

HCV QUEST

Global Patient Survey

Country-Specific Report

Malaysia





“The biggest barrier I have faced in the fight against viral hepatitis is... the side-effects of the medication”

“The biggest barrier I have faced in the fight against viral hepatitis is... mental and physical weakness and pain”

“The biggest barrier I have faced in the fight against viral hepatitis is... lack of information and access to professionals, financial burden”

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.

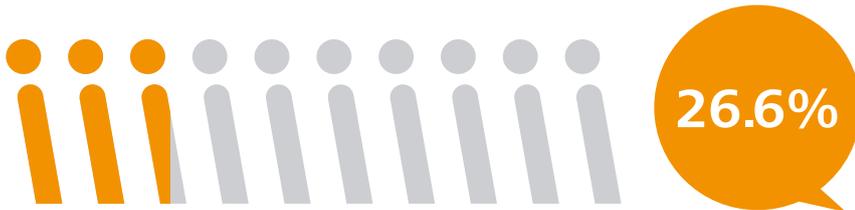
A global report of findings was launched in April 2015 at the International Liver Congress in Vienna.

This country-specific report summarises responses of 131 people from Malaysia, with insights into the experiences they shared and pertinent comparisons with regional findings.

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

Public awareness and understanding of hepatitis C

Less than **3/10** people knew what hepatitis C was before their diagnosis



Based on 128 responses. Excludes information given immediately before a test

Survey findings



- Public awareness of hepatitis C in Malaysia (27%) is low compared with the average in the Western Pacific Region (34%) and globally (31%)
- Only China had lower awareness of hepatitis C before diagnosis (25%) in the Western Pacific Region
- People who had knowledge about the disease before their diagnosis had received this information through patient organisations (9%), medical professionals (29%), news and media (29%) and other undefined sources (27%)
- Government campaigns were relatively successful in Malaysia, informing 24% of people who had knowledge prior to their diagnosis. This compared well against the regional average of 11%, and the global average of just 5%

FAST FACTS

Hepatitis C is one of the most common causes of liver disease worldwide [1]

Around 329,000 adults (1.5%) in Malaysia had hepatitis C in 2013 [2], with a total of 80–150 million people living with the chronic condition worldwide [3]

Deaths related to hepatitis C are increasing and 700,000 died worldwide in 2013 [1]

There is currently no vaccine for hepatitis C [3,4]

What does this mean?

Public awareness of hepatitis C remains unacceptably low

Wider awareness of hepatitis C and its impact is required to improve treatment success and disease prevention.

1. Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2015;385:117-71.
2. Gower E et al. Global epidemiology and genotype distribution of the hepatitis C virus infection. *J Hepatol* 2014; 61: 545-557
3. World Health Organization (WHO). Hepatitis C. Fact Sheet N. 164. Geneva, Switzerland, 2014. Available at: <http://www.who.int/mediacentre/factsheets/fs164/en/>
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26 for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2015;385:117-71.



Are patients sufficiently informed at diagnosis?

Only **23%** received “as much as or more” information than wanted/needed at diagnosis



Based on 126 responses

Survey findings



- 49% of patients were provided with information leaflets at the time of diagnosis, but comparatively few were referred to patient organisations for support (3%)
- However, the proportion referred to discuss their disease with specialist nurses, 51%, is one of the highest rates globally (global average 21%)
- 63% of people looked for further information following diagnosis; of these, most visited specific websites (30%) and used search engines (43%), rather than accessing patient organisation (4%) or government/health service (7%) websites
- 28% didn't know the state of their liver at the time of diagnosis
- 42% of people didn't know if they had achieved sustained virological response on interferon-based therapies. This is extremely high versus the regional average of 16%

What does this mean?

Insufficient information is being given to patients about hepatitis C – and about their own health

Many Malaysians are not satisfied with the information they receive at diagnosis and are also not aware of important information about their disease stage and treatment success. Despite a high proportion of people having the opportunity to speak with a specialist nurse, many seek more information online.

