan Kesehatan Nasional – JKN) in 2014, which aims to make basic care available to all of Indonesia's 261 million inhabitants by 2019, has increased pressure on these already limited resources, with previously uninsured pockets of the population beginning to make use of healthcare services.²⁹



1.2. The impact of decentralisation

The size of the country and the diversity of Indonesia's population, alongside the individual autonomy of each provincial or district government, may impede the efficacy of consistent national efforts to tackle viral hepatitis.

The national response to viral hepatitis is shaped by the process of decentralisation. Reform through the decentralisation of government services, which began in 1999, has resulted in health services being decentralised to provincial and district governments, which have taken on responsibility for planning, budgeting and managing service delivery. However, the limited capacity and capability of local governments in managing the health sector has resulted in heightened provincial discrepancies in the quality and availability of services.²¹

The geographical, cultural, economic and health-related diversity across Indonesia has a fundamental impact on the potential to implement any national strategy. Provinces differ in terms of where facilities are available, affecting the potential for implementation of any national strategy or clinical guidelines (Interviews 1, 2). There are areas of the country that could only be described as remote (Interview 10), over and above the intrinsic transportation challenges of an island-based nation (Interview 16).

Several participants highlighted that there was a broad range of health services available in the west of the country – including access to clinical specialists, the primary provider of viral hepatitis-related clinical management – that were not available in the east of the country (Interviews 1, 2, 9, 10, 16, 19).

At a practical level, this means that there are many provinces, primarily in the east of the country, in which there are no clinical specialists available to provide viral hepatitis clinical management including treatment. As a result, a person who has been diagnosed with viral hepatitis and who is willing to reduce the possible clinical impact of the infection may be required to travel frequently, often over long distances, to access basic specialist services. This essentially limits access to specialist services in these provinces to a minority of people with the economic resources available to undertake such travel.

Decentralisation has resulted in provincial and district governments having the autonomy to determine their own health priorities, severely affecting the potential efficacy of – and available funding for – a national strategy for viral hepatitis (Interview 14). National decrees which establish the priorities of the central government, such as Ministerial Regulation no. 53 on the National Control of Hepatitis (2015), only act as guidance to provincial or district governments, authorising them to take forward this work, but with no obligation to provide funding for, or implement, the guidance. The national-level priorities outlined in the decrees do not necessarily consider the variation in health needs and system capacities that exist among the different geographical regions of Indonesia.²¹ This situation complicates the development of a specific national elimination target for viral hepatitis: for example, where there may be other health issues that are more of a priority in certain provinces (Interviews 9, 19) or where HBV may be perceived as more of a priority than HCV (Interview 17).

Box 1. Governance of hepatitis in Indonesia

The central **Ministry of Health** has lead responsibility for providing direction for the management of programmes addressing public health issues at a national level, but these programmes are delivered by the network of public facilities at district level (hospitals and district health offices) and community level (puskesmas and their networks). There is also an active surveillance and outbreak response system, and regular national surveys to measure and monitor key aspects of population health (Riskesdas), although – as noted later – there are significant concerns as to their efficacy.

At a community level, it was noted by one participant that a minimum package of health services is provided at a district level, and in all districts across the country (Interview 4). This participant reported that the Ministry of Health, while being able to provide strategic guidance and technical advice to provinces and districts, had little role in the delivery of these services.

Monitoring and reporting of activity conducted within district and provincial health services occurs through the **Ministry of Home Affairs**, which oversees the implementation of decentralisation, rather than the Ministry of Health which has the technical and strategic responsibility. This reflects a situation where the funding provided by the national government for the delivery of health services through the provinces, and then to the district, is channelled through the provincial and then district government representatives, both of which are political positions (Interviews 14, 19). In practice, this means that the person filling these positions may not have any expertise in health, or – given the variation in expertise available across the country – have the requisite knowledge or be provided with accurate advice. This is further complicated by the varying and often inadequate levels of data available across Indonesia and where there is a varying level of expertise within the different provinces (Interviews 7, 14).

2. AWARENESS AND INFORMATION ABOUT HEPATITIS

As is the case in many countries,⁹ a key issue raised by respondents was the lack of knowledge about viral hepatitis in the general community (Interviews 7, 16) as well as among people with hepatitis, healthcare professionals, and people working in government.

2.1. Lack of access to information for people infected with HBV or HCV



Limited access to information means people may not understand a diagnosis of viral hepatitis, or be prepared for what it may entail.

'I'm positive – what can I do? How can you help me?' (Interview 13)

Lack of access to information about viral hepatitis, care pathways and available treatments for people infected was reported as an issue by several respondents. One person working for an unfunded community-based organisation reported providing essential information to people diagnosed with HBV, and information about access to treatment for people with HCV. This was being done without any government or philanthropic resourcing and was dependent on the skills, resources and energy of a small number of individuals. This individual expressed concerns that people with HCV had little awareness about the availability of DAAs (Interview 11). Limited information also means people are largely unprepared for a positive diagnosis of either HBV or HCV, and do not anticipate its evolution from a symptomless condition to end-stage liver disease. The lack of scientifically proven information about the infections for patients in Indonesia means that answers may be provided by traditional community understandings of the infections, with one respondent describing end-stage liver disease as being perceived as 'magic', particularly when a person has 'blood vomit, big stomach, belly... this is a disease that is a disease that is sent by another person' or a curse (Interview 10).

