



# Holding Governments Accountable

World Hepatitis Alliance Civil Society Survey  
**Global Findings Report**



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### Executive Summary

In May 2016, the 194 Member States of the World Health Organization adopted the Global Health Sector Strategy on Viral Hepatitis, 2016-2021 (GHSS). The Strategy sets a goal of eliminating hepatitis B and C by 2030 and includes a number of priority actions for countries which, if reached, will strengthen health systems, reduce annual deaths by 65% and increase treatment to 80%, saving 10<sup>1.2</sup> million lives globally in the next 13 years. Prior to this historic resolution two other resolutions relating to hepatitis were adopted, in 2010 and 2014. These resolutions included key clauses which urged governments to address stigma and discrimination, involve civil society in their response to viral hepatitis and use World Hepatitis Day as an opportunity for improving awareness and education.

The purpose of this survey was to ask civil society to evaluate how their governments are doing in regards to these earlier resolutions. An ongoing political commitment to the clauses set out in these resolutions is required as reaching them will bring countries closer to achieving the elimination of viral hepatitis. The survey also aimed to measure the level and types of stigma and discrimination experienced in countries.

Responses were received from 72 countries with every region reporting that stigma and discrimination is experienced by the affected community. The outcomes of this on people living with viral hepatitis are far-reaching, impacting not only on their ability to access diagnostics and treatment but on their personal lives, mental health and ability to earn. Despite this, few respondents felt that their government was effectively addressing it on a national level, making stigma and discrimination a significant barrier to the elimination of viral hepatitis. The survey revealed that civil society have had little involvement in their government's response to stigma and discrimination and only marginally more in the national response to viral hepatitis, and this must change if we are to reach elimination. World Hepatitis Day is an opportunity to both work with civil society and increase awareness of hepatitis, but despite the commitments made at the World Health Assembly in 2010 we are yet to see all countries acknowledge the day. The Civil Society Survey shows that there is much to be done if countries are to honour the commitments they made in 2010 and 2014. Doing this will be an essential part of achieving the elimination targets set out by the GHSS.

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## Survey Background

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### Survey Background

The survey was developed by the World Hepatitis Alliance (WHA) with input from the World Health Organisation (WHO) and Glasgow Caledonian University (GCU). It was designed alongside the WHO Country Profiles Report and, while the surveys are different, they were designed to be complimentary.

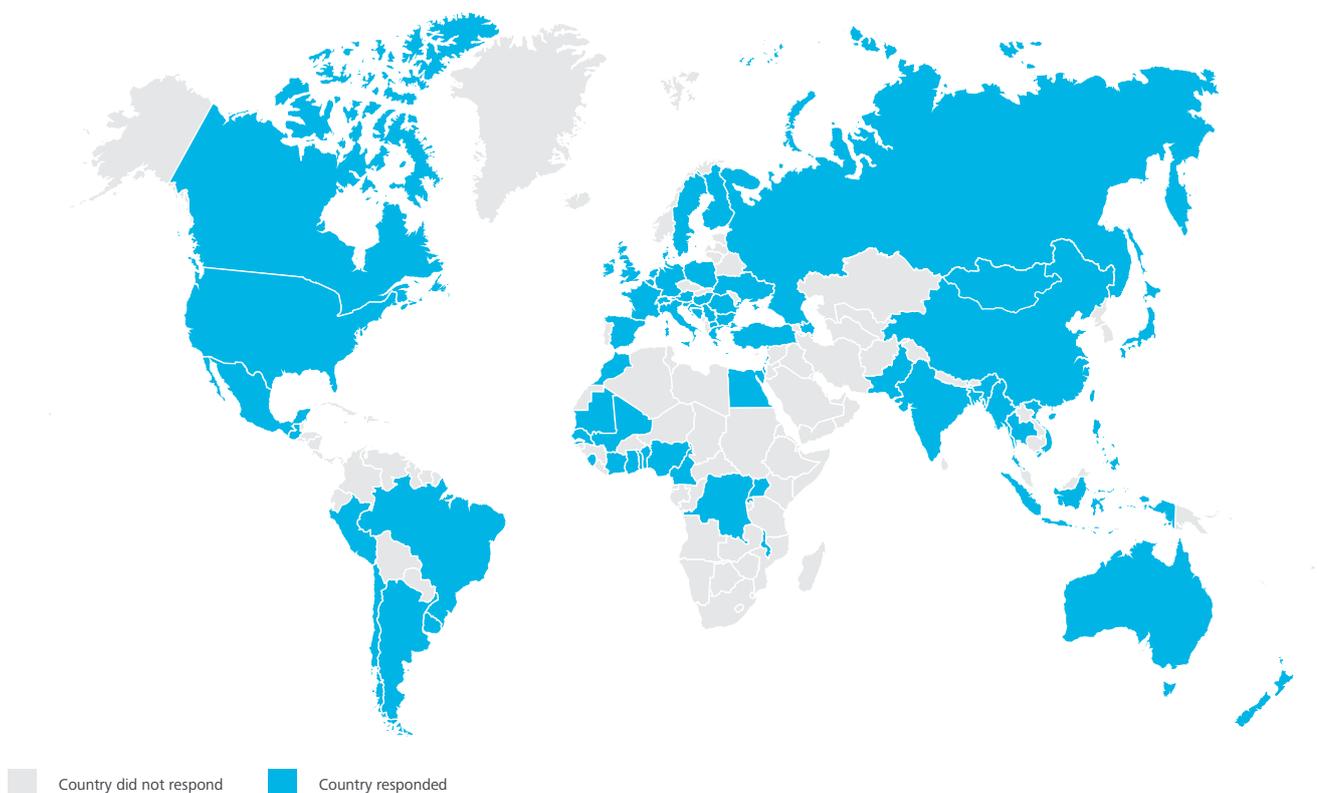
The survey was translated into French and Spanish and was circulated in October 2016. It was sent to all 245 members of the World Hepatitis Alliance, who are civil society organisations working in viral hepatitis in 82 different countries.

