HEPATITIS B
FOUNDATION
www.hepb.org

A Guide to Address Hepatitis B Discrimination & Know Your Rights

Discrimination Toolkit

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BACKGROUND:

Over 250 million people live with chronic hepatitis B, making it the world's most common chronic infection(1). Despite effective tools for prevention, diagnosis and treatment, hepatitis B is the world's leading cause of liver cancer, with two people dying every minute, and limited change in hepatitis B mortality over the past 20 years(1). Globally, only 13% of people with hepatitis B are aware of their infection, and access to treatment and care is limited, particularly in low- and middle-income countries. As a result, most people living with hepatitis B remain at risk of developing liver disease, including cancer.

The Hepatitis B Foundation serves to find a cure and improve the quality of life for those directly impacted by hepatitis B globally. Since the inception of the Foundation in 1991, people living with or impacted by hepatitis B from around the world reach out by email, mail, phone and social media, requesting information, education, and help and support with their diagnosis. Each year, the Foundation receives thousands of inquiries from around the world. These inquiries inform the Foundation's programming and priorities.

In 2020, the Foundation saw a significant increase in discrimination-related challenges experienced by people living with hepatitis B. Stigma and discrimination remain significant barriers to eliminating hepatitis B as a public health threat by 2030 as sought by the World Health Organization (WHO) (1-6). Much of the stigma and discrimination results from poor knowledge and misunderstanding over transmission and disease progression. This translates to unjust practices and consequentially uncertainty and fear manifesting into discrimination. While most hepatitis B transmission occurs due to blood exchange during childbirth (perinatal transmission), community assumptions focus on other transmission routes that are behavior-related and seen as shameful in many cultures, including sex and drug use. Miscommunication and assumptions about hepatitis B infectivity heightens fears and are often used to justify (without evidence) excluding others from fully participating in society.

We hope this guide can serve as a resource for you to document discrimination happening in your respective country. For change to occur through policy and protections against discrimination, advocacy efforts are needed to define the problem and demonstrate its impact on the ground. This document can be a resource for you to first define discrimination in your communities and bring it to the attention of political leaders to advocate for policy change and protection against discrimination.

Important Definitions to Know

WHAT IS STIGMA?

Stigma is a social process characterized by the exclusion, rejection, blame and devaluation of a person due to misconceptions and cultural beliefs about hepatitis B.

WHAT IS DISCRIMINATION?

Discrimination is defined as the unjust, unfair and prejudicial treatment of a person on the grounds of their hepatitis B status.

WHY DO STIGMA AND DISCRIMINATION HAPPEN?

- **Low knowledge** of hepatitis B and how it is spread among the general public and health care workers
- **Misunderstanding and misinformation** about hepatitis B transmission
- **Lack of policies** to prevent discrimination from happening at all levels of government
- **Lack of protections** in place to report or prevent discrimination from taking place

WHAT CAN WE DO ABOUT IT?

- **Educate** our communities and health care workers about hepatitis B and how it is transmitted.
- **Advocate** for policies and protections to prevent discrimination.
- **Empower** people with hepatitis B to share their stories and get involved - **you have the power to make change happen!**

The Negative Impact of **Discrimination**

Hepatitis B is a manageable chronic health condition. Our research demonstrates that hepatitis B discrimination has a significant impact on the lives of those affected. Discrimination can occur in a cyclic nature at various points in an individual's life from education, to seeking employment, to marriage, to restrictions upon entry, travel and stay in other countries. Hepatitis B discrimination impacts mental and physical health of those experiencing it firsthand, limits overall well-being and quality of life, and can lead to poor health outcomes and avoidance of testing and management. Below we have an infographic that highlights the impact of discrimination.

Psychological Impact

- Poorer health outcomes and hesitation seeking care for hepatitis B.
- Fear of disclosure due to the fear of being treated differently because of a hepatitis B positive status
- Trauma, suicide, mental health challenges, depression and social isolation due to hepatitis B
- Fear of transmission to loved ones

Individual Impact

- Stigma: Both self-stigma or internalized stigma - guilt and fear of transmission to loved ones
- External stigma or public stigma - being treated differently in a community setting often due to misunderstandings associated with transmission or poor knowledge at the community level

Denial of Growth Opportunities

- Denial of employment due to hepatitis B in some settings
- Denial of work visas for immigration
- Denial of educational opportunities

Economic Setbacks

- Employment can be difficult to find or revoked for people who test positive for hepatitis B due to cultural and social perceptions about disease transmission. Many employers also require mandatory health screenings.

All discrimination related to **hepatitis B is unjustified.**
Hepatitis B-related discrimination is
unethical and violates human rights.

What we are doing to address discrimination?

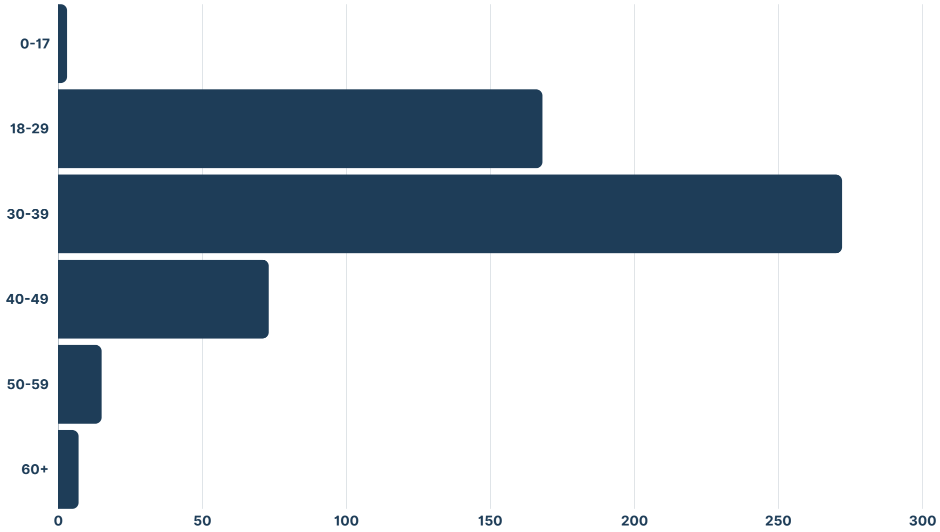
Hepatitis B Discrimination Registry

The Hepatitis B Foundation's Hepatitis B Discrimination Registry is an initiative designed to collect information and track discrimination related to hepatitis B on a global scale.

