HCV Quest Country-Specific Report

ABOUT HCV QUEST

HCV Quest was a global survey of almost 4000 people with hepatitis C. The results give a striking – and sometimes shocking – insight into the experiences of people living with hepatitis C.

The global survey was developed and run by the World Hepatitis Alliance during July–December 2014. The survey was promoted via social media and through World Hepatitis Alliance channels, and received support from many patient groups and healthcare professionals, who shared links to the survey online or distributed hard copies in their clinics.

All responses were translated and analysed, including many thousands of free-text responses sharing insights into the reality of life with hepatitis C.

A global report of findings was launched in April 2015 at the International Liver Congress in Vienna.

This country-specific report summarises responses of 825 people from China, with insights into the experiences they shared and pertinent comparisons with regional and global findings.

For the purposes of this report, China is defined as part of the World Health Organization (WHO) Western Pacific Region, and has been contrasted against responses from this region including Australia, Japan and Malaysia.

“Because of the side effects of IFN, I cannot get close to my children”

“1. Medical insurance/Social insurance does not cover specialist care. 2. General hospital HCPs are cold and unsympathetic while those in smaller hospitals are not knowledgeable about HCV. 3. 30 years of treatment and its costs wrecked my family, and the illness gave a double whammy on my physical and mental health”

“It is hard for the patients with hepatitis C to use the new medicine in China, and we need the help of WHO (World Health Organization)”
Low public awareness of hepatitis C

Less than $\frac{1}{4}$ of people knew what hepatitis C was before their diagnosis

Survey findings

• Public awareness of hepatitis C in China (25%) is the lowest within the Western Pacific region – the average is 34% for the Western Pacific region and 31% globally

• Those who were aware of hepatitis C prior to their diagnosis were informed mainly through a medical professional (47%), news and media such as television and radio (27%), and patient organisations (17%)

• Government awareness campaigns in China are the least successful when compared with other Western Pacific countries. Such campaigns informed around 9% of the people in China vs. an average of 24% in Malaysia and 11% in Australia

What does this mean?

Public awareness of hepatitis C in China is unacceptably low

Despite China having one of the highest hepatitis C burdens in the world, public awareness of the disease is considerably lower than both the regional and global average. Significantly more must be done to raise awareness in order to strengthen efforts to prevent, diagnose and treat the epidemic.

The burden of informing people about the risks of hepatitis C is falling on the medical profession. The lack of success of more broad-based awareness campaigns, such as government awareness campaigns or through TV and radio, indicates large numbers must be going undiagnosed.

Governments made a commitment in the World Health Assembly Resolution 63.18 to raise public awareness of viral hepatitis and have a responsibility to recognise hepatitis as a major public health issue. Neighbouring countries’ government awareness campaigns have been noticeably more successful, suggesting China should significantly step up its efforts to ensure important public health messages are reaching its population.


Good family doctor awareness, testing and referral but too many people already have significant liver disease by the time they are diagnosed

State of liver at the time of diagnosis

Country data based on 810 responses

Survey findings

• A large proportion of the respondents (70%) from China were offered a hepatitis C test after telling their doctor about their symptoms, which is relatively high compared with the Western Pacific regional average of 45%

• The most common route to hepatitis C diagnosis in China was via a routine health screen (30%), followed by 24% of respondents whose doctors had suggested a test and just under 20% who themselves had requested a test

• All respondents diagnosed by their family doctor were referred to a specialist within 3 months (75%) or within a year (25%). No patient had to wait longer than a year to see a specialist

• 46% of the respondents from China were diagnosed early and had no liver damage at diagnosis. However, over a third had fibrosis (22%) or compensated cirrhosis (12%) and 4% had very advanced disease (decompensated cirrhosis or liver cancer)

What does this mean?