Responses were collected from October 2016 to February 2017 with a total of 156 responses received from 72 countries. Seven of these responses were received from civil society organisations who were not members of the World Hepatitis Alliance but who work in viral hepatitis. Three of these responses were from countries where WHA did not have members at the time, increasing the range of countries represented.

#### Potential limitations of the survey include:

- Need for access to internet
- Bias of organisations
- Small sample size

However, the responses obtained are from a diverse range of countries with a wide geographic spread and so the findings should be indicative of the global situation. The results of this survey highlight the opinions and experiences of civil society organisations from the 72 countries represented.



## Stigma and Discrimination

Globally 325 million people are living with chronic viral hepatitis B and C. These life-threatening infectious diseases cause 1.3 million deaths every year<sup>3</sup> and are responsible for one in every 12 cancer deaths<sup>4</sup>. In 2016, the 194 member states of the World Health Assembly committed to eliminating viral hepatitis; however, this will not be possible without overcoming barriers to access for those living with these diseases.

### What is stigma and discrimination?

Stigma is a negative attitude held by society that discredits a person or group because of a particular attribute, such as an illness. This negative belief is often related to a lack of understanding about the disease or illness, in particular transmission, for example where it is believed the illness is self-inflicted as a result of lifestyle choices.

The stigma surrounding hepatitis is due in part to a lack of understanding of the disease and its transmission routes. In many countries it is closely linked with injection drug use<sup>5,6</sup>. While this is one route of transmission, the large majority of hepatitis C transmission is through unsafe healthcare practices, including the use of unsterilised equipment and poorly-screened blood transfusions, and hepatitis B is most often passed from mother to child during birth.

Discrimination is the behavioural consequence of stigma and it means treating an individual unfairly or unjustly because they have certain characteristics.

Stigma and discrimination are not only faced by those living with viral hepatitis but are also experienced by at-risk groups, such as people who inject drugs and men who have sex with men. The stigma and discrimination they face can make them more vulnerable to contracting hepatitis as the subject may not be discussed and important prevention information shared or they may feel unable to come forward and take advantage of any prevention programmes available.

### How common is stigma and discrimination?

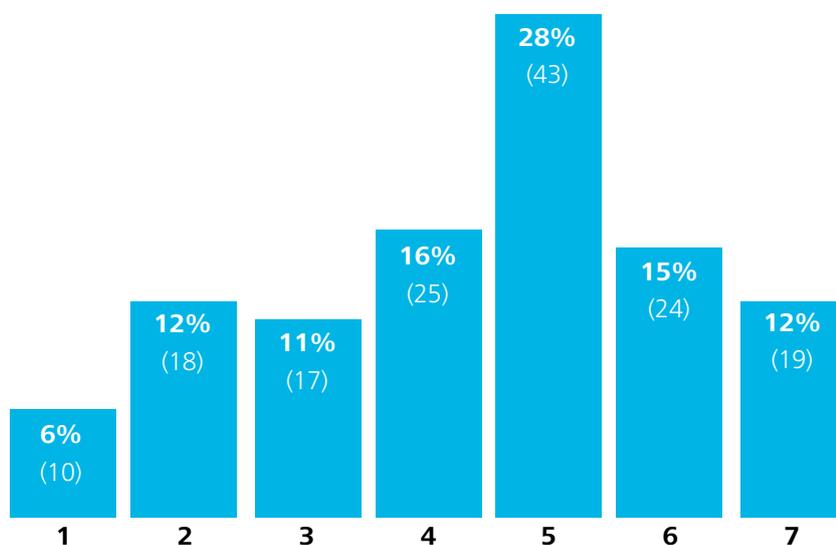
Of the 72 countries that responded only 5 reported that there was no stigma or discrimination in their country. This means that, 93% of countries in the response group reported stigma and discrimination to some degree towards those living with viral hepatitis.

#### Countries who reported no stigma or discrimination:

- Taiwan
- Sierra Leone
- Romania
- Malawi
- Gambia

# Stigma and Discrimination

Level of stigma and discrimination in their country



(156 responses) Respondents were asked to rate the level of stigma and discrimination in their country on a scale of 1-7, where 1 indicates that there is no stigma and discrimination, 4 that there are moderate levels of stigma and discrimination and 7 that there are extremely high levels of stigma and discrimination.

More than half of respondents felt that in their experience the level of stigma and discrimination in their country towards those living with viral hepatitis was moderate to high (59%), with just over 10% reporting extremely high levels.