'Sometimes they think it's the end of life when they're told this is hepatitis B.' (Interview 10)

In a country with the fourth largest number of mobile phone subscribers in the world, the messenger service WhatsApp was mentioned by several participants as an essential tool for providing information about viral hepatitis throughout a range of networks in Indonesia. This information included: debriefing and providing information to people who had been diagnosed with viral hepatitis but had not been provided with sufficient information about the infection when they were diagnosed (Interview 13); treatment availability and access (Interview 3); and the provision of information to service and policy providers (Interview 18).

2.2. Lack of expertise and limited professional awareness of viral hepatitis

Knowledge gaps among government and healthcare workers may lead to problems with diagnosis and referral.

Lack of expertise in viral hepatitis among government employees, particularly within public health services (Interviews 2, 3, 16, 18), may inhibit the achievement of viral hepatitis elimination targets (Interviews 9, 10, 16). Public health employees may not be effectively monitoring people with HBV (Interviews 10, 17), and doctors working within puskesmas may not be aware of their role in testing, diagnosing and referring people with viral hepatitis (Interview 12).

Limited knowledge about viral hepatitis is an issue among some clinical specialists. One participant, a clinician working with people co-infected with HIV and HCV, and who was aware of potential interaction between HIV medications and DAAs, noted the resistance of some HIV clinicians in adapting their HIV drug regimens as a result of these interactions (Interview 3). Specialists in gynaecology and obstetrics were also noted as having gaps in knowledge about HBV, resulting in poor referral practices (Interview 3).

3. EPIDEMIOLOGICAL DATA

3.1. Overview

Lack of routine surveillance leads to variation in the availability of epidemiological data on viral hepatitis in Indonesia.

A key issue noted by most interviewees was the lack of reliable epidemiological data available on viral hepatitis resulting in insufficient understanding of the magnitude of viral hepatitis infection in Indonesia to inform the national response²⁵ (Interviews 9, 10). No routine surveillance of HBV or HCV infection is carried out,³⁰ with surveillance data primarily coming from the submission of doctors' reports based on clinical diagnosis, without the serological testing necessary for accurate diagnosis.³⁰

The initiation of periodic surveys on child immunisation coverage (Indonesia Demographic and Health Survey)¹⁸ and viral hepatitis infection rates (Riskesdas)^{12 31} since 2002 and 2007, respectively, has improved the range and detail of national-level data on viral hepatitis. With several rounds of these surveys completed, trends can be charted and geographic areas with greater levels of need can be identified. However, methodological issues with both surveys leave question marks over the accuracy and scope of the data.¹⁴

3.2. Existing prevalence figures



Data suggest the national prevalence of HBV infection in Indonesia may be falling; however, there is a lack of publicly available data on provincial prevalence rates.

Based on the Riskesdas data, Indonesia had a prevalence rate of 7.1% for chronic HBV (HBsAg) and 1% for HCV in 2013,¹² suggesting that a reduction in HBV prevalence had moved Indonesia from high endemicity to moderate endemicity since 2007. The 2007 survey highlighted that hepatitis infection rates vary significantly between provinces, ranging from 0.1% to 1.7% for HCV,¹⁴ and from 2.4% to 19.3% for HBsAg (see Table 2). The 2013 survey again highlighted significant provincial variation, with the highest prevalence rates being found in the east of the archipelago,³¹ possibly due to the lower availability of the HBV vaccine in these areas¹⁷ and a lower percentage of children who received the full vaccination course.¹⁸

Table 2. Provincial HBV infection rates based on Riskesdas 2007 data⁹

Province	HBV infection rate
Bali	5.6%
Bangka Belitung	4.4%
Bengkulu	19.3%
Central Java	6.7%
East Java	10.1%
East Kalimantan	6.4%
Gorontalo	13.0%
Jakarta	5.9%
Jambi	8.3%
Jogja	2.5%
Lampung	17.0%
Nad	12.8%
North Sumatra	11.7%
Riau	2.4%
South Kalimantan	6.6%
South Sulawesi	13.4%
South Sumatra	9.7%
West Java	8.2%
West Nusa Tenggara	5.5%
West Sumatra	15.1%

3.3. Prevalence among vulnerable groups

Haemodialysis patients, people who inject drugs (PWID), and healthcare workers have all been found to be at greater risk of viral hepatitis infection in Indonesia.

Prevalence rates for HCV infection among haemodialysis patients range from 61% to 83.2%,^{15 32 33} with HCV infection found to be independently associated with haemodialysis duration and the number of blood transfusions.¹⁵ The prevalence of HBV and HCV infection among healthcare workers has been estimated at 8.8% and 2.2%, respectively,³⁴ with HBV prevalence rates as high as 13.3%.³⁵

Risk factors include a lack of adherence to infection control guidelines leading to sharps injuries,^{34 36} and low levels of full HBV vaccination among this group.³⁶ HCV infection among PWID has been estimated at 40–80%.³⁷

There is a general lack of data on other potentially vulnerable groups, including men who have sex with men,³⁵ female commercial sex workers,³⁸ and transgender individuals.³⁹

3.4. Lack of confidence in available data



Concerns around the availability and quality of existing data lead to a lack of confidence in reporting figures on viral hepatitis in Indonesia.