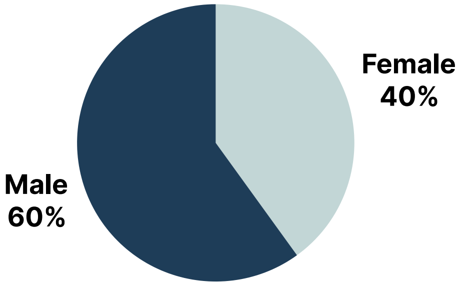
This registry aims to document the discriminatory experiences of individuals affected by hepatitis B. The registry represents the lived experiences of people with hepatitis B and their experiences with stigma and discrimination from across the globe. Since its inception in 2021, the registry has collected over 640 individual experiences related to discrimination from over 70 countries. In the registry analysis, the most commonly reported occurrences by country were in the Philippines, Nigeria, India, Pakistan, Uganda, Ghana, the United States and Ethiopia.

Among those who responded to the survey, 86.1% reported that they experienced discrimination due to hepatitis B. Approximately 60% of those who reported discrimination due to hepatitis B identified as male and 40% were female. 186 individuals who reported discrimination due to hepatitis B were in the age range of 18 to 29 years. 272 individuals were in the age range of 30 to 39 years. 73 individuals were in the age range of 40 to 49 years. It is crucial to note that hepatitis B related discrimination impacts more men than women. Since men are more likely to be the breadwinners in their homes, HBV related discrimination can present unique economic and social challenges for families and communities in many areas of the world. Additionally, HBV related discrimination can occur at any age. In recent years, there has been an uptick in the rise of HBV related discrimination incidents among younger age groups.

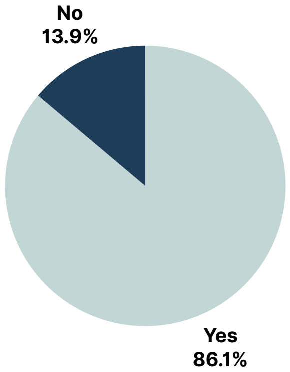
Discrimination Related to HBV by Age Ranges



