

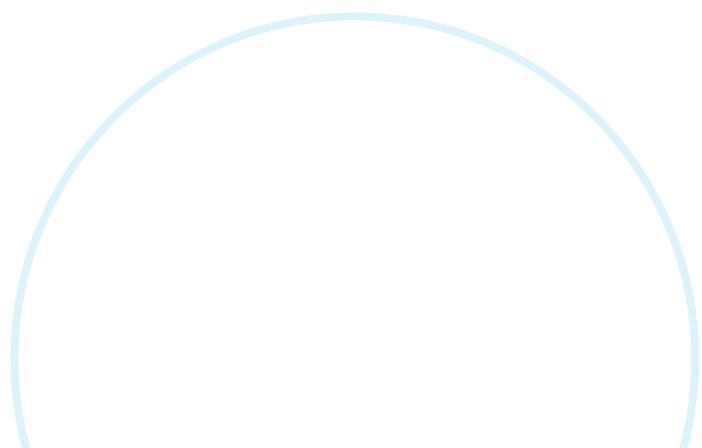
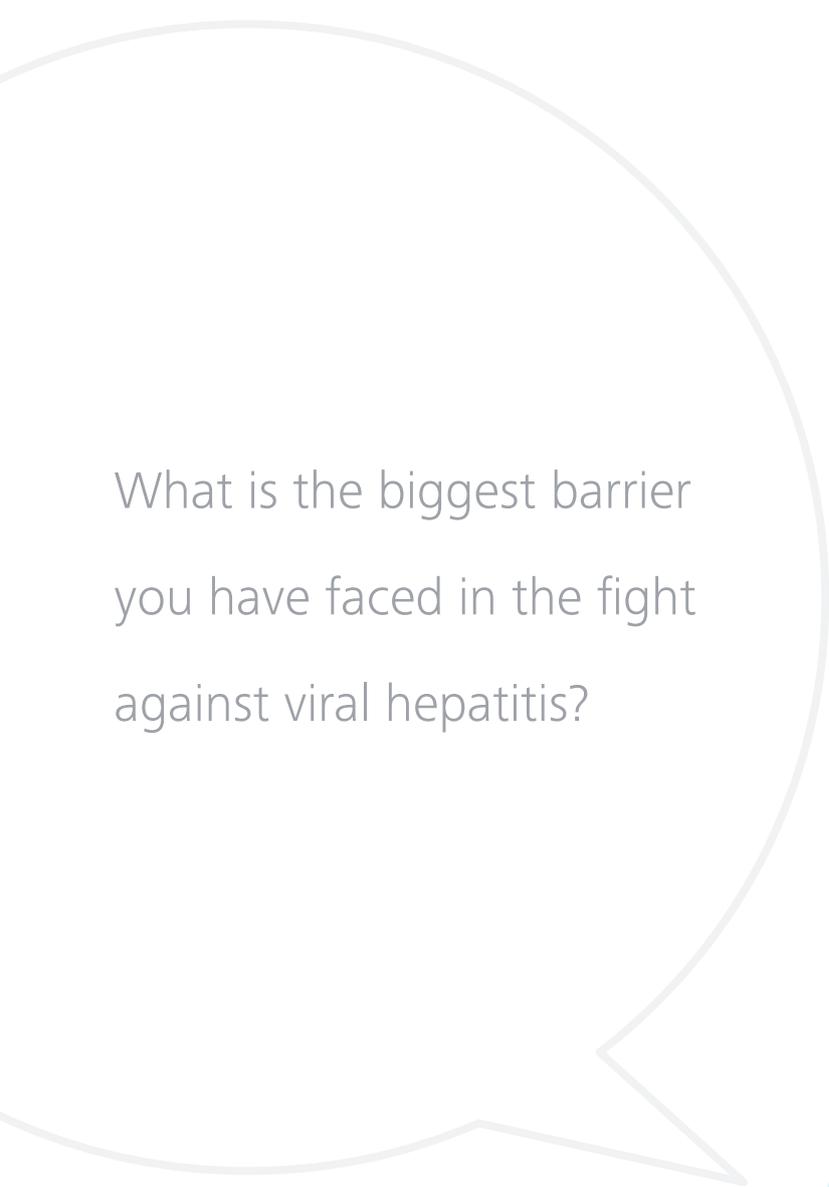
HCV QUEST