'We have to know the magnitude of the problem.' (Interview 17)

Despite the availability of the above figures, many respondents lacked confidence in their ability to provide an accurate picture of the burden of viral hepatitis across Indonesia. This lack of confidence is reflected in the breadth of numbers of people with viral hepatitis quoted by participants during the interviews. Estimates provided ranged from 2.5 million people with HBV to 20 million hepatitis 'patients'. This breadth of misunderstanding of the estimates may not merely reflect a lack of accurate data but also suggests that key stakeholders involved in the response to viral hepatitis in Indonesia may understand the magnitude of the problem in different ways, leading many to query the need for an effective political and programmatic response.

There were also concerns that even when data are collected, they are not effectively disseminated (Interviews 14, 17). One participant described this as a 'culture of hogging' data (Interview 4), whereby data were collected but then not effectively analysed and/or not widely or transparently disseminated. Some of this occurred as a result of personnel changes within Riskesdas or the Ministry of Health, where 'the data is lost' (Interview 15) after being kept by individuals, rather than being held by the position the individual was employed in.

3.5. Factors contributing to inaccuracy of available data

Provincial gaps in data, limited data from the private healthcare sector, inconsistency in data collection and a lack of training and skills among personnel are the key factors potentially compromising the quality of data on viral hepatitis.

'If there is no good recording and not good reporting from the health services, the government cannot [know] how much money to allocate for this one.' (Interview 7)

Limitations to existing data may stem from four main factors:

- i. **Gaps in available data from certain provinces:** The decentralisation of the Indonesian health system means that surveillance data must be collected from all districts and provinces – and gaps inevitably occur. One participant noted that the central government receives less than 70% of the monitoring and data reports from provinces.
- ii. **Limited data from private hospitals:** The private sector accounts for a significant proportion of health provision in Indonesia, yet private sector services are not obliged to submit clinical reports to the government (Interviews 7, 19), so these data are often absent from any national epidemiological estimates.²¹
- iii. **Lack of standardisation in data collection:** Each hospital, district and province often constructs its own health information system (SIKDA), leading to potential overlap, duplication and inconsistencies. As a result, aggregated data may be difficult to interpret at a central or national level.²¹ Both the types of data and how they are collected may vary between sources.
- iv. **Inadequate training and skills in data collection overall:** Finally, decentralisation of the healthcare system means that the quality of available data is often 'variable' (Interview 15). Many centres lack the necessary skills and research methodologies to adequately analyse data available (Interview 15). Data analysis is thus often outsourced to universities – with little focus on trying to examine epidemiological patterns over time (Interviews 4, 15, 19).

4. PREVENTION

6.6%



Fundamental public health programmes to tackle viral hepatitis are hindered by a reduction in spending on preventive services: in 2014, it was estimated that just 6.6% of total health expenditure went on prevention and public health services.²¹

Public health interventions are fundamental to prevent transmission of viral hepatitis. For HBV, this includes childhood vaccination and the provision of immunoglobulin to prevent mother-to-child transmission. For HCV, it consists of infection control, particularly within healthcare settings, and the operation of the needle and syringe programme. Indonesia has seen an increase in public health spending over the last decade; however, the government's focus on the health insurance mechanism means funding has principally addressed curative services. As a result, preventive programmes, public health services and health promotion have suffered from relative neglect and underfunding. This inattention has directly impacted the range and scope of the preventive measures in place to address viral hepatitis, and resulted in a lack of national policy relating to screening and referral to care.²⁵

4.1. Prevention of hepatitis B

4.1.1. Childhood immunisation

Indonesia's childhood immunisation programme against HBV has been largely successful, but notable gaps remain.

Since 1997, the cornerstone of HBV prevention efforts in Indonesia has been the routine immunisation of all newborns as part of the National Immunization Program,⁴⁰ which has led to a gradual and significant decline in the incidence of HBV.

High numbers of children are now receiving the full course of the vaccine, with official country figures estimating that 73% of the target population received the final vaccine dose in 2012, rising to 84% in 2015;⁴¹ WHO estimates are 83% and 81%, respectively.⁴¹ Innovation has also occurred with the introduction of a prefilled, single-use injection device (Uniject) to deliver the first full dose of HBV vaccine.⁴² This device can be stored by community midwives in their own homes, allowing babies born outside of healthcare settings to receive the first dose of the vaccine within the optimum period after birth.

However, despite this innovation, newborns do not always receive the birth dose of the vaccine within 24 hours, as is recommended by WHO guidelines, because in Indonesia the protocol is for the first dose to be given within one week (Interview 2).^{43 44} This protocol is likely to have an impact on the rates of perinatal transmission of HBV, as the vaccine alone is most effective at preventing horizontal transmission from mother to child if it is administered within 24 hours of birth, with effectiveness declining progressively in the subsequent days.⁴⁵

Despite the overall success of the vaccination programme, there are large discrepancies in vaccination coverage between provinces.¹⁸ Factors affecting coverage include an unequal distribution of the hepatitis vaccine,¹⁷ a high number of home births,^{46 44} and a lack of general health education around the vaccine.⁴⁷

There are also question marks over the future sustainability of the programme, as the support given for the pentavalent vaccine by Gavi, the Vaccine Alliance – which has amounted to more than US\$44 million since 2000⁴⁸ – will end this year.⁴⁹

A further concern is that there is no national catch-up vaccination programme for people who missed out on the birth dose (Interview 2). There is also no systematic provision of immunoglobulin across the provinces, with one participant noting that 'if the mother lives in Papua, in Maluku, Sulawesi, there's no free immunoglobulin, they should buy it and it's very expensive for them' (Interview 10).

