

The World Hepatitis Atlas

Completing the data map



The World Hepatitis Alliance

The World Hepatitis Alliance is a newly-established non-governmental organisation (NGO) representing a global coalition of patient groups committed to tackling the huge public health challenge of hepatitis B and hepatitis C and changing the fate of hundreds of millions of people. It also aims to educate people about the risks of contracting hepatitis and encourage governments to implement public health campaigns to help reduce the incidence of the diseases at a national level. Its Board of patient groups from seven world regions - Australasia, Eastern Mediterranean, Europe, North Africa, North America, South America, and the Western Pacific – are providing the leadership for the campaign in 2008/09.

Support from other NGOs (e.g. Médecins Sans Frontières) and supranational organisations are key to the campaign's success. Funding for global activities is coming from a range of sources, from a cross-section of industry to media sponsorship, as well as grants from philanthropic organisations.

The World Hepatitis Campaign

One part of the campaign involves raising public awareness of hepatitis B and C, by addressing the lack of understanding of the diseases and the risk factors, and encouraging those people most at risk to get tested.

Patient groups across the world will also present '12 Asks' to their national governments to combat hepatitis B and C. The 'Asks' correspond to a series of commitments that recognise the impact of the diseases and the importance of adopting measures that address the issue from a public health perspective. The '12 Asks' to governments are a central element of the campaign aimed at setting objectives both internationally and nationally for improvements in health outcomes for patients. Six Asks are uniform across the world and a further six are country specific.

All governments are being asked to sign up to the '12 Asks' by 2012. This does not mean that all '12 Asks' have to be achieved by 2012. Rather governments should commit to including hepatitis in their public health policy plans.

The Experts

In order to inform and guide the campaign, the World Hepatitis Alliance has recruited a group of medical experts from diverse regions of the world, with significant experience in hepatitis and/or large public health campaigns. This group, known as the Public Health Panel, acts as an advisory board or expert reference group to the Alliance.

The Atlas

The World Hepatitis Atlas is a global compendium of statistics and is the backbone of the campaign. Both the public awareness and policy programmes are aimed at raising awareness of the burden of hepatitis B and C and highlighting to governments the need for public health campaigns, universal screening, prevention and treatment programmes. The Atlas will ultimately demonstrate on a global basis where progress is being made and where much is still to be accomplished. The first stage in this process will be filling in the vast gaps in data relating to incidence, prevalence and mortality of the disease. Without such information, governments cannot be held to account.

“World Hepatitis Day has succeeded in bringing together all the major forces engaged in fighting the hepatitis menace”

Prof S.P. Singh

Member of the World Hepatitis Alliance Public Health Panel

Welcome from the World Hepatitis Alliance

Dear friends, colleagues and supporters,

This document is a call to action for the development of the first ever World Hepatitis Atlas.

One of the main concerns of the World Hepatitis Alliance, and something that the Atlas will demonstrate, is the lack of available data on hepatitis B and C. As it stands, even the most recent data from the World Health Organization (WHO) dates back to 1999.

Without up to date statistics, governments cannot understand the depth of the problem or measure the effectiveness of public health campaigns and are working in the dark when directing resources to awareness, prevention, screening and treatment.

The World Hepatitis Alliance, with support from the Public Health Panel, supranational organisations and “early adopter” governments, will work to develop the World Hepatitis Atlas. The Atlas will provide the first truly global monograph of statistics and information relating to chronic viral hepatitis B and C – showcasing country statistics and highlighting where no data exists.

This Atlas will become a useful visual tool with a powerful story to illustrate the seriousness of the problem on a global scale, to a global audience. It can be used as part of a consumer awareness campaign or to lobby governments to monitor and maintain records on hepatitis.

The Hepatitis Atlas will evolve over time, with the first edition serving as a template to show the kinds of data that we are looking for and demonstrate the extent to which it is lacking. As the campaign evolves, we hope the Atlas will grow, which in itself will be a sign that change is happening and governments are starting to take note. In the next few years, we expect to be able to include projections for 2012, tying in with the ‘12 Asks’ to governments by 2012.

In subsequent years the Hepatitis Atlas will provide increasingly sophisticated data, such as information about services available to patients, vaccination statistics and best practice case studies demonstrating initiatives that really work in improving the experience of patients around the world. Our intention is that the Hepatitis Atlas will become the number one global resource for patient groups, governments and the general public.

Together we can make a difference!