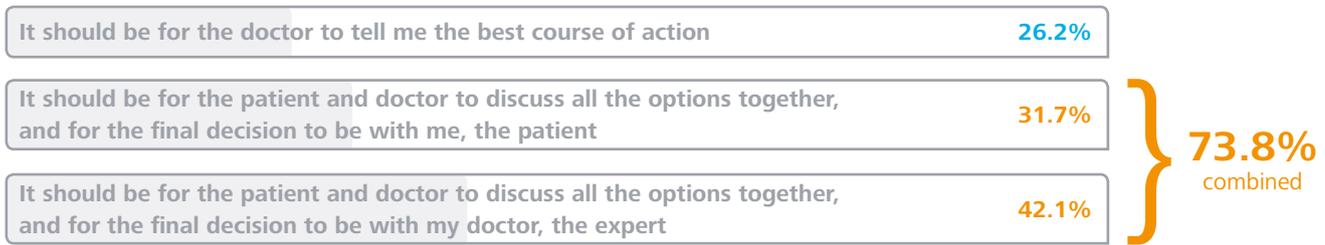
Currently, most online searches are via search engines, which suggests that patients are not being signposted to specific, high-quality sources of information and support by their healthcare teams.

Governments have a responsibility to ensure clear, high-quality information is easily accessible to the public when they need it. Governments and healthcare teams can also draw on the expertise of patient organisations in Malaysia to provide supplementary information, support, and advice for people diagnosed with hepatitis C. It is inappropriate and unnecessary for patients to be left in the dark.

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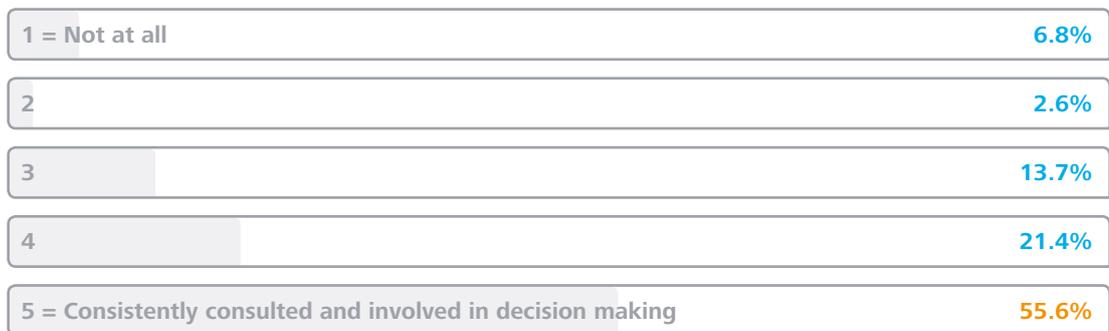
Patients want to be involved in decision making

Most people (**74%**) feel they should be involved in decisions regarding their treatment



Based on 126 responses

Just over half of patients in Malaysia feel they are 'consistently consulted and involved in decision making' about their treatment



Based on 117 responses

Survey findings



- Of the 74% who would like to be consulted and involved in their treatment strategy, 42% would defer the final decision to the expert and 32% would prefer to make the decision themselves
- 26% said they would prefer their doctor to have full discretion over treatment decisions. Across the Western Pacific region, opinions on this issue differed widely. In Japan, only 3% of respondents said their doctor alone should make treatment decisions, but in China this figure was 41%
- Patients' faith in their doctors to make treatment decisions is also reflected in their overall trust in their healthcare teams. 92% of respondents from Malaysia said they felt they had access to a doctor who they trusted as an authority on hepatitis C. This compares to a European average of 74% and Americas average of 88%
- However, only 56% of Malaysians said they were consistently consulted and involved

What does this mean?

Communication and trust between patients and doctors is strong in Malaysia, but many patients want more involvement in decisions around their treatment

Nearly 75% of respondents want to participate in discussion with their healthcare professionals about their treatment and care. Partnership and dialogue between patients and their healthcare teams can result in benefits such as improved adherence to medications, which may in turn mean that treatment is more effective.

Patients in Malaysia told us that they had a very high level of trust in their physicians as experts in hepatitis C care, and 70% said they felt comfortable to ask questions in their consultations with their doctor. Both findings are indicative of good communication and relationships between patients and physicians, but more needs to be done to make patients feel they are consistently consulted around their treatment.

