

HCV QUEST

Global Patient Survey

Country-Specific Report

Mexico





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

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

“The biggest barrier I have faced in the fight against viral hepatitis is... The public are confused by information on HCV, we are labelled a risk, promiscuous, (which) closes social, health and working options to us”

“The biggest barrier I have faced in the fight against viral hepatitis is... The lack of information and apathy and frosty reception from the doctor”

“The biggest barrier I have faced in the fight against viral hepatitis is... The fact that the treatment I was taking was not correct and I need another drug to complete it but you can't get it on the social security”

HCV Quest Country-Specific Report

Public awareness and proactivity regarding hepatitis C and testing is low

Only **1 in 8** people were prompted to get tested as a result of their knowledge of hepatitis C



Patients prompted to get tested based on hepatitis C knowledge.
Country data based on 94 responses

12.8%

Survey findings



- Public awareness of hepatitis C in Mexico is low (20%). This is comparable to the regional average (17%) which is also low at approximately half the global average (31%)
- Those who did know about hepatitis C were rarely prompted by their knowledge of the disease to get tested (13%). Elsewhere in the region, this information did prompt more people to seek testing (22% in Argentina and 34% in Brazil)
- Of those who were tested, 21% had a disease-specific or blood-borne virus screening and 25% had a test as part of a routine health screen
- By contrast, only 15% had their test suggested by their family doctor
- 70% of people who reported their symptoms they were not offered a test
- More than 90% made lifestyle changes after diagnosis – 74% changed their diet and 62% stopped or reduced alcohol intake.

FAST FACTS

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

Around 938,000 adults (1.4%) in Mexico 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 and proactivity regarding hepatitis C testing in Mexico needs to be raised

In general, public and physician awareness of hepatitis C in Mexico needs to be raised, based on low reported awareness prior to diagnosis and low physician awareness of symptoms. In light of the lack of physician understanding of the symptoms of the disease, screening of those most at risk may be needed.

The importance of diagnosis itself is underlined by patients' willingness to change and improve their lifestyle after diagnosis. Without this knowledge, patients are not equipped to take proactive steps to protect their health in this way.

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: S45-S57

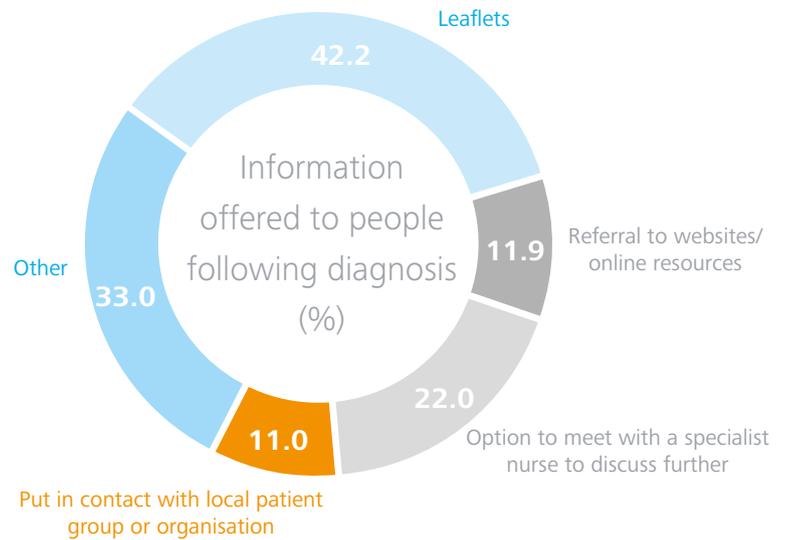
3. World Health Organization (WHO). Hepatitis C. Fact Sheet N. 164. Geneva, Switzerland, 2014. Available at: <http://www.who.int/mediacentre/factsheets/fs164/en/>

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 for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2015;385:117-71.



Is patient support following diagnosis adequate?