Discrimination Related to HBV by Gender



Self-Reported Incidence of HBV Related Discrimination

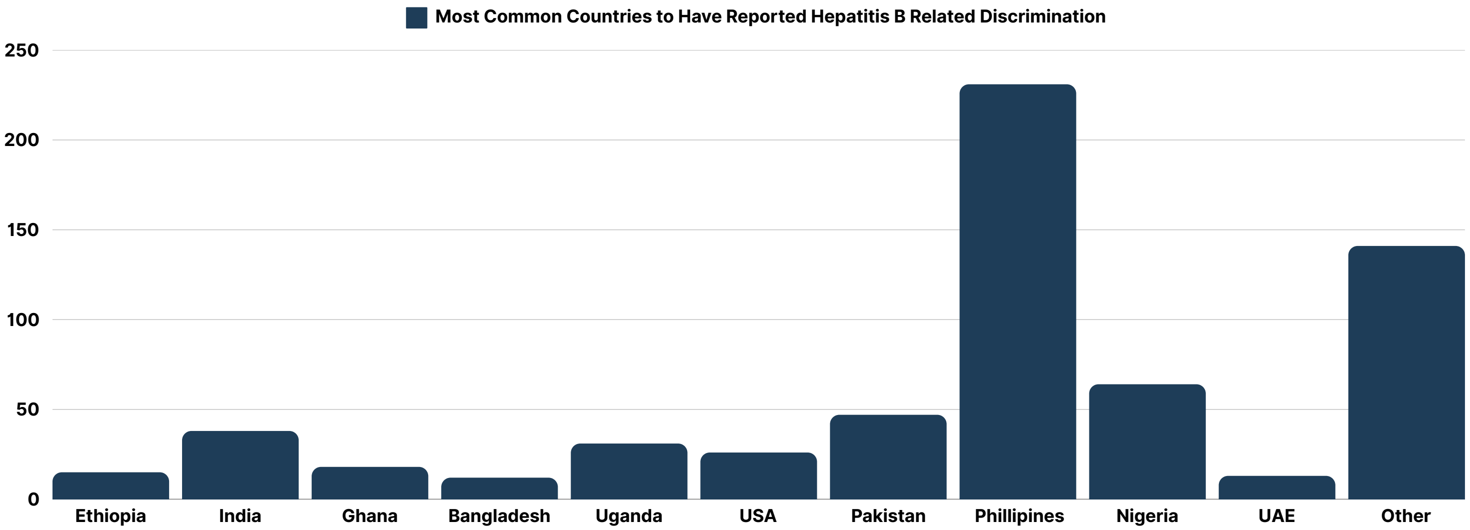


>70 **Countries Represented**

>640 **Respondents**

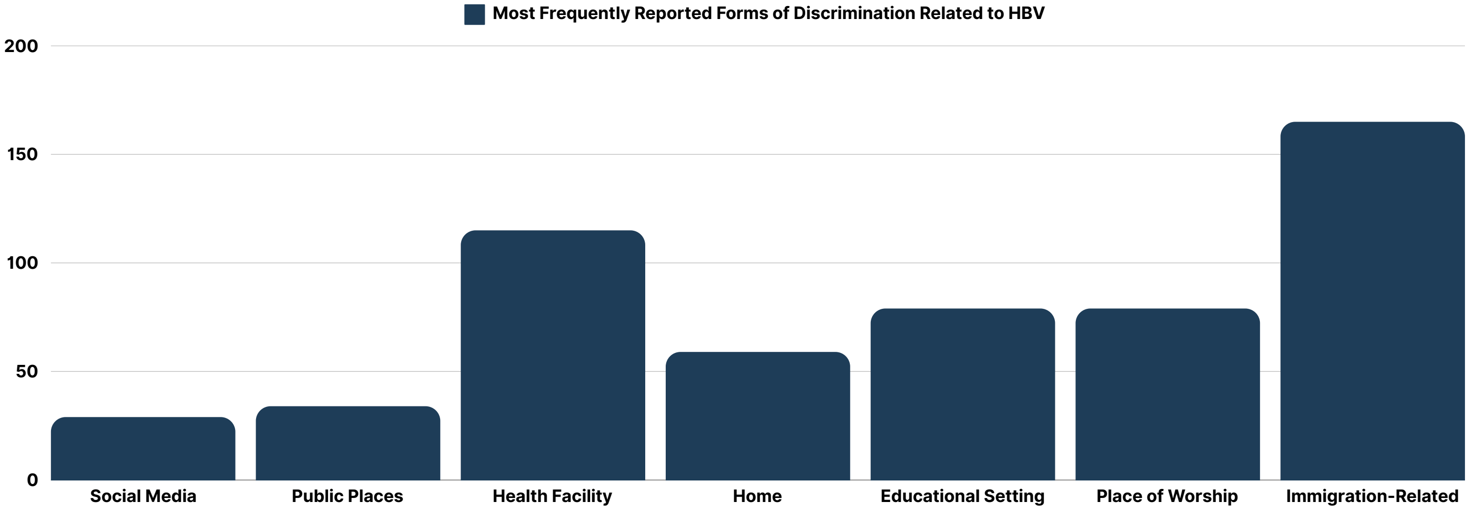
What we are doing to address discrimination?

Most Frequently Reported Countries for HBV-Related Discrimination



HBV-related discrimination manifested in various ways, with immigration-related discrimination being the most frequently reported. Numerous individuals faced denial of visa entry for work, education, and tourism because of their hepatitis B status.

Most Frequently Reported Forms of Discrimination Related to HBV



HBV-related discrimination occured in many different forms with immigration related discrimination the most commonly reported. Many individuals were denied visa entries for work, education, and tourism related reasons due to their hepatitis B status.

POLICY RECOMMENDATIONS

The absence of enforceable policies and laws addressing discrimination fosters a culture of stigma, thus diminishing the quality of life for individuals living with hepatitis B. This situation restricts their access to economic opportunities and personal growth. It is crucial to implement proactive measures to improve the response to discrimination faced by those living with hepatitis B.

The Hepatitis B Foundation has created a policy guide toolkit. Featured in the policy toolkit is recommended policy language as well as case examples from specific countries.

ANTI-DISCRIMINATION WORKING GROUP DEVELOPMENT

The working group has conducted research to understand the specific challenges faced by those living with hepatitis B. This research involves gathering data through surveys, interviews, and focus groups with individuals who have experienced discrimination to understand the lived experiences. Based on these insights, the working group has put forth data to support expansion of policy protections and awareness efforts surrounding addressing stigma and discrimination. In the future the working group will develop support networks and training programs for employers and healthcare workers to ensure these groups are equipped with the knowledge and skills to foster inclusive and respectful environments.

The working group also continues to advocate for stronger anti-discrimination policies and work towards the inclusion of protective legislation at both regional and national levels. Regular monitoring and evaluation of these initiatives will be conducted to measure their effectiveness and adapt strategies as needed. Through these concerted efforts, the working group aims to create a society where people living with hepatitis B can thrive without fear of prejudice or discrimination.

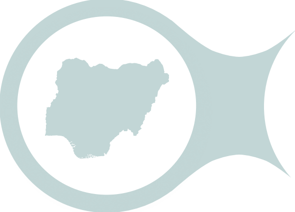
Research Examples:
Freeland, C., Qureshi, A., Wallace, J. et al. Hepatitis B discrimination: global responses requiring global data. BMC Public Health 24, 1575 (2024). https://doi.org/10.1186/s12889-024-18918-8

Freeland, C., Adjei, C., Wallace, J. et al. Survey of lived experiences and challenges in hepatitis B management and treatment. BMC Public Health 24, 944 (2024). https://doi.org/10.1186/s12889-024-18425-w

Freeland, C., Mendola, L., Cheng, V. et al. The unvirtuous cycle of discrimination affecting people with hepatitis B: a multi-country qualitative assessment of key-informant perspectives. Int J Equity Health 21, 77 (2022). https://doi.org/10.1186/s12939-022-01677-6

COLLABORATION WITH STAKEHOLDERS

Collaboration between governments, civil society organizations, patient advocacy groups, and healthcare providers is essential for pooling resources, sharing best practices, and coordinating efforts effectively. By working together, these diverse stakeholders can address complex health challenges more efficiently and ensure that healthcare systems are resilient and responsive to the needs of all individuals. Such partnerships can lead to the development of innovative solutions, improved access to care, and the implementation of policies that prioritize patient well-being. Furthermore, fostering open communication and trust among these groups can enhance transparency and accountability, ultimately leading to better health outcomes for communities worldwide.



NIGERIA

OVERVIEW

Nigeria has a high prevalence of hepatitis B with over 8% prevalence (about 20 million people). Nigerians are often subject to discrimination in employment and educational settings. Cultural perceptions about disease influence the social norms and policies that perpetuate discrimination against people living with hepatitis B

In Nigeria, the Discrimination Against Persons with Disability Act of 2018 and the HIV and AIDS Act of 2014 prohibit discrimination against individuals living with HIV and those with disabilities. However, many Nigerians have reported experiencing discrimination and stigma in their workplaces.

In Delta State, Nigeria, there have been significant efforts to address hepatitis B discrimination. The First Lady, Deaconess Tobore Oborevwori, has recommended including hepatitis B and C within the existing HIV/AIDS anti-discrimination, prevention, and protection law of 2022.