The HCV Quest survey reported that doctors are recognising symptoms of hepatitis C, and referral from family doctors to specialist is generally rapid. However, at diagnosis over half of the respondents had liver damage. This indicates that raising awareness and increasing routine screening are extremely important in diagnosing hepatitis C before the onset of liver damage.
Social stigma and discrimination around hepatitis C are major challenges facing people with hepatitis C in China

75% of respondents have not told anyone that they have hepatitis C.

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your close family</td>
<td>11.1%</td>
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<tr>
<td>Your wider family</td>
<td>1.9%</td>
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<tr>
<td>Family friends</td>
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<tr>
<td>Friends</td>
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<tr>
<td>Colleagues</td>
<td>1.2%</td>
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<tr>
<td>Social media</td>
<td>0.4%</td>
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<tr>
<td>Patient organisations</td>
<td>1.7%</td>
</tr>
<tr>
<td>Or none of the above</td>
<td>75.4%</td>
</tr>
</tbody>
</table>

Country data based on 810 responses. Respondents could select more than one option.

Survey findings

• Only 11% of respondents from China have told their close family about having hepatitis C – this is very low compared with other Western Pacific countries; 99% in Japan, 83% in Australia and 75% in Malaysia.
• Around 20% of respondents felt that their hepatitis C had a negative impact on their relationships with their colleagues (21%), friends (20%), family (18%), and partners (22%).
• Nearly 40% of respondents from China said they felt they had suffered discrimination in work or education, or that their prospects had been affected because of their hepatitis – this compares strikingly against countries such as Malaysia, where this was rated at only 16% and Australia where 21% said they felt they had been discriminated against in this way.

What does this mean?

More than just a liver health concern: the isolating impact of hepatitis C

So many of the survey respondents have indicated the extremely significant impact hepatitis C has had on their physical, emotional and psychological well-being. Yet, with as many as 3 in 4 people not telling anyone at all about their hepatitis, vast numbers of patients are clearly not receiving the support they need and deserve.

This silence is undoubtedly the result of high levels of stigma associated with the disease. It is unsurprising that so many suffer in silence given the high number of respondents in China revealing the levels of discrimination experienced in work or education.

Furthermore, many of those brave enough to disclose their hepatitis C to friends, family and colleagues report a negative impact on these relationships. If we are to significantly improve the lives of those with hepatitis C, people must feel comfortable enough to reveal their status without fear of stigma and discrimination and confident that by doing so, those around them will help to provide the support so clearly needed. The government has an important role to play in ensuring anti-discrimination laws are in place and, critically, are enforced while raising public awareness to tackle stigma amongst the population.
Poor communication and treatment decision making between patients and healthcare professionals

Patient satisfaction with the advice received at the time of diagnosis

Country data based on 793 responses.

Survey findings

- 29% of respondents were not satisfied (14%) or not at all satisfied (15%) with the level of help and advice they received at diagnosis. In general, with the exception of Malaysia, people in the Western Pacific region were not very satisfied with the information provided.

- A high proportion of patients felt that their physicians (19%) and nurses (31%) did not understand the full impact of hepatitis C on their life.

- Of the 601 respondents who had taken interferon-based treatment, 18% did not know if their treatment had been successful, suggesting poor feedback and communication.

- A large proportion of people (41%) in China felt their doctor should have the final decision around their treatment options. This is a completely different picture from the other countries in the Western Pacific region, where only 2% in Australia, 3% in Japan and 26% in Malaysia shared this opinion.

- The remaining proportion of respondents from China feel the treatment strategy should be discussed between themselves and the doctor with 24% believing the final decision should be made by the doctor vs. 35% by the patient.

- Less than half of the respondents in China discussed new therapies with their doctor – whereas healthcare professionals had discussed this with 75% of patients in Japan.

- Nearly 3 in 10 patients said they did not feel they had access to an authoritative doctor who they could trust – which is the lowest level of access found in the Western Pacific region – compared with 8% in Malaysia, 17% in Japan, and 19% in Australia.

What does this mean?