Only **11%** of patients with hepatitis C in Mexico were put in contact with support groups following their diagnosis



Membership of patients groups is **lower in Mexico** than in the rest of the region

Are you a member of any patient organisations?

Mexico **18.1 %**

Regional **28.0 %**

Country data based on 105 responses

Survey findings



- Many people in Mexico received a high level of information from their doctor following diagnosis (57% scored 4 or 5, where 5 = as much or more information than I wanted/need)
- However, very few (11%) of those receiving information were put in contact with support groups, similar to the global average (12%) but much lower than Argentina (29%) and Brazil (34%)
- More than a third of patients were unaware of patient organisations in Mexico (36%)
- Perhaps as a result of this, there is a low level of patient support organisation membership in Mexico (18%), compared with a regional average of 28% and membership in Brazil of 44%. Across the world, 30% of patients were members of patient organisations.

What does this mean?

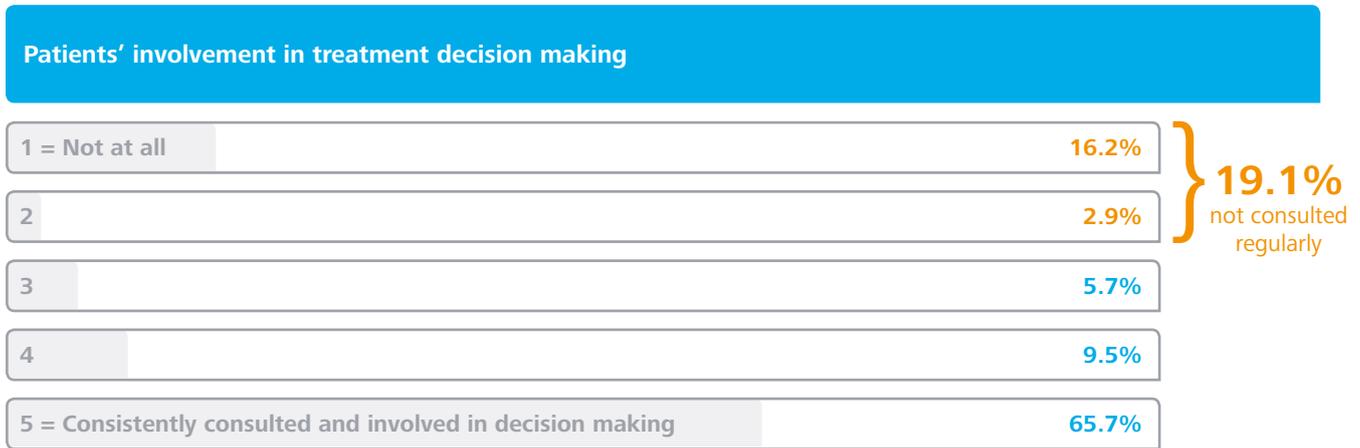
Support for patients following diagnosis needs to increase to improve patient awareness and engagement

Patient organisations can offer a lifeline to patients with hepatitis C, reducing the sense of isolation and increasing a feeling of being an informed member of a community. This resource is clearly being wasted if healthcare professionals do not signpost patients to these organisations.

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Could patients be more involved in decision making?

Two thirds of Mexican patients said they felt consistently consulted and involved in decision making regarding their treatment; however, a significant portion are not consulted at all



Rating 1-5 (1 = not at all, 5 = Consistently consulted and involved in decision making). Country data based on 105 responses



Country data based on 109 responses.

Survey findings

- Most patients (56%) in Mexico see their physicians and discuss their disease and its symptoms frequently (more than three times per year), which is comparable with Argentina (59%) and Brazil (58%)
- However, the proportion of patients reporting that they do not feel consulted at all in decisions about their treatment is 16% – which is comparable with both regional (15%) and global (17%) averages

What does this mean?

