

HCV QUEST

Global Patient Survey

Country-Specific Report

Japan





What is the biggest barrier you have faced in the fight against viral hepatitis?



“Not letting others know I have hepatitis C”

“Side effects of treatment are hard and I cannot live a normal life. Treatment costs are a problem”

“No understanding from boss, suppliers or customers. As I looked fine, I was thought to be faking it and other people said the same in hospital. Still thought so by neighbors”

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 72 people from Japan, with insights into the experiences they shared and pertinent comparisons with regional findings.

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

HCV Quest Country-Specific Report

In Japan, knowledge and awareness of hepatitis C is low



Fewer than 1 in 2 respondents knew what hepatitis C was before their diagnosis

Awareness of hepatitis C before diagnosis among HCV Quest respondents. Country data based on 72 responses



Only 1 in 5 respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor

Percentage of HCV Quest respondents. Country data based on 72 responses

FAST FACTS

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

Around 1,603,000 adults (1.5%) in Japan had hepatitis C in 2013, with a total of 80–150 million people living with the chronic condition worldwide [2,3]

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]

Survey findings



- 54% of respondents did not know what hepatitis C was before they were tested. Of those who were aware of hepatitis C, none said they had received their information from a government campaign
- Just 29% of respondents were tested because their doctor suggested a test. 19% of respondents were tested for hepatitis C as part of a routine health screen and 10% had asked to be tested
- Of the 26% of respondents who had hepatitis C symptoms at the time of diagnosis, less than 20% were offered a hepatitis C test when they reported these symptoms to their doctor
- For those respondents who were diagnosed by a family doctor, 25% of respondents waited 1–3 years to be referred to see a specialist and 25% had to wait for longer than 3 years to be referred

What does this mean?

More must be done to raise awareness of hepatitis C among the public and physicians

While public awareness of hepatitis C prior to diagnosis was relatively high versus the regional average (34%), awareness among doctors was very poor, with few patients being offered tests on reporting symptoms.

Among those who did have prior knowledge of hepatitis C, more than 20% had been reached by patient organisations; in contrast, not one person had received their information from a government awareness campaign.

Referral rates in Japan are by far the worst in the region. It is completely unacceptable that one quarter of patients are waiting more than 3 years to see a specialist – and a further 10% wait longer than 1 year. This should be an urgent focus for improvement.

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 2015. *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: S45–S57

3. World Health Organization (WHO). Hepatitis C. Fact Sheet N. 164. Geneva, Switzerland, 2014. Available at: <http://www.who.int/mediacentre/factsheets/fs164/en/>

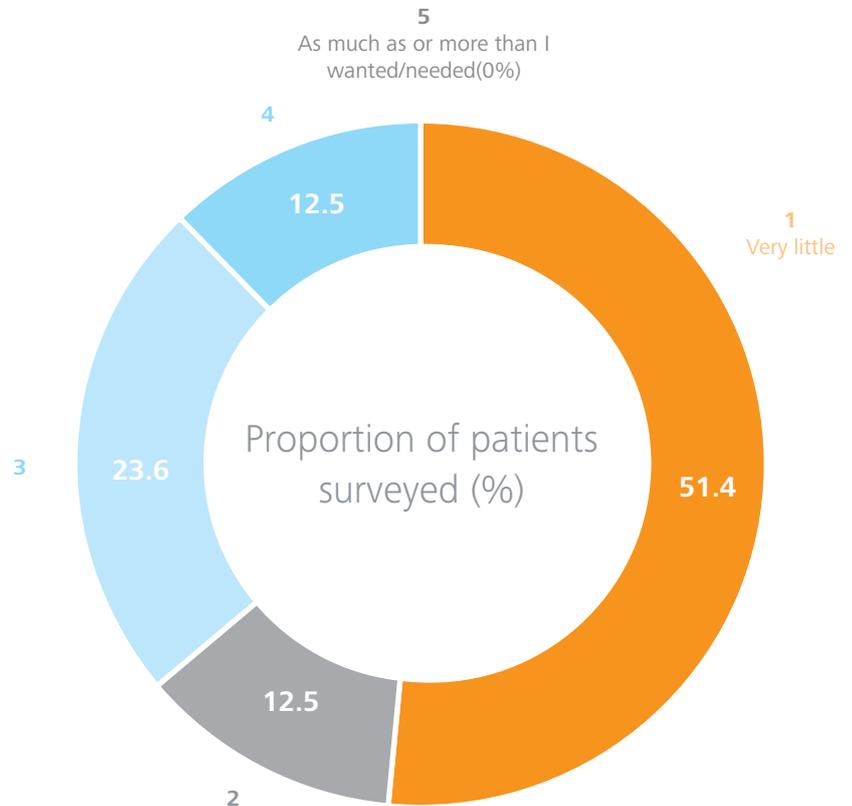
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26