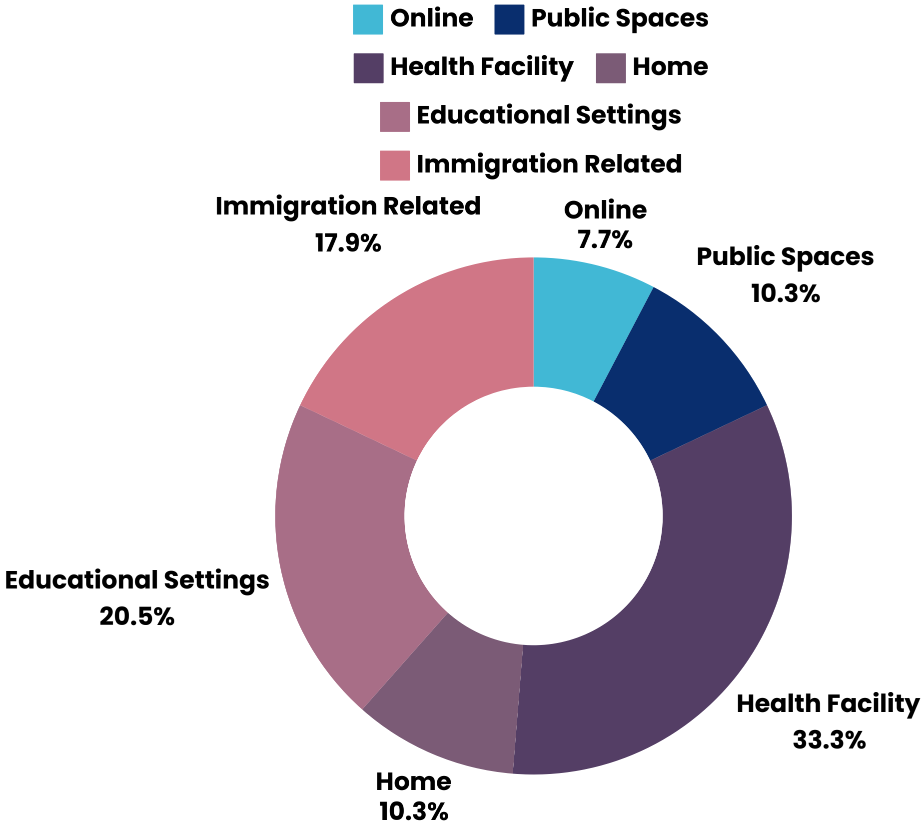
This recommendation aims to provide legal protections against discrimination for individuals living with hepatitis B and C. Additionally, the Delta State government has approved free hepatitis B and C screening for all pregnant women, which is a step towards improving healthcare access and reducing stigma

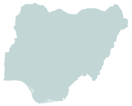
20,000,000 People are living with hepatitis B in Nigeria.

Most Common Settings Where Discrimination Occurs in Nigeria

As indicated by the data shown above, Nigerians commonly experienced discrimination in:

- health facilities and hospitals
- educational spaces such as schools and during college admission process
- while applying for a visa to work, study or visit abroad.





UGANDA

OVERVIEW

Uganda has a high prevalence of hepatitis B with over 6% of the national population living with chronic hepatitis B. There is no policy that focuses on anti-discrimination and no national effort to address discrimination.

While Uganda has scaled up their programs and activities to address the burden of hepatitis B by expanding access to screening and vaccination, there is still more that needs to be done to address discrimination against people living with hepatitis B.

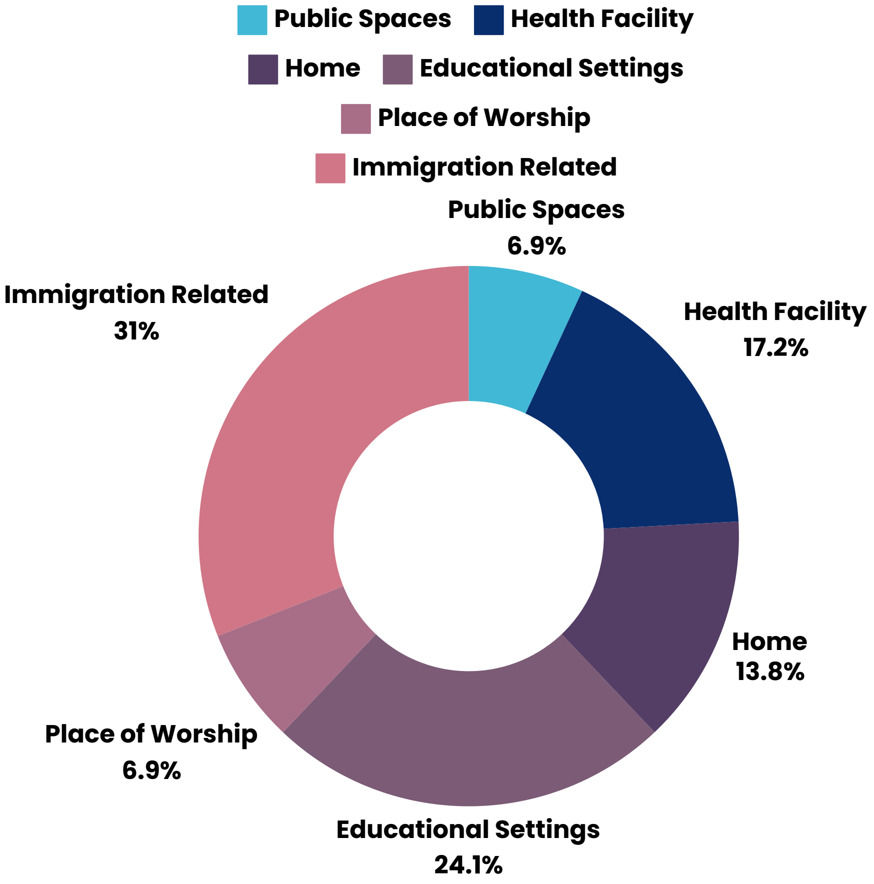
While Uganda has a National Viral Hepatitis Control Program aimed at prevention, treatment, and management of hepatitis B and C. This program includes public awareness campaigns and vaccination efforts to reduce the prevalence of hepatitis B. Programs specific to addressing hepatitis B related discrimination are not present or poorly enforced.

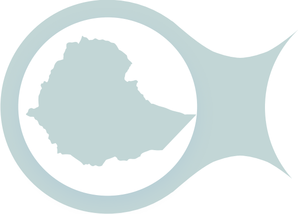
3,000,000 People are living with hepatitis B in Uganda.