4.1.2. Mother-to-child transmission

There is no national screening programme for HBV among pregnant women in Indonesia,³⁰ and mother-to-child transmission of HBV remains a significant risk.⁵⁰

The risk of mother-to-child transmission is exacerbated by low levels of health literacy, with expectant mothers not always knowing whether they have received immunisation.⁵⁰

Box 2. Mother-to-child transmission: what are the risks?

- Each year, around 150,000 pregnant women are estimated to be at risk of transmitting HBV to their babies.⁵
- 5–10% of infants born to HBV-infected mothers are likely to become infected themselves⁴⁰ – so potentially 7,500–15,000 cases per year.

Even when the mother's HBV infection status is known, the high cost of the HBV immunoglobulin treatment means that newborns do not always receive it.⁴⁰ The national government has recognised this, and is providing budgets to a limited number of provinces to begin screening pregnant women for HBV.²⁵ However, to have significant impact the scheme will require further expansion and continued investment beyond the end of the pilot, as well as active implementation from district and provincial governments.

4.1.3. Prevention control in healthcare settings



In 2005, sharps injuries led to an estimated 1,445 infections with HBV and 399 infections with HCV among healthcare workers;³⁴ however, a lack of available data and potential under-reporting means that the actual numbers, and potential risks, may be higher.

There has not been a specific national strategy for implementing appropriate infection control practices against HBV and HCV infection in healthcare settings.³⁰ For example, there is no government programme to vaccinate healthcare workers against HBV,³⁰ and there is no scheme to cover the cost of post-exposure treatment. Even when infection control strategies exist within healthcare settings, studies have suggested that healthcare workers are often not aware of, or do not adhere to, appropriate infection control practices.³⁶ This situation not only puts healthcare workers' health at risk, but also the health of their patients, with haemodialysis patients in particular being found to have extremely high rates of hospital-acquired viral hepatitis.³³

4.1.4. Harm reduction strategies for people who inject drugs

The provision of harm reduction services for PWID in Indonesia is inadequate, including in correctional facilities, despite evidence that high levels of injecting drug use occur in prisons.

Harm reduction services and strategies for PWID are an important part of preventive measures to reduce viral hepatitis transmission, as this is a vulnerable group for infection. However, provision is inadequate in Indonesia: while the number of needle and syringe programme services and sites offering methadone maintenance therapy has increased,⁵¹ provision is still low according to UN guidelines,⁵² with the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimating that only 44 syringes are distributed per PWID per year.⁵³

While harm reduction programmes for PWID have benefited from at least nine supportive national regulations since 2009,⁵¹ legal provisions diverting people from prison and towards drug rehabilitation are rarely implemented; the percentage of prisoners incarcerated for drug-related offences grew significantly from 10% of all prisoners in 2002 to 31% in 2016.⁵⁴ Evidence suggests that high levels of injecting drug use also occur in prisons;⁵⁵ however, harm reduction services in correctional facilities are extremely limited. There is no provision of sterile injecting equipment,⁵⁶ despite its recommendation by WHO, UNAIDS and the United Nations Office on Drugs and Crime (UNODC),⁵⁷ and there is a severe shortage of opiate substitution therapy.⁵⁸

4.1.5. Harm reduction measures – including nosocomial transmission

Sterile injecting equipment is being distributed through many puskesmas (community health clinics), with up to half of those in Jakarta providing this service (Interview 11). However, several issues affect the needle and syringe programme's potential to reduce HCV transmission:

- The procurement and disbursement of needles and syringes previously occurred through the now-disbanded National AIDS Committee, and no alternative dissemination strategy has been established (Interview 4).
- The number of people injecting drugs has decreased due to the expense of injectable drugs, and there are concerns that this reduction may hamper practical and strategic support of the programme (Interviews 4, 6, 19). The programme is already experiencing lower levels of support than other HIV-related public health interventions (Interview 4).
- There is a general lack of commitment to harm reduction from the Ministry of Health, in spite of a ministerial decree in support of the programme (Interview 11). Continuing support of the programme is needed in case the numbers of PWID increase, as has occurred in other countries (Interview 4).
- In 2016, the current President claimed support for the Philippine response to drug use. Respondents explained that, as Indonesia is an island state (Interview 5), drugs are imported by drug suppliers operating from foreign countries, and the President needed to be seen to 'display strength' (Interview 4) to an increasingly conservative populace (Interviews 4, 7).