Global Patient Survey

Country-Specific Report

Brazil





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



“When I try to get treatment with a new medication and it is refused by my country’s health service”

“Resting. I have to work 8 hrs a day. I get very tired and weak and the doctors say that I am well and that I have to go on working 8 hrs”

“Not being able to talk freely to anyone. Fear of the prejudice you will suffer. My boyfriend is not so close as before”

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

For the purposes of this report, Brazil is defined as part of the World Health Organization (WHO) region of the Americas, and has been contrasted against other nations in this region including Argentina and Mexico.

HCV Quest Country-Specific Report

Public and physician awareness and knowledge of hepatitis C is poor

Almost 9 out of 10 respondents did not know what hepatitis C was before their diagnosis



Awareness of hepatitis C before diagnosis among HCV Quest respondents. Country data based on 63 responses

Just **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 59 responses

FAST FACTS

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

Around 2,409,000 adults (1.6%) in Brazil 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



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- Just 13% of respondents knew what hepatitis C was before they were tested for the disease
- Of those who knew, 25% said their information came from a medical professional and only 13% said their information came from government awareness campaigns
- Overall, just 27% of respondents were tested for hepatitis C because their doctor suggested a test
- Almost 80% of respondents who told their doctor about hepatitis C symptoms were not offered a hepatitis C test
- Half of all respondents had fibrosis of the liver when they were diagnosed with hepatitis C and 13% had cirrhosis

What does this mean?

More must be done to raise public and physician awareness of hepatitis C

Among those surveyed, a very low proportion were offered a test for hepatitis C by their doctor, even when they reported symptoms of the disease.

This is indicative of poor physician awareness of the risk factors and symptoms of the disease, which leaves patients at significant risk of liver damage from undiagnosed hepatitis C, as these data also show.

How many people are ill and have not sought testing? How many of them will wait years for a proper diagnosis, and what will be the state of their health by the time this happens?

Governments need to take a much more proactive and responsible approach to educating the public and healthcare professionals about hepatitis C.

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



Hepatitis C has a significant impact on health and relationships, and some individuals suffer discrimination at work or in education

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

Does hepatitis C affect your physical, emotional or psychological and mental health?

Very significant impact on physical health	25.9%
Very significant impact on emotional health	27.1%
Very significant impact on psychological and mental health	35.1%

Responses based on country data (physical, n=58; emotional, n=59; psychological and mental health, n=57)

Survey findings



- Over 60% of respondents said that hepatitis C has negatively affected the way or the amount they are able to work
- 19% of respondents in Brazil felt their education had been 'significantly' impacted by having hepatitis C
- Nearly 20% of respondents felt that they had suffered discrimination either at work or in education and/or believed that their prospects have been affected because of their hepatitis C
- Over one quarter (26%) of respondents said they would feel uncomfortable talking about their hepatitis C to their boss or colleagues, and only 22% had told colleagues that they had hepatitis C
- Many people felt that hepatitis C had impacted their personal and professional relationships; nearly half reported some negative impact on relationships with colleagues and friends and around 40% reported a negative impact on relationships with family and partners
- Of the respondents who reported a negative impact on relationships, 9% of respondents said that the impact had been 'very strong' with partners. 8% said the same of relationships with colleagues and friends; this was double the regional average across the region

What does this mean?

Hepatitis C affects all aspects of a person's life

More than a quarter of those surveyed reported a 'very significant' impact on physical health and many more (35%) rated the impact on their psychological health as being 'very significant'.