Most Common Settings Where Discrimination Occurs in Uganda

As indicated by the data shown above, Ugandans commonly experienced discrimination in:

- educational spaces such as schools and during college admission process,
- while applying for a visa to work, study or visit abroad
- their home environments





ETHIOPIA

OVERVIEW

Ethiopia has a significant hepatitis B prevalence, with 8-12% of the population chronically infected. Viral hepatitis is not part of the Integrated Disease Surveillance Response (IDSR). Although risk-based testing and treatment guidelines exist, they are not universally applied.

The Ethiopian Ministry of Health's strategic plan does not have a policy or focus on discrimination related to hepatitis B. Discrimination against individuals with hepatitis B is common, particularly in immigration settings, fueled by misconceptions about transmission.

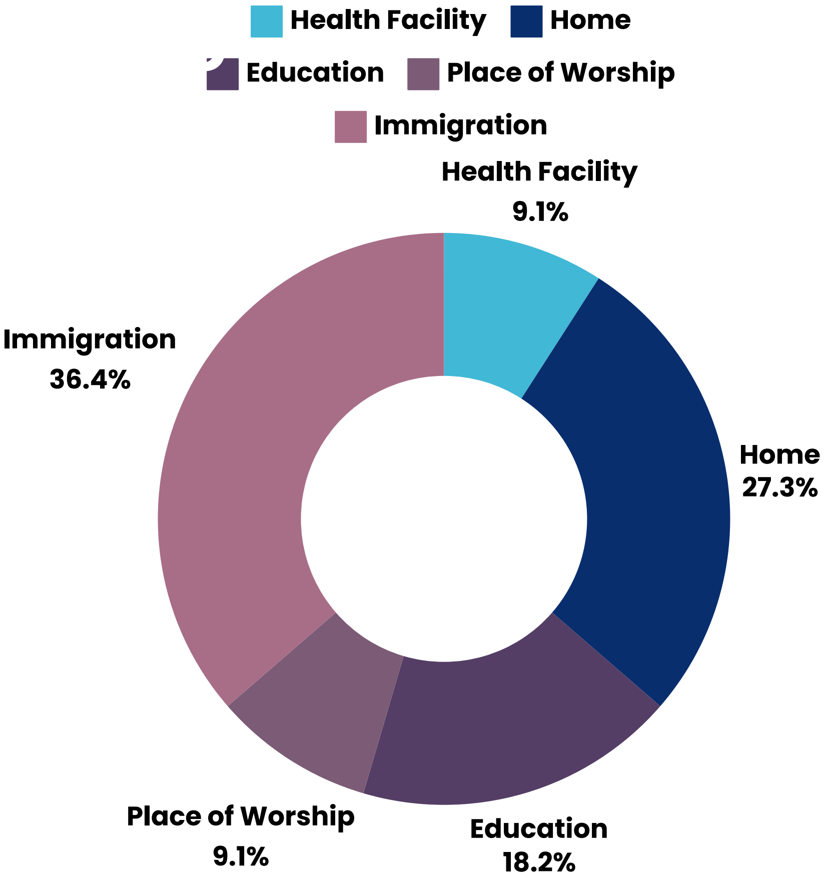
While Ethiopia has policies and strategies aimed at controlling viral hepatitis, including hepatitis B, these efforts focus on prevention, treatment, and public awareness to reduce the prevalence and impact of the disease. While improving awareness and increasing access to universal testing may help reduce the impact and incidence of stigma related to hepatitis B, tangible efforts need to be made to address discrimination at the policy and structural levels.

10,000,000 people are living with hepatitis B in Ethiopia.

Most Common Settings Where Discrimination Occurs in Ethiopia

As indicated by the data shown above, Ethiopians commonly experienced discrimination in:

- immigration related setting while applying for a visa abroad
- educational settings
- their home environments.
- places of worship
- health facilities



PHILIPPINES

OVERVIEW

The Philippines has a high prevalence of hepatitis B, with 8.2% of the total population living with hepatitis B. The National Action Plan is out of date; There are no national systems for tracking HBV but universal screening is recommended for HBV.

There is no national budget for hepatitis B and the Philippines lack a formal HBV elimination plan. Although the Philippines has established a policy to safeguard individuals living with hepatitis B, its focus appears to be limited to employment-related matters.

These policies help protect people from getting terminated or demoted due to their hepatitis B status and it protects the confidentiality of their test results as employers are not allowed to disclose this information.

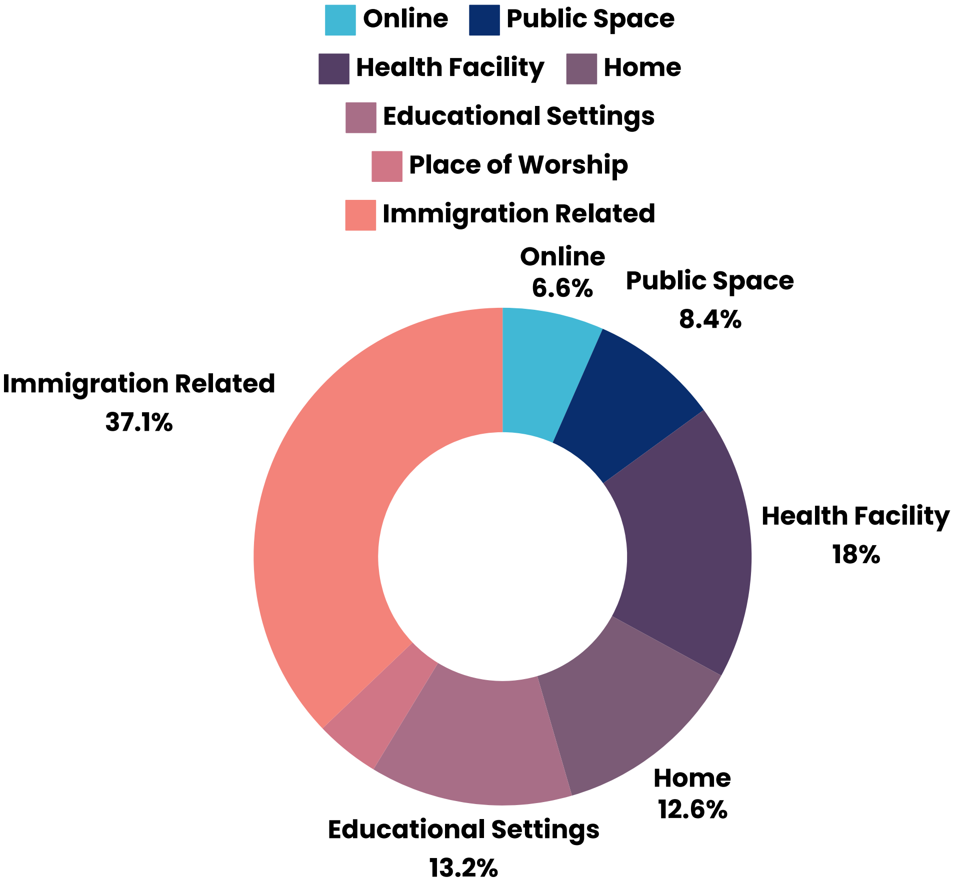
It is crucial to extend these protective policies against HBV-related discrimination to various contexts, including immigration, education, and public spaces.
It is crucial to extend these protective policies against HBV-related discrimination to various contexts, including immigration, education, and public spaces.