5. TESTING AND DIAGNOSIS



It has been estimated that, at most, 10% of the HCV-infected Indonesian population is aware of their infection.⁵⁹

The testing and diagnosis of viral hepatitis has several objectives: for the person with viral hepatitis, to understand that they are infected and be provided with information to reduce the impact of the infection; to identify the clinical state of the infection; and to provide data to the health system. The development of an effective process for the delivery of testing and diagnosis services is an essential element in the elimination of viral hepatitis, with this issue affecting access to clinical management services including access to treatment.

5.1. Underdiagnosis and low levels of testing

'The length of survival after a diagnosis of liver cancer had not changed between 2000 and 2016.'
(Interview 1)

Underdiagnosis is a prominent issue for viral hepatitis in Indonesia, and occurs for a variety of reasons. Low levels of health literacy may be a contributing factor, with patients not knowing, for example, whether they have received primary HBV immunisation.⁵⁰ Several participants noted the challenge of viral hepatitis being largely asymptomatic (Interviews 9, 10, 18), affecting people's willingness to be diagnosed, particularly if they have to pay for this test. Most people only present to clinical specialists after symptoms appear – which, given the natural history of the infection, is when cirrhosis or even liver cancer has developed – and thus have very poor prognosis (Interviews 9, 10). This reduces the role of the specialist to being one of palliative care, rather than improving liver health and preventing chronic liver disease for infected patients.

According to our interviews, the lack of testing is less of a problem for people who identify as being at greater risk of exposure to HCV, such as PWID who, while knowing that they may have been at risk given their injecting behaviour, are also provided with cost-free access to testing. However, given that PWID only represent a small proportion of people with HCV in Indonesia, the vast majority of people with HCV remain undiagnosed and are unable to take steps to reduce the impact of the infection. Estimated rates of underdiagnosis in people infected with HBV were not available.

5.2. Geographic disparities in access to testing

Improvements are being made to ensure there is effective testing technology available across Indonesia, and that a full range of tests for viral hepatitis is obtainable. However, the decentralisation of the healthcare system means that the necessary facilities are not available in every district, or even every province, restricting people's ability to identify whether they are infected, and as a consequence to undertake necessary measures to reduce further transmission.

For example, respondents noted the following gaps in access:

- One clinician located in Jakarta stated that a key barrier to the elimination of viral hepatitis was lack of access to rapid direct testing technology. The lack of this technology meant that patients needed to be referred to private laboratories where this testing was expensive (Interview 3).
- Access to PCR testing varied across the country (Interviews 7, 9).
- The number of Fibroscan machines available was limited across the country; however, availability of access to GeneXpert was thought to be increasing (Interviews 6, 7).
- Serologic testing for HBsAg, anti-HBs, HBeAg, anti-HBe, anti-HBc is available in some provincial hospitals in Indonesia.
- HBV-DNA and HCV-RNA testing are only available in larger cities.
- HCV genotype testing is restricted to Jakarta.

5.3. Financial barriers

'You have the test, and don't eat for a month.' (Interview 5)

Even when physical access is not an issue, the price of diagnostic tests acts as a significant barrier to diagnosis. These are not covered under the National Health Insurance scheme, and the cost must be met by the patient.³⁰ At present, the only mechanism that exists for free HBV and HCV testing for the general population is through a person providing a blood donation to the Red Cross, which coordinates Indonesia's blood donation and supply system.²⁵

Tests, particularly when accessing treatment, include a number of components, including antibody, antigen, viral load and genotype (Interviews 2, 3, 5). The WHO reports that the price for HCV testing and pre-treatment assessment can be as high as US\$580,⁶⁰ while the average income in Indonesia is only US\$330 per month (Interview 6).

Figure 2. Cost of supporting diagnostic tests for HCV⁶⁶

- Hepatitis C antibody test: US\$25–30 (IDR 250,000–300,000)
- Hepatitis C RNA test: US\$120 (IDR 1,200,000)
- Hepatitis C genotype test: US\$325 (IDR 3,250,000)
- Abdomen ultrasound: US\$25–30 (IDR 250,000–300,000)
- Liver functions tests: US\$7.50 (IDR 75,000)
- Liver biopsy: US\$60 (IDR 600,000)
- Fibroscan: US\$85 (IDR 850,000)

Source: PKNI (2013). The urgent need for improved hepatitis C prevention, care and treatment for people who inject drugs in Indonesia.

For each of the test components there are exclusions for payment, including whether a person is at high risk of HIV infection, or has been diagnosed in a hospital. Ability to pay affects access to testing services (Interview 3), sometimes even when there is a clear public health rationale for conducting the tests, such as the testing of close family members of a person who has been diagnosed with HBV (Interview 13).

Diagnostic services are not routinely incorporated into harm reduction activities for PWID,⁶¹ despite a desire from this group to get tested.⁶²

5.4. Limited information given to people being tested

A further issue of concern is the quality of the information provided to people who have received testing for viral hepatitis. There is no systematic testing policy developed or implemented. This means that individuals diagnosed with viral hepatitis are not necessarily told about the implications of the infection – such as how they may respond to the infection – or provided with referral information. For example, one respondent suggested there was clear evidence that women tested and diagnosed through antenatal testing often remained unaware of their infection (Interview 10).

6. TREATMENT

In 2013, an estimated 350 people were treated for chronic HCV out of a potential 1,007,022 in need (0.03%).⁶³ Other research has put the number even lower, at only 230 patients (<0.01%).⁵⁹

Treatment rates for viral hepatitis in Indonesia are low, which is unsurprising given how few people are tested for HBV or HCV. Publicly available national data on treatment access for HBV are not available; however, one would assume that they are similar to those for HCV.