Charles Gore

World Hepatitis Alliance President

Disease Information and Risk Factors

About Hepatitis

Hepatitis means 'liver inflammation' and is most often caused by a virus. Although there are five completely different viruses that cause hepatitis (A,B,C,D & E), B and C are the only two that can become chronic, causing long-term illness.

Together, hepatitis B and C represent one of the biggest threats to global health, killing approximately 1.5 million people a year. It is estimated that over 500 million people around the world are currently infected with hepatitis B or C and one in three people have been exposed to one or both viruses.

Infection

The hepatitis B virus is spread through direct contact with infected blood as well as most major body fluids including blood, semen, sweat, tears and breast milk. The hepatitis C virus is spread through direct contact with infected blood. Very rarely, hepatitis C can also be passed on through other body fluids. Many people do not have any symptoms if they contract hepatitis B or C, although they can still transmit the virus to others.

The most common routes of infection are:

- blood transfusions and receiving blood products before screening was introduced
- sharing equipment for injecting drugs
- medical or dental interventions in countries where equipment is not adequately sterilised
- sharing straws, notes etc. for snorting cocaine
- sharing razors, toothbrushes or other household articles
- tattooing and body piercing if done using non sterile equipment
- mother to infant during childbirth

Some people may have symptoms, including tiredness, aches and pains, headaches and fever, loss of appetite, nausea or vomiting, diarrhoea, abdominal pains, and jaundice.

Prevention

There are various ways to reduce the risk of contracting hepatitis B and C, given their transmission through blood and other bodily fluids. The best starting point is education and raising awareness among the public on how to avoid contracting the disease.

For hepatitis B, getting immunised is the best way of preventing infection. More than one billion doses of the hepatitis B vaccine have been used since the early 1980s and it has been shown to be effective in approximately 95% of cases. Unfortunately despite its excellent record, the hepatitis B vaccine is not available in all parts of the world. As of March 2006, 158 countries had included the vaccine on their national immunisation schedules, including most countries in East and South-East Asia, the Pacific Islands, Australia, North and South America, Western Europe and the Middle East. There is currently no vaccine for hepatitis C.

Many low income countries in Sub-Saharan Africa and the Indian subcontinent do not use the hepatitis B vaccine. Today 350 million people around the world are living with a disease that can be prevented and which kills approximately one million people every year.

The price of the hepatitis B vaccine has been one of the main obstacles to its introduction in many countries, but since 1991 the WHO has called for all countries to add hepatitis B vaccine into their national schedules. Since its creation in 2000, the Global Alliance for Vaccines and Immunisation (GAVI Alliance) has also been instrumental in improving access to the hepatitis B vaccine. WHO estimates show that 158 million additional children have been immunised against the disease for the period 2000-2007.

“Viral hepatitis: Be alert: Millions are silently infected!”

Dr João Mendonça
Member of the World Hepatitis
Alliance Public Health Panel

About the World Hepatitis Atlas

Background

When we started out, we intended to compile data on hepatitis B and C in a book that we hoped would serve as a default source of information on the diseases. What we found through the course of our work was that this data is not readily available, either on patient group websites or Health Ministry pages. This does not mean that this information is not available, rather that through research, we were not able to find it in the most obvious places.

We decided instead to focus on developing a call to action to encourage the collection of this data in countries all around the world. We are therefore calling on people who have access to this information, to help us build the Hepatitis Atlas and bring this information into the public domain.

N.B. Everything on the map overleaf therefore reflects data and information availability, rather than disease based information.

Information we need

There are no limits to the information that the Hepatitis Atlas can ultimately provide and we would welcome any that you can supply, provided it has a reliable data source for referencing.

Our immediate needs are for the following data on hepatitis B and C: incidence, prevalence, mortality and information on government policies on hepatitis.