9,618,600 people are living with hepatitis B in the Philippines.

Most Common Settings Where Discrimination Occurs in the Philippines

As indicated by the data shown above, Filipinos commonly experienced discrimination in:

- immigration related setting while applying for a visa abroad
- health facilities and hospitals
- at schools
- their home environments.



PAKISTAN

OVERVIEW

Pakistan has a 1.1% prevalence of HBsAg as of 2021 with over 12,000 deaths attributed to HBV related causes. Only 5% of those who are diagnosed with hepatitis B are receiving appropriate care. Pakistan's national strategy for hepatitis B elimination requires not only an update to align with current guidelines and best practices, but also a commitment to address discrimination related to hepatitis B as there is no policy on discrimination against people living with hepatitis B. It is essential to implement a national policy that safeguards the rights of individuals living with the virus.

Pakistan's policymakers have recognized the importance of addressing hepatitis B and C as public health priorities

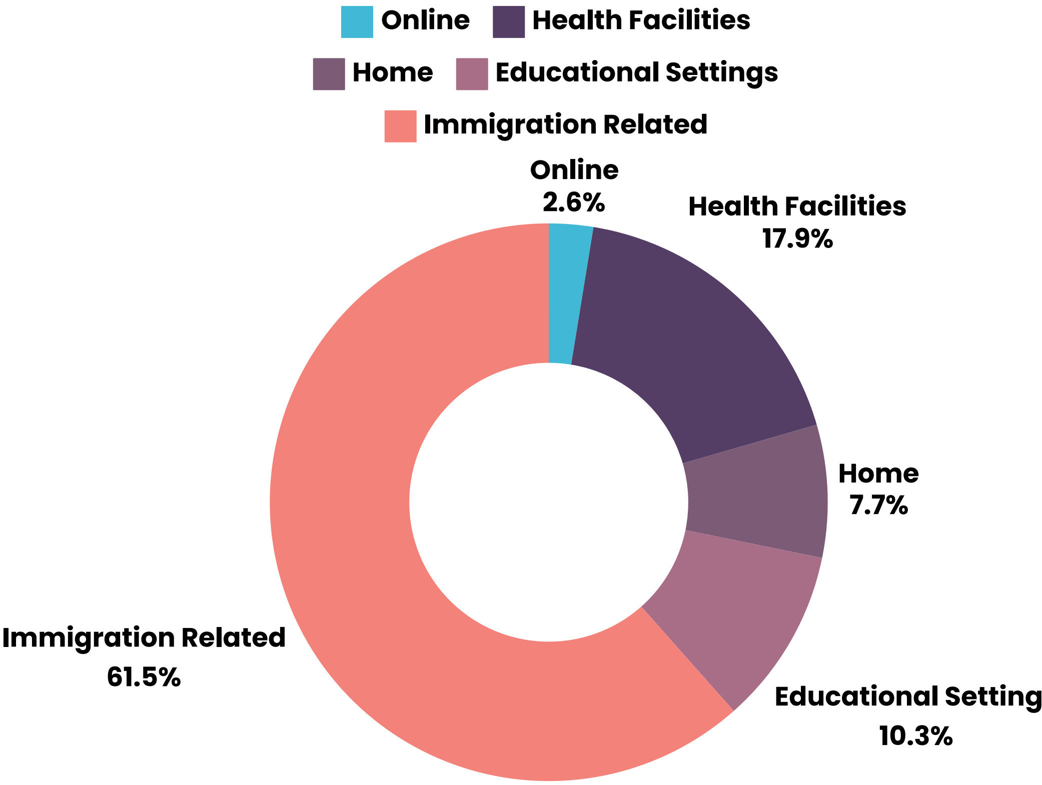
However, discrimination against people with hepatitis B remains a challenge, and efforts to combat this discrimination often involve broader health and human rights policies rather than specific laws targeting hepatitis B discrimination

2,645,500 people are living with hepatitis B in Pakistan.

Most Common Settings Where Discrimination Occurs in Pakistan

As indicated by the data shown above, Pakistanis commonly experienced discrimination in

- immigration related setting while applying for a visa abroad
- health facilities and hospitals
- schools
- their home environments.



GHANA

OVERVIEW

In Ghana, it is estimated that around 9% of the population is living with hepatitis B. Ghana has developed a comprehensive policy framework that includes various initiatives to address HBV. The policy emphasizes advocacy, communication, and social mobilization to raise awareness about HBV and reduce discrimination. Additionally, the government actively participates in events like World Hepatitis Day to engage the public and promote inclusive environments for individuals affected by HBV. Although Ghana has taken strong efforts to address HBV prevention and care, especially access to birth dose and vaccination, **legal protections for people living with hepatitis B are virtually non-existent.**

Most Common Discrimination Settings

Although Ghana has a National Health Policy designed to promote healthy living for all citizens, this policy encompasses strategies to enhance healthcare delivery and accessibility, which can indirectly aid in minimizing stigma and discrimination towards individuals with hepatitis B.