Global average for low levels of stigma and discrimination



Global average for high levels of stigma and discrimination



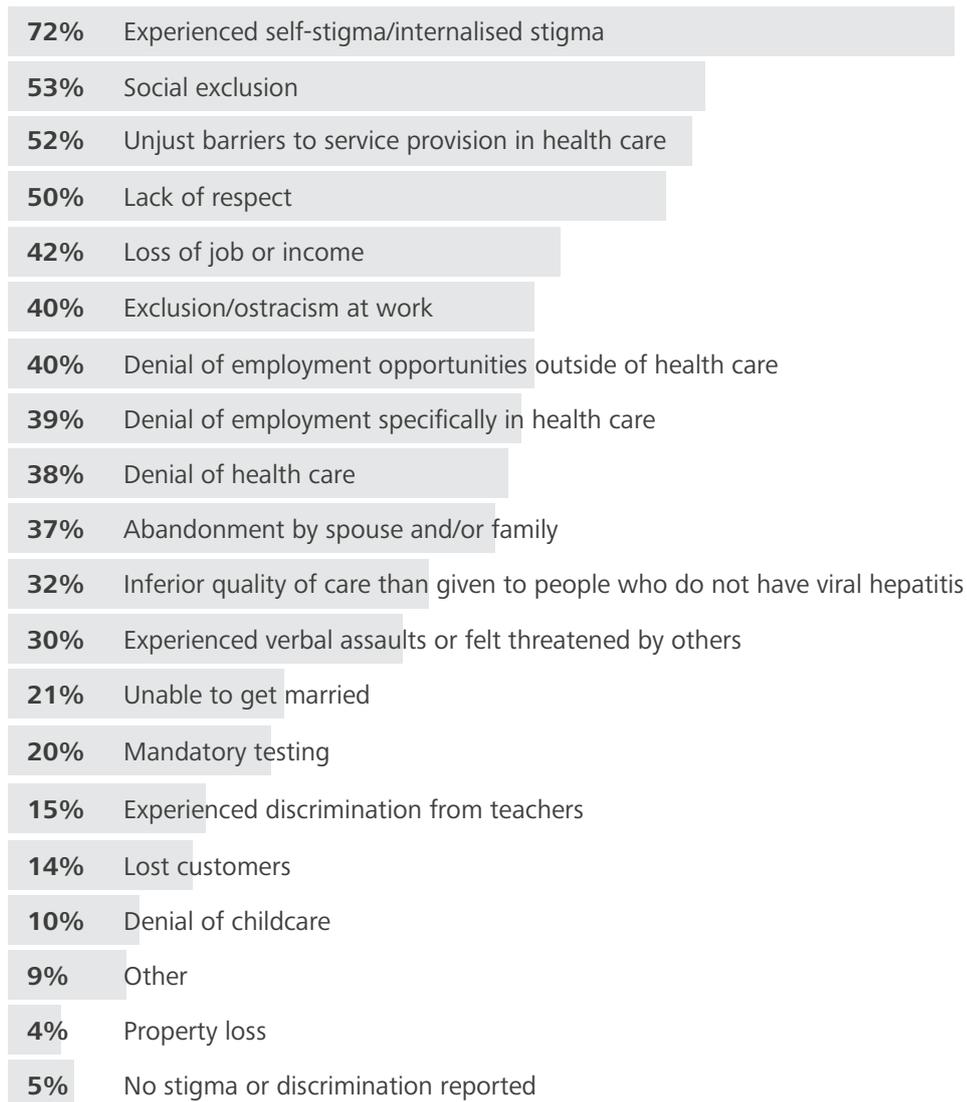
Examining this at a regional level shows variations in regions from the global average above. The Pan-American (PA) region reported much higher levels of stigma and discrimination, with 78% of respondents from that area reporting high levels of stigma, while the African (AF) region only had 32% of respondents report high levels of stigma and discrimination. Two other regions reported levels of stigma and discrimination above the global average, Europe (EU) (58%) and the Western Pacific (WP) (57%). The PA, EU and WP regions all had the majority of their responses coming from high income countries and so, while stigma and discrimination is clearly a global problem, the results show that it is slightly more prevalent amongst high income countries.

Countries reporting lower levels of stigma and discrimination may have higher prevalence rates as this can lead to a better understanding and awareness of hepatitis.

## Types of stigma and discrimination experienced

Civil society organisations were given a list with 19 different forms of stigma and discrimination and asked to indicate which occurred within their country, with respondents reporting 6 different types of stigma and discrimination on average. The results showed that diverse examples of stigma and discrimination were occurring across countries and regions, demonstrating that stigma and discrimination in all its forms is a global problem.

**Form of stigma/discrimination** (Percentage of respondents who gave this answer)



(151 respondents) Respondents were able to select all the responses that applied allowing for multiple responses from one individual.

# Stigma and Discrimination



## Societal impact Self-stigma

Over 70% of respondents reported that they were aware of self-stigma/internalised stigma occurring within their country. Self-stigma occurs when individuals internalise the negative perceptions of a disease or illness that are prevalent amongst society. This has serious consequences on the way in which people view themselves and creates a sense of shame and fear of revealing their diagnosis to others. This not only perpetuates the silence around viral hepatitis but can also leave people feeling vulnerable and alone.

Self-stigma has serious consequences on people's health as they can delay seeking life-saving healthcare. It can also result in people failing to get tested for hepatitis putting not only their health at risk but potentially placing them at risk of passing the infection on to others. Both of these have a cost to society as delaying diagnosis and treatment can result in people requiring more expensive health care interventions later on.



## Respect

Fifty percent of respondents reported that they were aware of people having experienced a lack of respect. This can lead to low self-esteem which has a number of negative side effects including depression and anxiety.



## Social needs

One of the fundamental needs that all people have is the need to belong and stigma and discrimination can act to prevent this.

53%

of respondents reported that they were aware of people being excluded socially

40%

reported they were aware of people being excluded at work

37%

reported they were aware of people living with viral hepatitis being abandoned by a spouse or family

The ostracism of an individual by family, friends and colleagues can leave them vulnerable to loneliness, social anxiety and depression. Beyond affecting an individual's mental health, studies have shown it can also impact cognition by reducing performance on difficult intellectual tasks. Poor social connections can also impact an individual's physical health as it has been found they do not have immune systems that function as well as those with strong connections<sup>7</sup>.