Individuals with hepatitis C want more support and information about their condition, both at diagnosis and throughout their care

Over 50% of respondents felt that they were given **'very little'** information when they were diagnosed with hepatitis C

Country data based on 72 responses



Survey findings



- 51% of respondents said 'very little' information was made available to them through their doctor when they were diagnosed, versus just 13% in Malaysia. Not one respondent felt they had received as much information as they had wanted or needed at the time of diagnosis
- 40% of respondents were 'not at all satisfied' with the level of help and advice they received at diagnosis, and only 4% said that they were 'very satisfied'
- Only 6% were put in contact with a patient organisation on diagnosis, but more than four times that proportion (27%) then used patient organisation websites for further information. Additionally, 40% said they were currently a member of a patient organisation, well above the regional average of 24%
- 60% of respondents said they had made changes to their lifestyle because of having hepatitis C. Of these, 66% had reduced their alcohol intake and 39% had changed their diet

What does this mean?

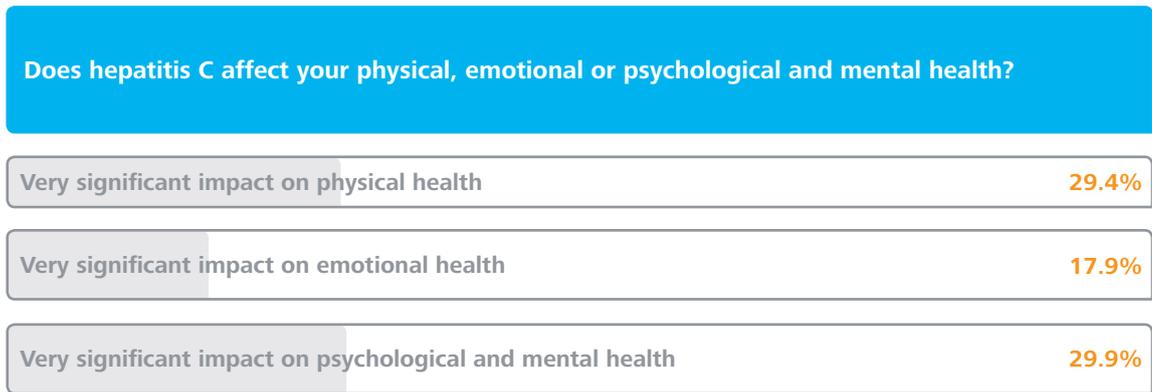
Patients are not receiving anywhere near enough information and support

These findings make for shocking reading. This is another area in which Japan is lagging far behind other nations in the Western Pacific region, and one which makes a huge difference to people coming to terms with a diagnosis of hepatitis C. Every patient deserves the information and tools to look after their health, especially when facing a serious diagnosis.

It is hardly surprising that patients are looking to patient groups for the information and support they need, but with just 6% put into contact with these organisations at diagnosis, healthcare teams are not doing enough to signpost people to the resources they offer.