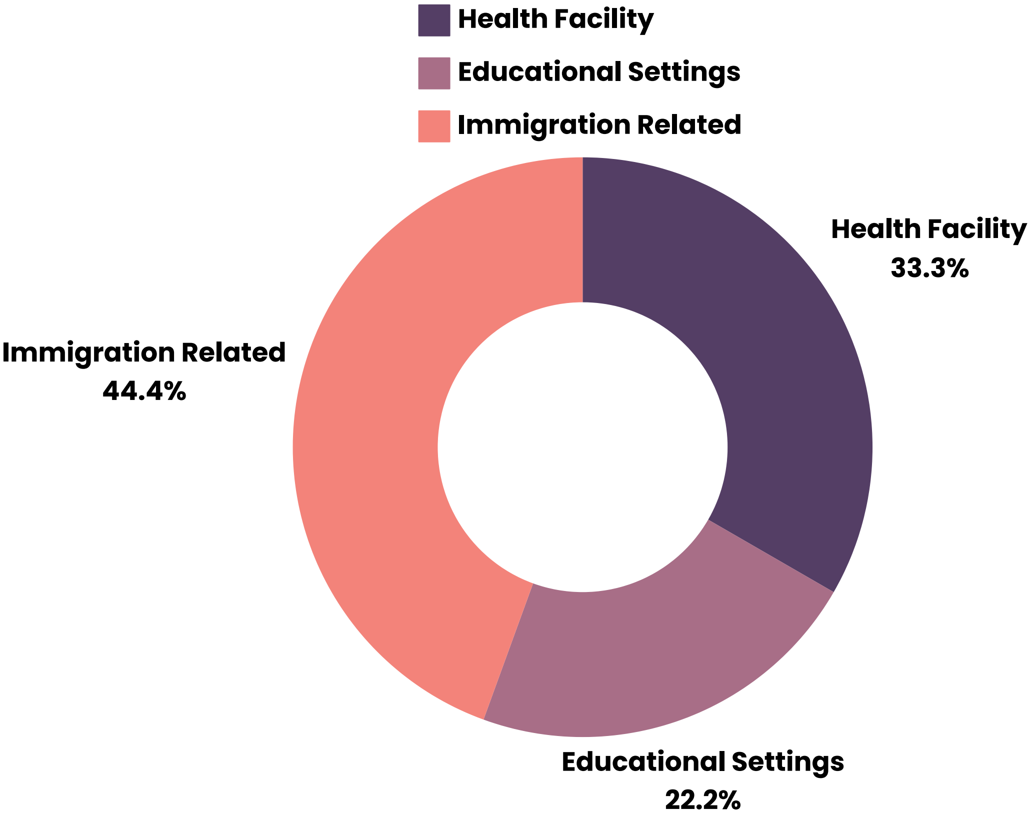
Additional efforts are necessary at both the policy and structural levels to confront discrimination and stigma associated with hepatitis B.

3,000,000	People are living with hepatitis B in Ghana.

Most Common Settings Where Discrimination Occurs in Ghana

As indicated by the data shown above, Ghanaians commonly experienced discrimination in:

- schools
- health facilities
- during immigration related procedures



INDIA

OVERVIEW

In India, it's estimated that more than 40 million individuals are living with hepatitis B. The National Viral Hepatitis Control Programme aims to achieve elimination goals by enhancing vaccine uptake and expanding testing efforts. However, there is currently no specific policy or law that tackles discrimination related to hepatitis B or offers protections for those affected in India.

There is an increasing national and international movement advocating for the inclusion of HBV-related discrimination as a priority in the national viral hepatitis plan. Community based organizations have been crucial in the advocacy efforts.

In India, advocacy groups and scientific organizations have called on the national government to provide better protections for people living with hepatitis B. The Institute of Liver and Biliary Sciences (ILBS) has urged the central government to implement laws to prevent discrimination and social stigma faced by people living with hepatitis B. More efforts need to be made to reduce the impact of stigma and discrimination.

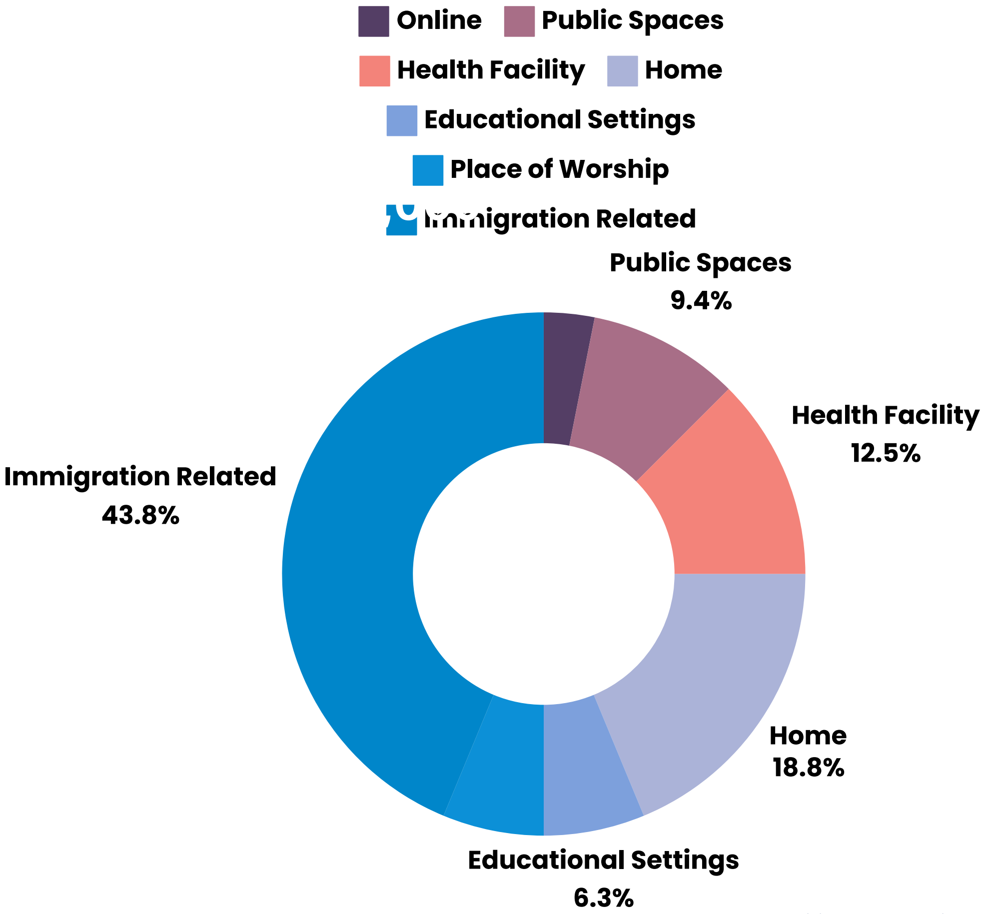
40,000,000

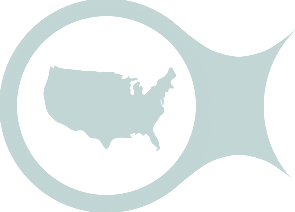
People are living with hepatitis B in India.