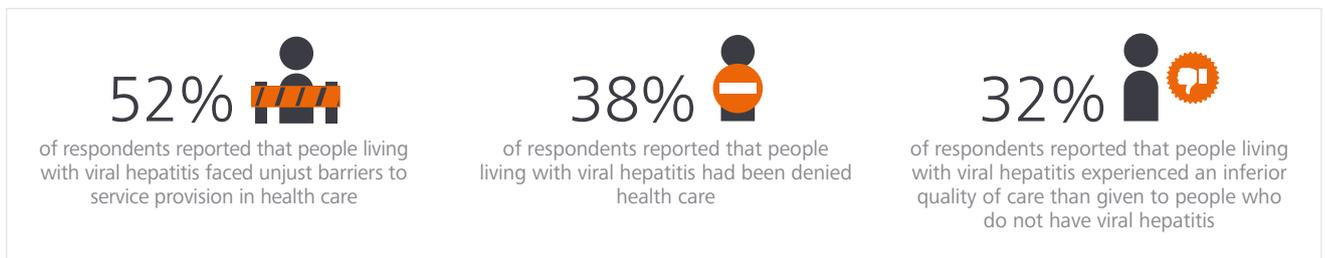
## Health care

Stigma and discrimination acts as a barrier to health care for those living with viral hepatitis.

The below shows that stigma and discrimination can be experienced in different ways within the health care system but all will reduce the ability of those living with viral hepatitis to receive the appropriate health care. Hepatitis B and C not only put people at risk of liver damage but also of developing other extra-hepatic manifestations<sup>8,9</sup> such as:

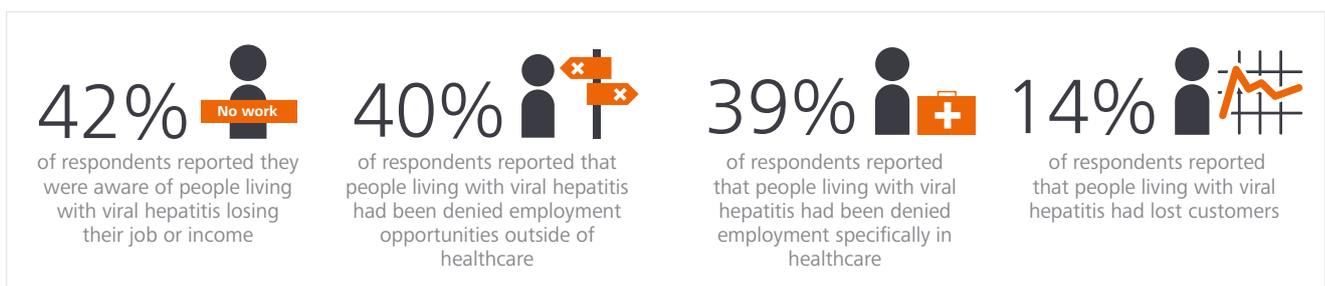
- renal disorders
- dermatologic manifestations
- insulin resistance and type 2 diabetes
- lymphomas
- neuromuscular disorders
- neuropsychiatric disorders
- cardiovascular disease

Given the consequences that these diseases can have on different areas of an individual's health, it is imperative that people with viral hepatitis have access to effective and timely health care.



### Financial security

Viral hepatitis causes escalating health problems which can leave people too unwell to work and placing them at risk of financial insecurity. This risk is increased if those living with viral hepatitis have previously faced difficulties in finding employment. The findings of the survey highlight that for many people stigma and discrimination can lead to decreased employment opportunities.



Any of the above scenarios can contribute to pushing someone into financial insecurity. The effects of this are compounded if the person unable to find employment is the breadwinner for their family. Given that hepatitis is often diagnosed later in life, this is a very real possibility and can lead to children growing up in poverty.

The testing, treatment and monitoring of viral hepatitis can be costly, especially in those countries where either full payment or patient co-payment is required. These costs can act as a barrier to access and lead to financial hardship and for those on a low income, or who cannot find employment, the costs can be catastrophic.

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# Stigma and Discrimination

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## Property loss

Four percent of respondents reported that people living with viral hepatitis had experienced the loss of their property. This can put people at risk of homelessness and so is another form of stigma and discrimination that can lead to insecurity for those living with viral hepatitis. The effects of homelessness are far reaching and amongst other things it can have a serious impact on a person's physical and mental health. It also has a wider cost to society through impacting on communities<sup>10</sup>.



## Personal safety

Thirty percent of respondents reported that people living with viral hepatitis had been the victim of verbal assaults or felt threatened by others. This can leave people feeling vulnerable and afraid for their personal safety. It could also act to deter people from revealing their diagnosis to others.



## Rights

Stigma and discrimination also violates the rights that many of us take for granted, with 21% of respondents reporting they were aware of people being unable to get married and 20% reporting mandatory testing.



## Education

Fifteen percent of respondents reported that people living with viral hepatitis had experienced discrimination from their teachers. This could manifest in a number of ways, either through receiving poor grades, being ignored by teachers or unfairly treated. The long term effects of this are that the child being discriminated against may leave with a lower degree of education than their peers and is at a greater risk of dropping out<sup>11</sup>, which has the potential to adversely affect them and their families later in life.