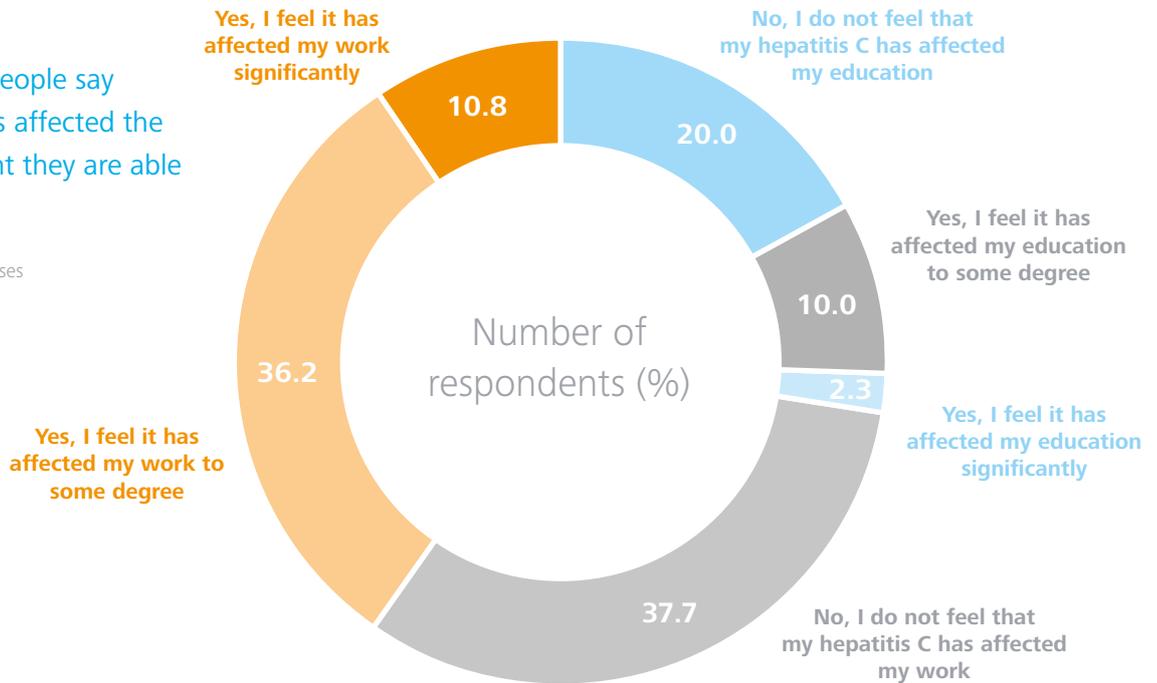
Including people in discussions about their treatment and care is fundamental to good healthcare. It makes sense for patients and the healthcare system – and we must find ways to do this better.



Hepatitis C affects people's working lives

47% of people say hepatitis C has affected the way or amount they are able to work

Based on 130 responses



Survey findings



- 47% of respondents from Malaysia felt that having hepatitis C had affected their work to some degree. Of these, 11% said their work had been impacted 'significantly'
- 26% said they would be uncomfortable talking about their hepatitis C with their boss, colleagues or with staff at their school or university
- Though most respondents said their relationships with their colleagues had not been affected by having hepatitis C, 12% said there had been some negative impact on this relationship
- 16% said they felt they had experienced discrimination or that their prospects had been affected in professional or educational settings because of their hepatitis C

What does this mean?

Nearly 50% of respondents from Malaysia felt their working lives had been affected by having hepatitis C

Policy makers should appreciate that, alongside the physical, emotional or psychological impacts of living with hepatitis C, people living with the disease also suffer practically and economically because of the impact on their ability to work. 22% of people said they had changed their working pattern since being diagnosed, which may impact earnings and limit individuals from achieving their full potential in the workplace.

While respondents in Malaysia reported lower levels of discrimination than the regional average (27%), more than a quarter said they would be uncomfortable discussing their hepatitis C with a boss, colleagues or staff in their place of education, indicating that there is still a significant level of shame and stigma attached to the disease in Malaysia.

Governments can support people living with hepatitis C by implementing and enforcing meaningful anti-discrimination laws, which support people to work flexibly if necessary, and to be open with their employers about their health. Employers gain their workers' trust and loyalty through considerate management, so everyone stands to benefit from this positive approach.

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
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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
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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
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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
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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
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“Cure would mean...
being healthy and carrying
on with daily activities without
thinking about the disease”

“Cure would mean... to
live life normally, not feel
physical pain so often, to be able
to eat normally and to have an
improved emotional state and self-
confidence”

“Cure would mean... peace
of mind & less anxiety about
my health. An extended timeline
for my life. A greater feeling of
wellbeing”



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World Hepatitis
Alliance