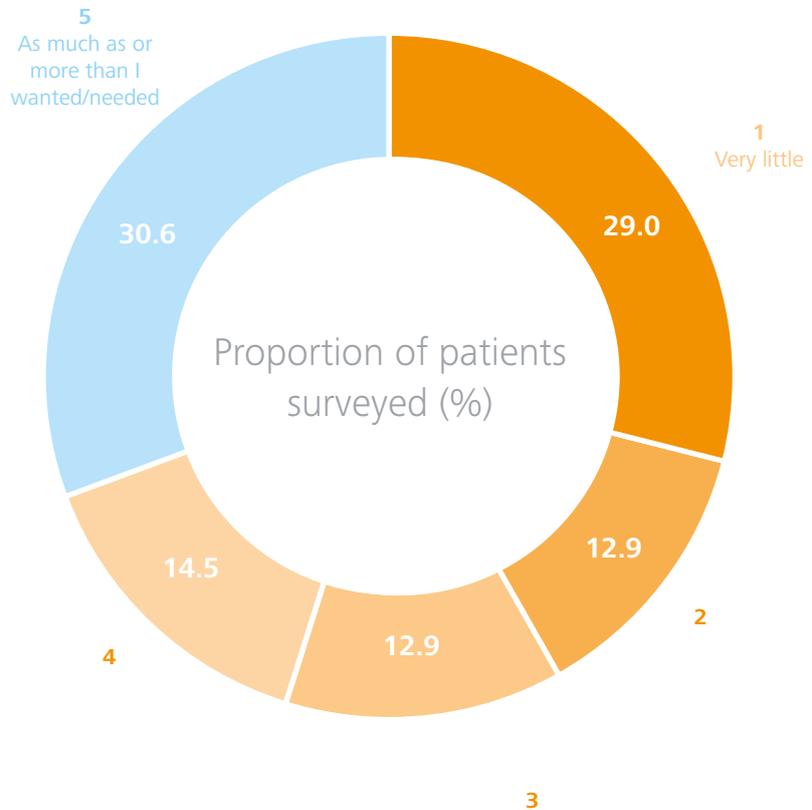
The emotional and psychological impacts of hepatitis C can affect personal relationships, just as the physical impacts might limit individuals' ability to work or get the most benefit from education.

Governments need to see that the true cost of hepatitis C is physical, emotional, psychological, economic and social, affecting families and workplaces, as well as individuals.

Individuals with hepatitis C want more information

70% of respondents felt that they were given **insufficient information** when they were diagnosed with hepatitis C

Country data based on 62 responses



Survey findings



- Almost 40% of respondents were not satisfied (rating 1–2 on 5-point scale) with the information they were given when they were diagnosed with hepatitis C
- 34% were put in contact with a local patient group or organisation at diagnosis, and many more (57%) then used patient organisation websites for further information
- Of those who said they were aware of patient organisations operating in their country, 84% said they saw hepatitis C patient organisations actively involved in supporting patients
- 44% of respondents in Brazil said they were a member of a patient organisation. This was much higher than other countries in the Americas region, where just 18% of Mexican patients and 27% of Argentinian patients said they were a member of a patient organisation

What does this mean?

Patient organisations are providing information where healthcare professionals are failing to

Only a small proportion of respondents told us they had received as much information as they wanted or needed when they were diagnosed. There is no reason why patients should not have the information they need to answer their questions at this time, as well as the support they need to adopt positive strategies for living with hepatitis C.