## Childcare

Ten percent of respondents reported that they were aware that people in their country were being denied childcare because they had viral hepatitis. This has serious repercussions, especially for women who are often the primary care giver, as it can stop them re-entering the paid workforce, leading to economic insecurity for the women or families affected and forcing them into financial dependence. Denial of childcare also adversely impacts on children rights. The United Nations Convention on the Rights of the Child clearly states that all children of working parents have the right to benefit from childcare services and facilities<sup>12</sup>, and governments must ensure this is not impeded by stigma and discrimination towards viral hepatitis.

Stigma and discrimination has far reaching consequences that can affect an individual's mental and physical health by denying them social needs and reducing their ability to access health care. It can also impact their ability to find employment and support themselves and their family. This cannot be seen as a problem facing just those living with viral hepatitis, but rather effects society as a whole, as these have consequences that go beyond just the individual. It is important that everyone understands the impact of stigma and discrimination and advocates for action to address it at a national level.

## Addressing stigma and discrimination at a National Level

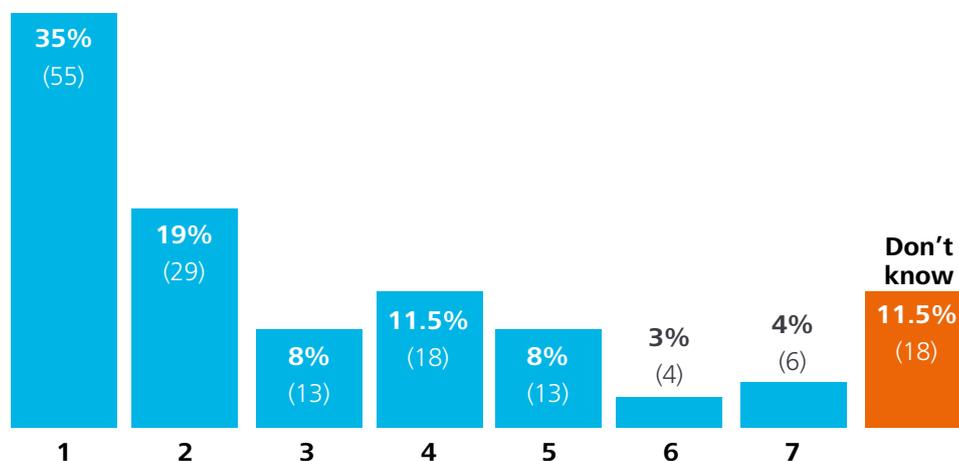
### In 2014 WHO Member States at the World Health Assembly adopted resolution 67.6 which urges member states:

*(16) to review, as appropriate, policies, procedures and practices associated with stigmatisation and discrimination, including the denial of employment, training and education, as well as travel restrictions, against people living with and affected by viral hepatitis, or impairing their full enjoyment of the highest attainable standard of health;*

Overall, respondents reported that little is being done by their national government to address stigma and discrimination with an average response of 2.6, on a scale of 1 to 7, being given. Respondents that reported either no or low levels of stigma and discrimination reported greater satisfaction with their governments response with an average of 3, on a scale of 1-7, compared to those who reported higher levels of stigma and discrimination who reported an average of 2.3. However, responses were mixed and 8% of those reporting high levels of stigma and discrimination reported they were satisfied with their governments' response.

This indicates that high levels of stigma and discrimination may exist even when governments are undertaking activities to address it, calling into question the effectiveness of these activities. In light of this and an average response rate that indicates many governments are not doing anything to address stigma and discrimination at all it is clear this is an area that requires considerable work.

### Respondents were asked to rate their government's response to viral hepatitis



(156 responses) Respondents were asked to rate their government's response to viral hepatitis on a scale of 1-7, where 1 indicated that their government is not doing anything to address stigma and discrimination, and 7 that the government was satisfactorily addressing stigma and discrimination.

Sixty two percent of respondents do not feel that their government is satisfactorily addressing stigma and discrimination. In large part this was felt to be due to a lack of awareness in the wider community and lack of commitment by governments. The role of the media in addressing awareness was also mentioned. As the media has a significant role in shaping social attitudes governments should be encouraged to use it as a tool for tackling stigma.

*'Our government has done nothing for viral hepatitis'*

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## Stigma and Discrimination

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*'They created much of the stigma and have done nothing to help take that away'*

Dissatisfaction was also the result of a failure to address this on a community wide scale with multiple stakeholders. It was felt there was a misconception that only at-risk groups, such as people who inject drugs or those who have HIV, face stigma and discrimination when stigma and discrimination can affect anyone living with hepatitis.

Only 15% of respondents were satisfied with their government's response. Where governments are doing something this was most often reported as being in the form of funding to civil society organisations to address stigma and discrimination in their campaigns. This was predominately experienced in Australia, Canada, New Zealand and the United States of America while other countries such as Italy, Nigeria and Uganda reported their government led awareness campaigns. These actions are an important first step by governments and should be encouraged as part of any plan to address this issue but a greater commitment is needed by governments to ensure stigma and discrimination is eradicated.

A small number of governments do have policies in place which affect stigma and discrimination and while this is important unless they are implemented on the ground they will not have any impact on the experience of those living with viral hepatitis. Unfortunately the survey found that the implementation of these policies is not guaranteed due to competing priorities or a lack of commitment.

*'they provide funding to organizations to work to address stigma'*

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## Stigma and Discrimination

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'The government has funded us for the last 18 years to provide education and health promotion on viral hepatitis. One of our main priorities was to address stigma and discrimination. We have been very successful at lessening the stigma and education among the general population [..It] has gone a long way towards relieving the fears and misconception about hepatitis.'