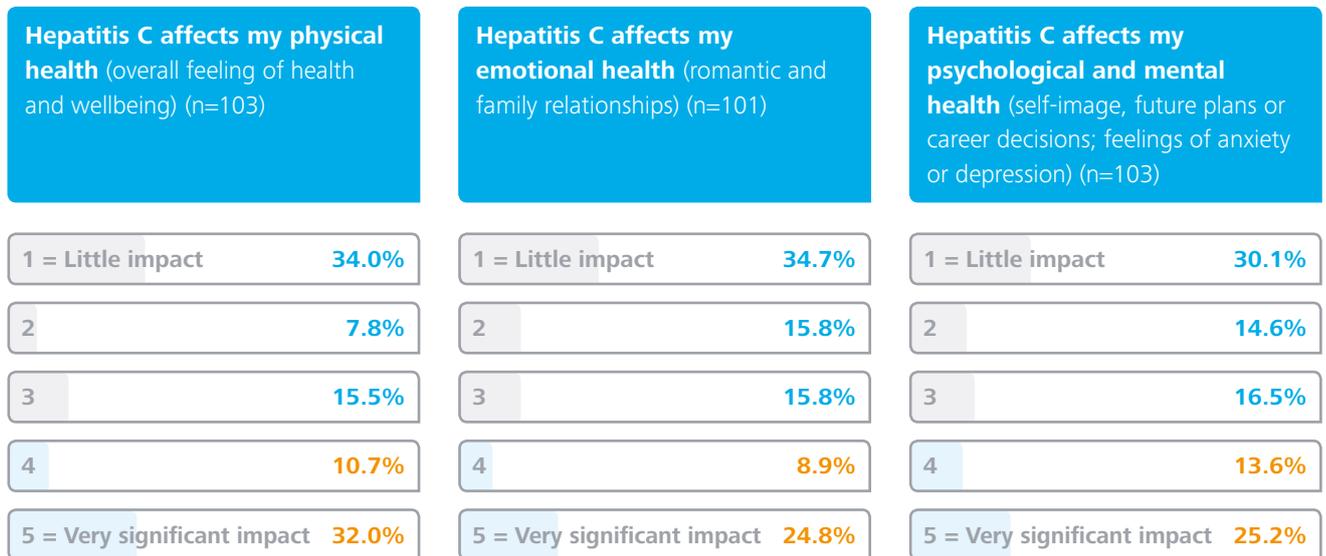
We know that a large majority of hepatitis C patients around the world want a participatory role in their healthcare. This is reflected in Mexican patients, with 78% preferring to discuss all management options with their doctor before a decision is taken. Although a large proportion of patients (66%) report that they feel consistently consulted, the number not being invited to join the discussion about their treatment is still a concern.

Including people in discussions about their treatment and care is fundamental to good healthcare. Healthcare systems that promote partnership and dialogue between patients and healthcare professionals can result in superior outcomes, such as improved adherence to medications, which may in turn mean lead to more effective treatment.



Impact of hepatitis C

Approximately **30%** of Mexicans surveyed described the impact of hepatitis C on their lives as significant



Survey findings



- Over 40% said that hepatitis C had an impact on their work life
- A quarter or more of respondents said that hepatitis C had a 'very significant' negative impact on their physical, emotional and/or mental/psychological well-being
- 19% said that nurses did not understand the breadth of this impact at all and 10% said the same of doctors

What does this mean?

More recognition of the impact of hepatitis C is needed

More education of healthcare professionals, and nurses in particular, is required to ensure that they offer sufficient support to patients. Patient groups are a great resource for providing this support, advice and information, and can complement the work of healthcare teams with their expertise.

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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“Being cured means... Enjoying each day, being positive, valuing health, family, hoping the virus does not reactivate in relation to other illnesses such as cancer”

“For me, cure would mean... To be able to live longer, seeing my children grow up, my dream is not to die young, not to leave my young children”

“To be cured would mean to return to life to be able to carry out my life plan, it would mean regaining the life I have lost”



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World Hepatitis
Alliance