Living with hepatitis C is challenging

Many respondents felt that hepatitis C had a **'very significant impact'** on their physical, emotional and psychological wellbeing



Responses based on country data (physical, n=68; emotional, n=67; psychological and mental health, n=67)

Survey findings

- Over 70% of respondents said that hepatitis C affects their physical, emotional or psychological and mental health
- Over 70% of respondents felt that having hepatitis C affects their work 'significantly' or 'to some degree'
- Approximately one third of respondents felt that hepatitis C had negatively impacted their relationships with friends, family and their partners
- 42% of respondents who were taking other medications related to their hepatitis C in addition to those directly related to treatment of hepatitis C were taking pain medication, and 16% of respondents were taking anti-depressant medications

What does this mean?

Hepatitis C affects all aspects of a person's life

People living with hepatitis C in Japan told us that the impact on their health was severe, particularly on their physical and psychological wellbeing.

Support for people with hepatitis C needs to take account the many ways in which living with this illness can affect a person's energy, confidence and overall physical wellbeing, and the impact this can have on their relationships. Newer treatments that offer the potential of a life without hepatitis C can relieve people of physical and mental pain, but also free them to achieve their fullest potential in professional life.



Individuals with hepatitis C are generally open about their condition, but are aware of its impact in the workplace

Almost **1 in 3** respondents felt that they had been discriminated against, either at work or in education



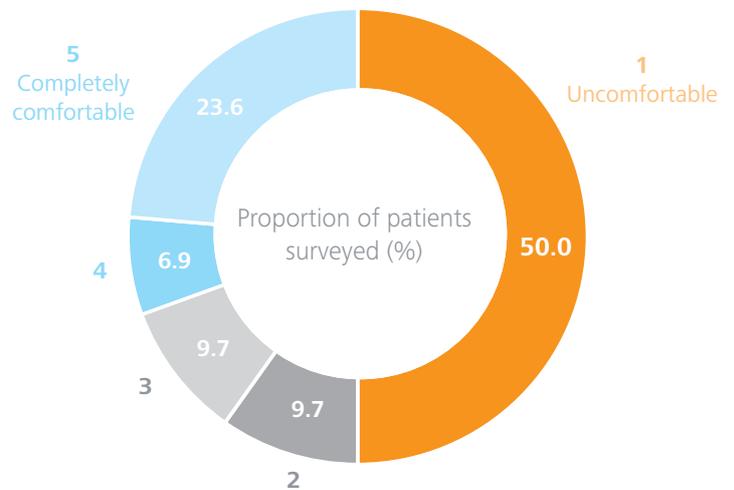
31.9%

Percentage of HCV Quest respondents. Country data based on 72 responses

50% of respondents would feel 'uncomfortable' talking about their hepatitis C with their boss or colleagues

Percentage of HCV Quest respondents. Country data based on 72 responses

Percentage of HCV Quest respondents. Country data based on 72 responses



Survey findings



- 99% of respondents had told their close family about their condition, 54% had told their friends and 40% had told their colleagues.
- 38% of respondents said hepatitis C had negatively impacted relationships with their colleagues
- 32% of respondents feel that they have suffered discrimination at work or in education because of their hepatitis C and 50% would feel uncomfortable talking about their hepatitis C with their boss or colleagues

What does this mean?

Discrimination impacts individual's well-being at work

The proportion of Japanese respondents who believe they have suffered discrimination in education or work because of their hepatitis C is double that reported in Malaysia and significantly higher than in Australia, though slightly lower than in China.

Despite the implications of disclosing their disease, a relatively high proportion of people in Japan are open about having hepatitis with their colleagues – though many said these relationships had suffered as a result.

Stigma and discrimination around hepatitis often stems from lack of public understanding. Government campaigns to dispel myths and offer real support to people living with hepatitis C would make a significant difference to people living with the disease in Japan. Individual workplaces should also outlaw discrimination on the basis of health status, to offer equal opportunities and allow everyone to achieve their potential.

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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If you have not had treatment, or have had treatment and it has not been successful so far, what would a cure mean to you?

“Physical and emotional release”

“I want to be able to relieve a large burden on my life”

“Live normally. Work”



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World Hepatitis
Alliance