'We have worked with the government to address stigma ... for a better understanding of how stigma impedes linkage to care, treatment and optimal health outcomes.'

'Government is trying to educate the masses with facts about Hepatitis and discourage stigma and discrimination'

'Both...Hepatitis B and C Strategies nominate addressing stigma and discrimination as a priority, in many cases including specific activities to help reduce these burdens. However, this issue is consistently treated as a lower priority than other, more clinical or treatment-based priorities.'

'In 2010 a joint-department-issued policy on job discrimination has been released to mandatorily stop job screening on hepatitis status. Meanwhile the implementation is not as good as it sounds on the ground level.'

'No specific intervention targeting stigma because the communities are lacking awareness about viral hepatitis'

'by having multiple conversations about it - press releases, flyers, meetings - they have increased the discussion, which takes it out of a "hidden" aspect of our society'

'Organizations ... try to address stigma and discrimination, though it is mostly for those who are marginalized, not for non-marginalized HBV+ or HCV+ populations which also suffer greatly from social and healthcare discrimination, and both external- and self-stigmatization.'

'The stigma points are discussed in professional circles only (between GP, infectionists, gastroenterologists)'

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## Stigma and Discrimination

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### Involving civil society in stigma and discrimination policies

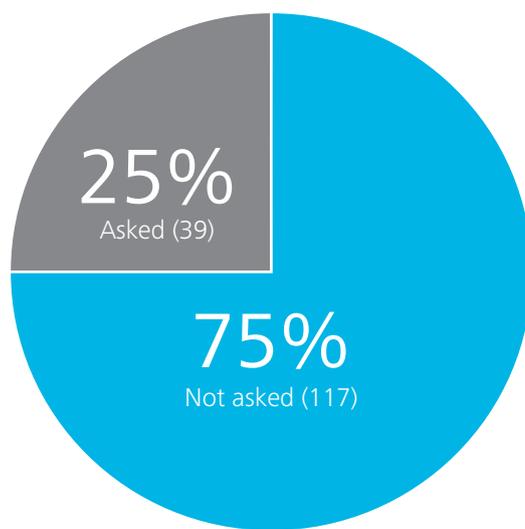
**In 2014, WHO Member States at the World Health Assembly adopted resolution WHA67.6 which urges Member States:**

*(3) to promote the involvement of civil society in all aspects of preventing, diagnosing and treating viral hepatitis*

It is the view of the World Hepatitis Alliance that this must extend to stigma and discrimination policies specific to viral hepatitis as stigma and discrimination poses a significant barrier to diagnosis and treatment for many patients. Respondents were asked if their government had requested they provide specific advice on stigma and discrimination policies.

35% of governments from the responding countries have asked at least one civil society organisation for specific advice on stigma and discrimination. This means that 65% of countries that responded have not involved civil society due to either a failure to include civil society when setting the policy or because no such policies exist.

**Respondents were asked if their government had requested they provide specific advice on stigma and discrimination policies.**



(156 responses)

*'The government does not address stigma and discrimination'*

## Civil Society involvement in the national response to viral hepatitis

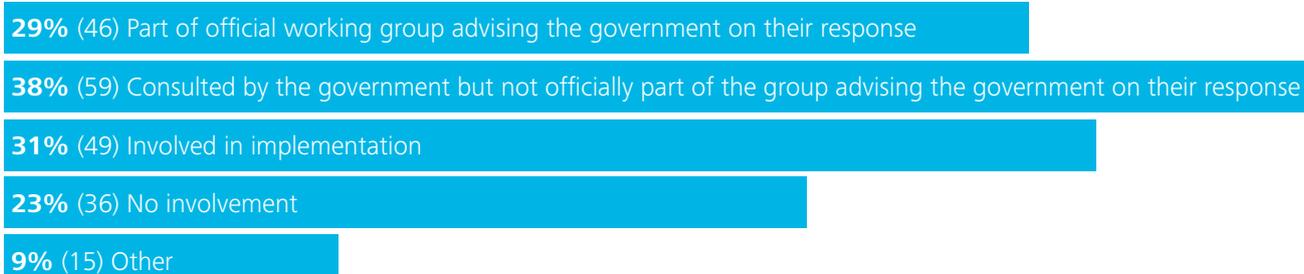
The adoption of the Global Health Sector Strategy on Viral Hepatitis was an important step on the path to elimination. To make this strategy a reality governments will need to put in place national plans or policies to address viral hepatitis and resolution WHA 67.6 was a clear commitment by member states to include civil society in this response. However, despite this commitment 23% of respondents reported that their organisation has had no involvement in their government's response. While some of these respondents were from countries where other civil society organisations had been involved by the government, 10% of countries had no civil society involvement.

Countries without any civil society involvement:

- Bosnia and Herzegovina
- Burundi
- Democratic Republic of Congo
- Finland
- Sierra Leone
- Switzerland
- Turkey

### Types of involvement in the government's response

Respondents were asked to select all the ways in which they had been involved with their government's response.