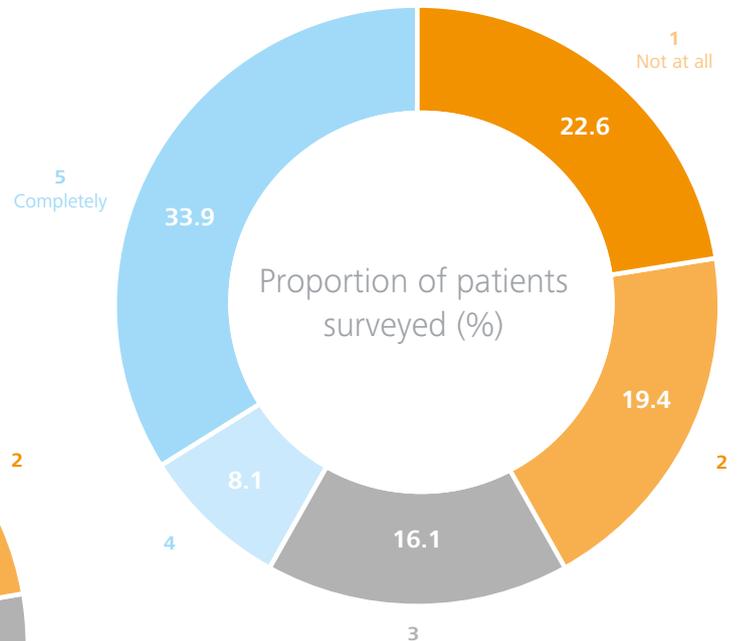
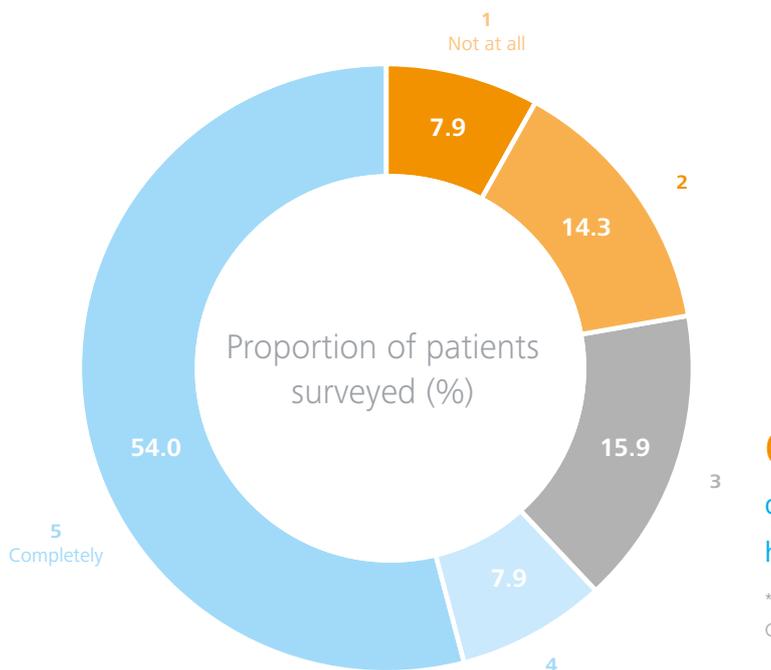
While information is lacking, patients are turning to patient groups for help, and perceptions of their support are overwhelmingly positive. Healthcare teams can and should do more to signpost patients to patient groups, who provide an ongoing source of support, understanding and high quality information.



While trust in doctors is high, patients do not always feel understood by their healthcare teams

Over 40% of respondents felt that nurses did not understand* the full impact of hepatitis C on their lives

*Rated 1-2 out of 5
Country data based on 62 responses



Over 20% of respondents felt that doctors did not understand* the full impact of hepatitis C on their lives

*Rated 1-2 out of 5
Country data based on 63 responses

Survey findings



- The majority (89%) of respondents said that they access to a hepatitis C specialist or doctor who they trusted as an authority on the condition
- However, while over one third (37%) of respondents in Brazil rated communications with their HCP as 'exemplary', nearly 20% rated communications as 'totally unsatisfactory' or 'unsatisfactory'
- While a high percentage (75%) of respondents felt confident to ask questions during consultations with their doctor, just 40% felt the same way during consultations with their specialist and only 20% felt the same way during consultations with their nurse
- 36% of respondents had not agreed on a treatment plan with their healthcare professionals, despite the fact that 77% of these patients felt that having a treatment plan would be beneficial to them

What does this mean?

Patients do not feel understood by healthcare professionals

The majority of patients answering the survey in Brazil told us they feel that they have access to expert hepatitis C care, but many feel less than confident to ask their questions, especially with specialists or nurses.

Healthcare professionals need to demonstrate an understanding of the impact of living with hepatitis C. Improved communications would allow patients to make their concerns and preferences heard, and help to improve the quality of interactions with healthcare teams.

Every patient deserves a voice in decisions about their health and treatment.

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
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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?

"A new life, starting again"

"A great victory "

"Not seeing the fear of contagion in the people's eyes"



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World Hepatitis
Alliance