“The only way to win the fight against chronic viral hepatitis is to join forces”

Jean-Michel Pawlotsky
Member of the World Hepatitis
Alliance Public Health Panel

The Atlas: Our five year plan

Short term (Over the next 12 months)

Communicate the ‘call to action’ to patient groups, governments, media, healthcare professionals and pharmaceutical industry representatives, using the Atlas as a visual tool to share the message

Conduct in-country research, liaising with Health Ministries to obtain information

Publish an updated Atlas with revised figures, and information for countries for which information was previously unavailable

Medium term (Over the next two years)

Further the ‘call to action’ with requests for more detailed information including co-morbidities, sex ratios, age demographics and economic impact

Continue to pressure governments to collect data and provide evidence for policies or action plans

Partner with the WHO to provide endorsement and support to strengthen our ‘call to action’

Publish an updated Atlas with revised figures, and information for countries for which information was previously unavailable

Long term (By 2012)

Produce a full and complete Atlas that will use maps, graphs, charts and tables as comparative tools for analysis

Provide in-depth analysis of hepatitis B and C trends around the world, highlighting the ‘hot spots’

Publish the Atlas statistics on the WHO website to facilitate ease of access to all

Examples of Best Practice

Some governments are more actively confronting the hepatitis challenge than others. We would like all governments to be adopting policies and implementing campaigns as effectively as these countries highlighted below. Here are examples of countries which are already making progress towards achieving good standards in hepatitis education, prevention and treatment:

Australia



Achievements

The second National Hepatitis C Strategy 2005-2008 builds on the successes of the first strategy (1999). Key aims are¹:

- Prevention and Education
- Diagnosis, Treatment and Support
- Surveillance and Research
- Health Maintenance, Care and Support
- Workforce Development

This strategy is founded on a partnership between all levels of government, community based organisations, healthcare professionals, researchers and people affected by hepatitis C.

Actions²

- Annual Surveillance Reports
- Estimates and Projections of the Hepatitis C Virus Epidemic in Australia
- Annual National Hepatitis C Awareness Weeks - targeting the affected communities
- Hepatitis C Testing Policy
- Trial of a GP Prescriber Model of Care
- Economic Evaluation of Hepatitis C in Australia
- Development of Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings
- Educational Resources for priority populations
- Peer Education Programmes
- Workforce Development Programmes

China



Achievements

In 2006, the Chinese Ministry of Health initiated a five year National Hepatitis B Prevention and Control Plan to ensure the prevention of hepatitis B infection of newborns and other vulnerable groups. The objectives of the plan include:

- To achieve prevalence rates of less than 7% for the entire nation, and 1% for children under five years by 2010³
- To reach a vaccination rate greater than 90% for all newborns, and to vaccinate around 95% of those children who were born after 2002 and have not been immunised⁴

Actions

- Conducting a nationwide survey looking at the current epidemic situation, changing trends, transmission factors, financial burdens and an evaluation of the current immunisation programme⁴
- Developing sound systems to monitor hepatitis B prevalence, the progress of vaccination and number of infections in high-risk groups⁴

France



Achievements

An extremely effective government-led hepatitis C campaign has resulted in dramatic steps in the fight against hepatitis C across France:

- Detection of hepatitis C has doubled in ten years
- Patient awareness of infection more than doubled between 1994 and 2004 – with 56% of those infected in 2004 aware that they had the disease, compared to 24% in 1994⁵
- Deaths resulting from liver disease have significantly reduced across France

Actions

- Developing a hepatitis C virus specific network
- Establishing targets for detection and a suitable detection strategy with adequate funding
- Implementing a surveillance system that would not only reveal the extent of the hepatitis C problem, but also measure the impact of interventions
- Involving patient organisations and a government advocate throughout all campaign stages
- Providing anonymous testing facilities at various centres including family planning clinics, drug clinics, universities and prisons
- Using targeted media campaigns to raise awareness among those at risk of hepatitis C

Scotland



Achievements

In September 2006, Scotland launched its Action Plan for Hepatitis C. The two-stage plan aims to:⁶

- Prevent the spread of hepatitis C, especially among Injecting Drug Users (IDUs)
- Diagnose persons infected with hepatitis C, in particular those who would benefit most from treatment
- Make certain that those infected with hepatitis C receive the best possible treatment, care and support

Actions

Phase I (Sep '06 - Aug '08) of the Action Plan has involved collecting, collating and interpreting evidence⁷. Key points about Phase II include:

- Involvement of policy and patient representatives e.g. presentations by key government ministers and officials and patient testimonials at the launch event for Phase II of the Action Plan⁸
- Implementation of preventative services, such as improvement of services associated with the provision of injecting equipment for IDUs⁶
- Improving the accessibility of testing and support facilities, especially for target risk-groups⁵
- Implementation of a national awareness-raising campaign as well as training and education for children, and health and social care professionals⁶

How to Get Involved

If you would like to know more about the World Hepatitis Day Campaign in your country, please contact the World Hepatitis Alliance member nearest to you:

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