Communication between patients and healthcare professionals needs to improve

A large proportion of patients in China do not feel satisfied with the level of advice they receive from their healthcare professionals. Many feel their doctors and nurses do not understand the impact hepatitis C has on their life and yet more than 2 in 5 patients expect their doctor to choose their treatment.

Many patients (22%) do not feel comfortable about asking their healthcare professional questions and are therefore not likely expressing any concerns they may have about their disease or treatment. In China, nearly 20% of the respondents described healthcare professional communication (in writing, at consultations or over the phone) with them as “totally unsatisfactory”.

Healthcare professionals need to promote partnership and dialogue between patients and physicians, in order to reap benefits such as improved adherence to medications, which may in turn mean that treatment is more effective. In order to do this, healthcare professionals may need to initiate the conversation and encourage patients to be open about how they feel.
HCV Quest Toolkit

Driving change in your country to transform the lives of people with hepatitis C

How can you use this report? Our suggestions:

The HCV Quest country report is a resource that we hope you can use to support:

ADVOCACY – with the media, government, healthcare professionals
• To improve the government and health service response to hepatitis C
• To raise the profile of hepatitis C within government and the general population
• To reduce stigma and discrimination

COLLABORATION – with the media, government, healthcare professionals and patients
• To highlight the impact of specific issues in your country
• To offer support and advice on addressing the issues

Improve awareness and understanding of hepatitis C
• Use the survey data to communicate clearly to governments and medical professionals the true impact of hepatitis C and the importance of awareness about:
  - Unseen burden on mental/psychological and emotional health
  - Personal and social costs of untreated disease
  - Impact of stigma and discrimination on personal and professional life
• Offer the media expertise and access to survey facts and figures and patient stories to highlight the burden associated with hepatitis C infection
• Hold governments accountable to WHA63.18, in which they committed to using World Hepatitis Day to improve public awareness
• Offer to collaborate on or support government campaigns such as partnering for World Hepatitis Day

Improve testing and information available at diagnosis
• Highlight the report’s data on missed opportunities for testing and urge governments to improve awareness of symptoms among healthcare professionals
• Use country and regional comparisons in the report to show how practices in some countries such as routine testing has improved early detection and treatment outcomes
• Advise government on the type of information and materials to provide and collaborate with governments and healthcare professional to produce materials
• Highlight the lack of information available and offer to cooperate with medical professionals to ensure sufficient information and support is provided to patients at diagnosis, including access to patients groups, e.g. ask for patient group contact details to be included on government materials and websites of national organisations such as liver groups

End social stigma and discrimination
• Use quotes and findings from the report to highlight the life-changing impact stigma and discrimination can have
• Develop a body of evidence on discrimination through further research, such as running your own online survey
• Use data from the report to lobby governments to tackle discrimination through specific anti-discrimination legislation
Empower patients and increase involvement in treatment decisions

- Ensure doctors’ surgeries and hospitals have patient group contact details and information
- Inform patients themselves about their right to be involved in treatment decisions, e.g. run workshops, provide patient information on website, or through leaflets
- Educate physicians on the benefits of patient partnerships such as better adherence or more resources – engage physicians from other therapy areas where this has been successful to propose this discussion
“I have been injected interferon for 4 times, all relapsed. The pain was unimaginable, the expense was also amazingly shockingly huge. To pay my medical expenses, each of my parents do 6-7 jobs, we are broke. Curing hepatitis C will be a relief for my family and me. The disease has created a mountain-like burden on us, affecting our work and my love life. I can become normal if I am cured”

“I was cured but failed. Success is important for me, because I am only 22 years old now, and will be married in a few years and have baby, and I don’t want to bring the disease to the next generation, and I hope to be able to work”

“Misunderstanding and discrimination of the society to hepatitis C, and discrimination and worry of employment”

“It means to regain the life, so that I can practice filial piety for the parents and bury them, can accompany my wife until old, can raise children to grow up, and can continue to work”
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