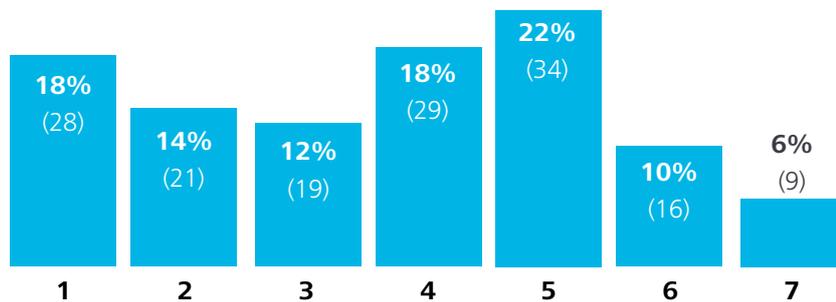
(156 responses)

While it is positive to see that the majority of respondents reported that they were involved to some degree in their government's response, less than a third were involved as part of the official working group. To truly see the patient voice harnessed and central to a national response to viral hepatitis, it is essential that they are meaningfully engaged as part of the official working group. It is also critical that countries that do not currently have any involvement by civil society urgently address this.

*'we are an active part to consulting and decisions regarding national programs on education and prevention on viral hepatitis, patients' rights and monitoring the treatment admission.'*

# Civil society involvement in the national response to viral hepatitis

## Satisfaction with the level of involvement in the government response



(156 responses) Respondents were asked to rate their satisfaction with their level of involvement in their government's response on a scale of 1-7, where 1 indicated they were extremely unsatisfied and 7 that they were extremely satisfied. A total of 32% of respondents reported they were very unsatisfied.

Overall those with no involvement in their governments' response indicated that they were extremely unsatisfied with the response from their government. This further reinforces that there is a clear need for governments to better incorporate civil society into the national response to viral hepatitis.

### Reasons for low levels of satisfaction included:

- A lack of any national plan or, where there is a plan, a lack of political will to implement and finance it.
- A lack of understanding and prioritisation by governments has led to hepatitis being consistently neglected.
- Where civil society have been involved, they have often not felt listened to and feel the patient voice and their experiences have been completely disregarded when the plan was finalised.

Thirty two percent of respondents were satisfied with their government's response but only 6% were extremely satisfied with their level of involvement. Higher levels of satisfaction were experienced in countries that had begun to address viral hepatitis such as Australia and Mongolia. It was also apparent that some governments do have the appropriate structures in place to meaningfully involve civil society groups. Although higher levels of satisfaction were reported many of the comments still reflected a desire for greater involvement, meaning that there is still much more to be done by all countries.

*'We know a lot about what's going on with people living with HCV and could have shared our knowledge with our government.'*

*'Somewhat satisfied at local, state and national level, though would welcome more opportunities.'*

*'not a single time have we been invited by the government'*

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## Civil society involvement in the national response to viral hepatitis

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'The government ignore patients' organisations'

'We are completely acknowledged in our strength to put in the patient perspective in the national plan.'

'We have been part of the strategies and plans developed but unfortunately patients' interests have still not been captured and addressed even when we have stood our ground to present the patients' interests.'

'There is full awareness at the level of national government. However there is insufficient funding for the implementation. So, I feel there is an inadequate participation from the government.'

'I feel they just don't really understand this is an epidemic'

'We have no national strategy'

'...we feel as though as we are valued partners in the Scottish and Welsh Government's national strategies, and we actively contribute towards the development and implementation of these strategies...'

'We feel we have been very fortunate to have had opportunity to give feedback and advocate to government officials. However, they listen politely then ignore our advice.'

# World Hepatitis Day

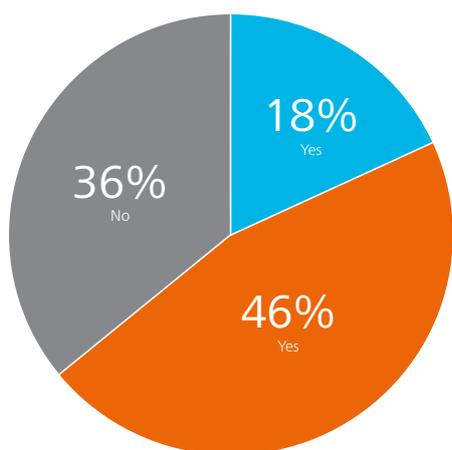
## World Hepatitis Day

### In 2010 WHO Member States at the World Health Assembly adopted resolution 63.18 which:

*Resolves that 28 July or such other day or days as individual Member States decide shall be designated as World Hepatitis Day in order to provide an opportunity for education and greater understanding of viral hepatitis as a global public health problem, and to stimulate the strengthening of preventative and control measures of this disease in member states*

This is just one of four disease-specific global awareness days officially endorsed by the World Health Organization (WHO) and in raising awareness of and educating people about viral hepatitis it has the potential to influence real change. This makes it an important opportunity for all governments to address this disease within their country. It should also be seen as a day for governments and civil society to collaborate and ensure the patient voice is central to the official message.

#### Respondents were asked if their national government officially observed World Hepatitis Day (WHD) in 2016.



Yes, they held their own events without involvement of civil society (18%)

Yes, events were organised in partnership with civil society (46%)

(156 responses)

'Governments participate in occasions such as World AIDS Day, but it is very difficult to arrange ministerial participation in hepatitis related events'

'Government made statements at last WHD addressing viral hepatitis - which also assists in fighting the silence and thus discrimination.'

It is encouraging to see 64% of respondents reporting that World Hepatitis Day was officially observed by their government. Official observation of the day can be a powerful tool in increasing awareness of the disease, which in turn can help overcome the stigma and discrimination people are facing. Moving forward we would encourage those governments who have not involved civil society to ensure that they are central to any activities

There was a mixed response in a number of countries in regards to whether their national government officially observed World Hepatitis Day in 2016. However, all respondents from 28 countries gave a definitive answer that their government did not officially observe World Hepatitis Day. This means that 39% of countries that responded did not officially observe WHD which is not only a failure to meet the World Health Assembly resolution but shows a lack of commitment to tackling viral hepatitis.