6.1. Drug coverage through the National Health Insurance scheme

Indonesia has taken important steps to increase healthcare access with the creation of the National Health Insurance scheme. The cost of treatments for drugs listed on the essential medicines list is now fully covered; previously, free treatment was restricted to government employees and those with private health insurance.³⁰ Drugs covered currently include pegylated interferon, lamivudine, adefovir dipivoxil and telbivudine for HBV, and pegylated interferon and ribavirin for HCV.³⁰ DAAs are not yet covered, despite being able to cure more than 90% of people with chronic HCV infection with an 8–12-week course,⁶⁰ and being recommended in Indonesian treatment guidelines.⁶⁰

Unfortunately, the fact that the supporting tests to assess whether and what treatment is feasible are not covered by the National Health Insurance, along with limited availability of testing facilities (as described previously),¹²¹ nullifies the potential benefit of accessible treatment for much of the population. As mentioned previously, testing can cost as much as treatment itself.⁶⁰

6.2. Access to direct-acting antivirals

Despite the lack of official coverage of the cost of DAAs, efforts are being made to make these drugs accessible to the population. The hepatitis sub-directorate is currently overseeing a pilot scheme which will provide free DAA treatment in the form of sofosbuvir, simeprevir and ribavirin for 6,000 people infected with HCV.²⁶ Access to the programme is limited to six provinces through 13 specialist services, primarily located in Jakarta. The location of these hospitals is likely to affect the breadth of people being able to access the free treatment (Interview 2). Concerns were expressed that this pilot programme is funded by the Ministry of Health rather than through the National Health Insurance scheme, which may compromise the chances of getting DAAs funded by the National Health Insurance scheme in future (Interviews 2, 6).

Respondents also expressed concerns that the lack of accurate information about the treatment programme limits the number of people accessing the treatment (Interviews 13, 19). For example, some hospitals limit access to treatment to people co-infected with HIV (Interview 13), and among respondents there were competing understandings of whether access to the government programme was only for people with a fibrosis score above F3 (Interview 7) or for anyone with HCV. Moreover, there appears to be no systematic promotion of the DAA treatment programme, with participants noting the use of peer education to inform people about its availability (Interview 3).

Aligned to this programme is the Clinton Health Access Initiative, which is supporting the pilot by providing sofosbuvir and daclatasvir for 2,000 people with HIV/HCV co-infection, as the simeprevir regime can interact with the antiretroviral drugs widely used in Indonesia.⁶⁴ However, this represents a tiny proportion of the infected population, and is restricted to the segment of the population who are aware of their HCV infection.

Generic versions of DAAs also have a role to play. Indonesia is now able to buy the cheaper generic versions of sofosbuvir,⁶⁵ the single-tablet regimen of ledipasvir/sofosbuvir and the investigational single-tablet regimen of sofosbuvir/velpatasvir, reducing the price of a 12-week course dramatically.⁶⁰ Nonetheless, the government would need to make a huge investment to provide DAAs as part of the National Health Insurance scheme. Conversely, without being covered by the scheme, DAAs will remain beyond the means of most Indonesians.⁶⁶ However, the immediate economic savings made by the government through restricting access to DAAs are likely to be negated as people with untreated HCV progress to cirrhosis and cancer and require more extensive medical care.

6.3. Access to hepatitis specialists

It is estimated that only 5% of people with viral hepatitis in Indonesia are able to access treatment (Interview 2).

The limited number and geographic spread of available hepatitis specialists is an important barrier to proper treatment and care for patients (Interview 2). Clinical management for viral hepatitis in Indonesia, including treatment with DAAs for HCV, is conducted primarily by gastro-hepatologists. There are only 165 gastro-hepatologists in Indonesia, most of whom are located in Jakarta and surrounding areas.⁶⁷ Approval to prescribe treatment is being expanded to include internists, who are general practitioners who have received additional training. Currently, approximately 50 of these internists are available to provide treatment, although their geographical spread is unclear. Another limit to treatment access was that some gastro-hepatologists may not be interested in responding to viral hepatitis, given the greater financial rewards involved in other clinical procedures (Interview 10).

The limited availability of specialists invariably leads to long delays in access to treatment for a number of patients (Interview 14). One respondent stated that the delay in seeing a clinician had resulted in the death of a friend from liver cancer (Interview 13). In addition, some clinicians only provide 28-day prescriptions for DAAs (Interviews 2, 3), as they fear treatment could be sold on the black market (Interviews 3, 8, 16). While short prescription duration causes no problems for people living close to a treatment service, it may be very problematic for patients living far from these services: one patient had flown for two and a half hours from his home in Batam to attend a specialist clinical service to get his DAA treatment, and was required to do this each month during his treatment.

7. COMMUNITY ENGAGEMENT

Patient advocacy is poorly developed, and not given due recognition in hepatitis – in fact, non-government organisations are often seen as a threat (Interview 16).