Most Common Settings Where Discrimination Occurs in India

As indicated by the data shown above, Indians commonly experienced discrimination in

- applying for a visa abroad
- schools
- health facilities
- their home environments





United States of America

OVERVIEW

The United States has a significant population living with hepatitis B. In the U.S., people with hepatitis B are protected under the Americans with Disabilities Act (ADA) and Title VI of the Civil Rights Act. Under American law, discrimination against people living with hepatitis B is unlawful and applies to educational settings, public spaces and employment settings. Additionally, people in the United States are not allowed to serve in the military.

Most Common Discrimination Settings

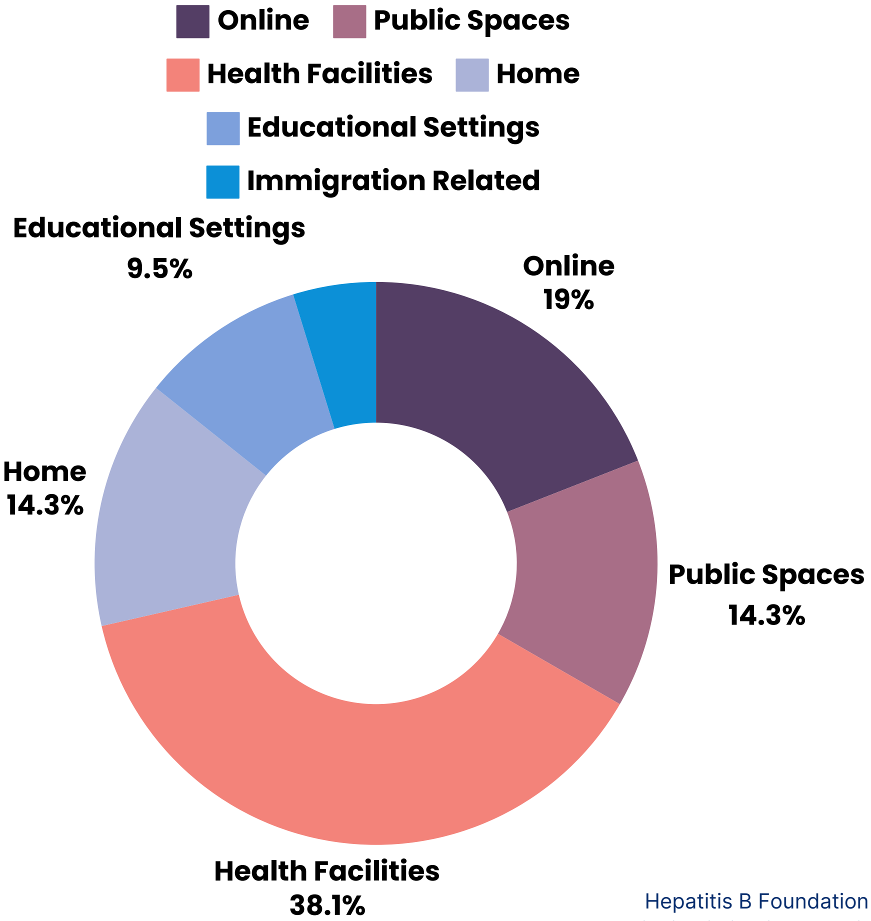
Despite progress, discrimination can still happen. The Hepatitis B Foundation, along with various advocacy groups, offers support to those facing discrimination due to HBV. Given that hepatitis B-related discrimination continues to exist in the U.S., it is crucial to promote fair policies and ensure the enforcement of laws that protect individuals from such discrimination.

1,200,000	People are living with hepatitis B in the USA.

Most Common Settings Where Discrimination Occurs in U.S.

As indicated by the data shown above, Americans commonly experienced discrimination in:

- when applying for a visa abroad
- schools
- health facilities
- their home environments



COMMUNITY INTERVENTIONS TO ADDRESS HBV RELATED INTERVENTION

Policy Change

- Discrimination against individuals living with hepatitis B is a violation of human rights and restricts their economic opportunities, social engagement, and access to education. It is essential for all countries to offer protections for those living with hepatitis B and to incorporate anti-discrimination initiatives in their national strategies aimed at eliminating the disease.

- Discriminatory policies include in the form of immigration, employment, and educational restrictions.

Stigma Reduction Interventions

Storytelling

- Amplify the voices of people living with hepatitis B through storytelling programs and initiatives.
- Develop storytelling campaigns by recruiting people living with hepatitis B to share their stories
- Utilize video techniques, letters, and other creative methods to help people share their stories
- Learn more about the Hepatitis B Foundation's Storytelling program here!

Sensitivity Training Programs

- Sensitivity training programs should be implemented for:
  - healthcare professionals
  - employers
  - educators
  - immigration officials
- These initiatives will help promote inclusivity and reduce the stigma and misconceptions associated with hepatitis B and liver cancer

Role Play

- This is a health education technique used to disband myths and misconceptions about diseases like hepatitis B and liver cancer while also educating people about important facts on prevention and treatment.
- These can be implemented in various settings such as public spaces, in schools, or at homes to educate people about what hepatitis B is and how it gets transmitted from person to person.

Focus Group Sessions

- This is a research and educational opportunity to learn more about attitudes related to hepatitis B and liver cancer, so efforts can be made to address any misconceptions with future programming.
- Focus group sessions help gather community members to freely ask questions, learn more about hepatitis B, and build a community with others living with hepatitis B.

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