## Conclusion

Stigma and discrimination is a barrier to the elimination of viral hepatitis and 93% of countries that responded reported some level of stigma and discrimination. Beyond being a barrier to elimination stigma and discrimination has far-reaching consequences on people's lives and a broader impact on society as a whole. Without a strong response to stigma and discrimination and well implemented policies elimination will not be reached, however; only 4% of respondents felt that their government was satisfactorily addressing stigma and discrimination and 75% of respondents have not been consulted by their government on stigma and discrimination policies.

Civil society should be meaningfully involved in their government's national response but nearly a quarter of respondents had no involvement and 18% were extremely unsatisfied with their level of involvement. Despite this there are encouraging signs of collaboration between civil society and governments. 46% of respondents reported that WHD events were held by the government in partnership with civil society, and 67% of respondents were either part of the government's official working group or were consulted by the government.

Civil society and governments both have an important role to play in reaching elimination and the findings of this report can be used to assist in their efforts.



### Stigma and discrimination is a barrier to elimination

Stigma and discrimination comes in many forms and the consequences of it can be devastating on people living with viral hepatitis. To effectively combat stigma and discrimination the underlying causes of it must be addressed.

#### Civil society have a role to play through:

- Conducting awareness campaigns to educate the public about viral hepatitis
- Using the media to increase awareness and change social attitudes towards those living with viral hepatitis
- Empowering those with viral hepatitis to speak out
- Advocating for their government to acknowledge the serious impact that stigma and discrimination can have on both the individual and wider community and implement effective policies to overcome this
- Advocating to ensure that civil society are central to the creation of these policies
- Advocating for governments to commit to increasing awareness of viral hepatitis



### Civil society should advocate to be involved in the government's response

Patients are the central piece in their government's response to viral hepatitis and as such should be part of its planning and implementation.

#### Civil society have a role to play through:

- Holding governments to account to the resolution passed at the World Health Assembly (2014 resolution, clause 1.3)
- Advocating for greater and more meaningful involvement in the government's response
- Advocating for viral hepatitis plans to be financed and implemented

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## Conclusion

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### World Hepatitis Day

This day has the potential to improve the understanding of hepatitis throughout the world and all 194 member states of the World Health Assembly should be officially observing the day.

#### **Civil society have a role to play through:**

- Advocating to ensure their government understands the importance of and officially observes World Hepatitis Day
- Advocating to ensure that government events are held in partnership with civil society organisations
- Advocating to ensure the patient voice is central to any government activities on this day
- Advocating for governments to use this day as part of their efforts to tackle stigma and discrimination



### Governments must harness the patient voice to reach elimination

With the adoption of the Global Health Sector Strategy governments committed to the elimination of viral hepatitis but this will not be possible without honouring their earlier commitment to include civil society in their response. The survey highlighted that in many countries there is still much to be done before civil society are meaningfully engaged. Governments need to recognise civil society as valuable partners and, moving forward, as they implement the GHSS, they should identify areas where greater collaboration with civil society would be of benefit.

#### **Governments can work with civil society to effectively deliver many of the actions set out in the GHSS, including:**

- Ensure access to appropriate injection equipment for people who inject drugs that meet their needs, including low dead-space syringes
- Remove legal, regulatory and policy barriers that hinder equitable access to hepatitis services especially for most-affected populations and other groups at risk
- Create institutional and community environments that make it safe for people to access hepatitis services, involving communities in the planning and delivery of services to improve their reach, quality and effectiveness
- Address legal and institutional barriers to the provision of harm reduction services
- Raise national awareness of viral hepatitis through campaigns, World Hepatitis Day and the appointment of community and political “champions”

This survey is a powerful tool to start addressing stigma and discrimination towards those living with hepatitis and ensuring a better engaged community and government response not just to stigma but to hepatitis prevention, treatment and diagnosis also.

Thank you to the civil society organisations that responded; we hope that the outcomes will help with your advocacy efforts.

## List of countries that responded

Country	Number of responses
Argentina	2
Australia	9
Austria	1
Azerbaijan	1
Bangladesh	3
Belgium	2
Benin	1
Bosnia and Herzegovina	1
Brazil	1
Bulgaria	1
Burkina Faso	1
Burundi	1
Cameroon	2
Canada	9
Chile	1
China	3
Cote d'Ivoire	2
Croatia	1
Democratic Republic of the Congo	1
Denmark	1
Egypt	1
Finland	1
France	1
Gambia	1
Germany	1
Ghana	4
Greece	1
Guatemala	1
Hungary	1
India	5
Indonesia	1
Ireland	1
Israel	1
Italy	1
Japan	1
Lebanon	1
Macedonia, the former Yugoslav Republic	1

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## Conclusion

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Country	Number of responses
Malawi	1
Mali	2
Mauritania	2
Mauritius	1
Mexico	2
Mongolia	1
Morocco	1
Myanmar	1
Netherlands	2
New Zealand	2
Nigeria	11
Pakistan	4
Peru	1
Philippines	1
Poland	1
Romania	1
Russian Federation	2
Rwanda	1
Senegal	1
Serbia	3
Sierra Leone	1
Slovenia	1
Spain	2
Sweden	1
Switzerland	2
Taiwan	3
Thailand	1
Togo	1
Turkey	1
Uganda	4
Ukraine	3
United Kingdom	2
United States of America	23
Uruguay	1
Viet Nam	1

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