While the new Ministerial Regulation highlights the importance of ‘active participation of society’, it is unclear what means are in place to encourage this participation. The only mention of people with HBV in the regulations is to support people with HBV in maintaining treatment adherence. Stigma and discrimination are specifically mentioned in the regulations, although no activities are proposed to address these issues except for increasing public awareness about viral hepatitis. This differs from other issues, such as vaccination and clinical management, in which detailed expectations are highlighted in the policy.

There is also no formal patient representation on the expert committee on hepatitis. Representatives of the Komunitas Peduli Hepatitis, a non-government organisation which receives no government or philanthropic funding, have regularly been sought to provide advice to the Ministry of Health. However, there is no systematic provision of advice to the expert committee from people with, or at risk of, viral hepatitis.

While several community-based organisations conduct significant grassroots activities which address viral hepatitis in Indonesia, a lack of funding is constraining their impact and their sustainability over time. All of the community development activities conducted by Komunitas Peduli Hepatitis are self-funded by individuals affected by viral hepatitis. Similarly, while evidence indicates that community-based organisations in Indonesia are more effective at preventing needle syringe sharing than community health centres,⁶⁸ there is very limited opportunity for these organisations to receive government funding, and continuous donor funding is often uncertain, leading to the cessation of services. For example, USAID stopped supporting community-based needle and syringe programme services in late 2009, which left many of these organisations with inadequate funding to continue.⁶⁹

8. SOCIAL IMPLICATIONS OF HEPATITIS

'Last week, I met a patient, a lady with hep B. There are six in the family and two of them already died to hepatocellular carcinoma, and the other four have hep B.' (Interview 10)

Viral hepatitis, particularly HBV given its transmission route, has a significant familial impact in Indonesia which is often felt across generations. Yet inadequate knowledge about the infections and marginalisation remain a critical issue for many people with hepatitis. Views of respondents on this, however, were mixed. One participant noted that one Indonesian media star had described the shame of dying with darker skin, which often occurs for people with cirrhosis, and which would lead people to think that they had sinned (Interview 10). Several participants reported being unaware of any marginalisation occurring as a result of infection or being at risk of viral hepatitis (Interviews 5, 7). In spite of this, some noted that selective disclosure of the infection occurred, reflecting a fear of marginalisation (Interviews 2, 9) and a lack of accurate information about the infection (Interviews 2, 13), and where one respondent noted descriptions of the virus being a 'congenital disease, or inherited disease, or people with hepatitis cannot have children' (Interview 9). Testing for viral hepatitis was reported to be occurring by some multinational companies and universities (Interviews 4, 10, 13), where a positive result for viral hepatitis infection would result in people being sacked or excluded (Interview 10).

'Her son cannot continue to the university due to him getting hepatitis B.' (Interview 13)



DISCUSSION AND CONCLUSIONS

1. DISCUSSION

Indonesia has made significant progress in addressing the challenges posed by viral hepatitis, but further action is required in each of the five strategic directions from the WHO's *Global Health Sector Strategy on Viral Hepatitis 2016–2021* if elimination of viral hepatitis as a major public health threat is to occur by 2030.

Strategic direction 1: Information for focused action

Indonesia has improved the level of data it collects on viral hepatitis; however, its response to HBV and HCV is hampered by the lack of both a distinct evidence-based national hepatitis strategy, and a robust strategic information system to analyse and translate up-to-date data on viral hepatitis into usable information. The development of the Ministerial Regulation no. 53 on the National Control of Hepatitis and the formation of the hepatitis sub-directorate have progressed the national policy response. However, a 'National Hepatitis Strategic Plan' was not mentioned by any of the key stakeholders interviewed, including those within the hepatitis sub-directorate. Without a distinct national hepatitis strategy with a well-defined governance and management structure – or clear national targets to monitor, evaluate and report on the national hepatitis response – interventions are unlikely to achieve the level of coordination and efficiency needed to eliminate viral hepatitis.

Significant development and expansion of data collection and use for viral hepatitis is needed in Indonesia in order to set national targets, plan for a focused response, advocate for resources and efficiently implement programmes. Despite having some methodological issues, the Riskesdas surveys have helped to improve the data available to public health officials. These surveys represent an impressive achievement, providing data on all of Indonesia's provinces despite the logistical difficulties of collection. However, for these data to translate into positive action they will need to be effectively analysed, and widely and transparently disseminated.



Strategic direction 2: Interventions for impact

The range of essential interventions, services and medicines aimed at addressing viral hepatitis in Indonesia has increased; however, gaps exist, and further expansion and parity of access are needed.

Indonesia now implements a range of interventions across the continuum of hepatitis services. However, many of these, such as harm reduction services for PWID, require significant scale-up to meet the current levels of need. There also remain large discrepancies in the availability of critical services, such as hepatitis-testing facilities, as a result of the different capacities and capabilities of local governments, combined with the geographic, cultural, economic and health-related diversity of provinces and districts.

For Indonesia to meet the WHO's goal of eliminating viral hepatitis as a major public health threat by 2030, an essential benefit package of viral hepatitis interventions, services, medicines and commodities needs to be clearly defined at the national level. The lack of a distinct, evidence-based national hepatitis plan, informed by robust strategic information and community engagement, is likely to be contributing to the gaps in service provision that currently exist, and impacting on the efficacy of new interventions. For example, treatment rates for viral hepatitis are likely to stay low despite the cost of most treatments now being covered, due to the omission of diagnostic tests from the coverage of the National Health Insurance scheme and the lack of interventions to raise public awareness of the need to get tested.

Strategic direction 3: Delivering for equity

Indonesia has made progress in achieving equitable access to hepatitis services; however, interventions aimed at vulnerable groups require scale-up, stigma and discrimination must be better addressed, and healthcare and community workers need to be better supported. Interventions targeting vulnerable groups have increased, with the provision of cost-free HCV testing for these populations and a small increase in harm reduction-activities for PWID. While these are positive steps, significant scale-up of these interventions is necessary if viral hepatitis is to be eliminated among vulnerable groups. Existing models of service delivery must also be adapted to better meet the requirements of these groups, and service gaps filled, such as a vaccination programme for healthcare workers. However, the development of these interventions may first require increased routine surveillance of vulnerable populations to better understand their needs, to generate the necessary data for targeted action, and to secure funding.

There does not appear to be any concerted move to end policies and practices that condone or encourage stigma and discrimination against people at risk of, or living with, hepatitis – despite viral hepatitis infection potentially leading to exclusion from places of work and study. To ensure that stigmatisation, discrimination and a fear of social marginalisation do not impede these groups' access to hepatitis services, legal, regulatory and policy reform may be needed. An encouraging example of where this has already occurred is the initiation of legal provisions for diverting PWID away from prison and towards drug rehabilitation, although these provisions will need to be used more frequently to impact on the viral hepatitis burden of this community.

To deliver equity in services, and move closer to the elimination of viral hepatitis, the lack of expertise in HBV and HCV noted among public health employees will need to be tackled. Defining the core hepatitis competencies of different cadres of health workers may help to highlight their training, accreditation and supervisory needs. Community-based organisations, and their role in linking people with chronic hepatitis to care, also require recognition and support.

Strategic direction 4: Financing for sustainability

Indonesia has significantly reduced the financial barriers to hepatitis services with the creation of the National Health Insurance scheme; however, to eliminate viral hepatitis, preventive public health interventions need to be prioritised, and funding mechanisms to cover the cost of diagnosis services and DAAs may need to be introduced, both supported by a robust viral hepatitis investment case.

To eliminate viral hepatitis, interventions need to be provided along the entire hepatitis continuum of care. To achieve this, Indonesia may need to shift some of its focus away from the health insurance mechanism and funding principally for curative services, and instead focus resources on preventive public health interventions. The pilot providing budgets to screen pregnant women for HBV represents an encouraging move in this direction but, to have significant impact, further expansion and continued investment will be needed.

Indonesia has addressed some of the economic obstacles to hepatitis services with the creation of the National Health Insurance scheme. The scheme's coverage of hepatitis treatments listed on the essential medicines list, as well as HCV testing for vulnerable groups, has reduced the need for out-of-pocket payments, helping to provide protection against health-related financial risk.

Critically, though, the progress already achieved by the National Health Insurance scheme may be curtailed without a mechanism to cover the cost of diagnostic tests for the general population. These costs are beyond the financial means of most Indonesians, preventing access to free treatment.

Further investment in testing facilities and trained personnel will also be required, at both the national and regional level, to address the unequal spread of testing facilities across the archipelago, and ensure that Indonesians' access to testing is not restricted by their geographic location.

The move by the hepatitis sub-directorate to cover the cost of free DAA treatment for 6,000 people infected with HCV is an encouraging first step towards achieving financial parity in access to these important medicines. However, to have a significant effect on infection rates, the cost of these drugs will need to be covered under the National Health Insurance scheme, at least for significant sections of the population, requiring a huge government investment.

A robust viral hepatitis investment case is required to achieve adequate funding for the range of health interventions needed to eliminate viral hepatitis, both to advocate for adequate allocation of domestic resources and to mobilise external funding support. This is particularly important given the current environment where health spending remains low, despite significant economic growth, and international aid for healthcare has reduced.

Strategic direction 5: Innovation for acceleration

Indonesia has seen limited innovation in its response to viral hepatitis; developing new innovative approaches would provide opportunities to improve the efficiency and quality of services and move closer to the elimination of viral hepatitis.

The use of the messenger service WhatsApp represents an innovative approach to tackling the logistical challenges of an island nation, with public health workers, government officials, and grassroots community organisations providing information on viral hepatitis to a range of stakeholders. The introduction of a prefilled injection device (Uniject) to deliver the first full dose of the HBV vaccine, which can be stored in community midwives' homes, also represents an innovative approach to meeting the difficulties of vaccinating infants born outside of healthcare settings.

However, further innovation concerning the existing medicines, technologies and service delivery may be needed, with collaboration between researchers and policymakers to ensure that research findings are translated into practice on a sufficient scale.

2. CONCLUSION

Indonesia has made considerable progress in each of the five 'strategic directions' from the WHO's *Global Health Sector Strategy on Viral Hepatitis 2016–2021*, although significant further action is required if it is to meet the goal of eliminating viral hepatitis as a major public health threat by 2030.

With targeted interventions at the national, regional and local level to create a more informed, efficient and coordinated national hepatitis response, the elimination of viral hepatitis in Indonesia is an achievable goal.

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