

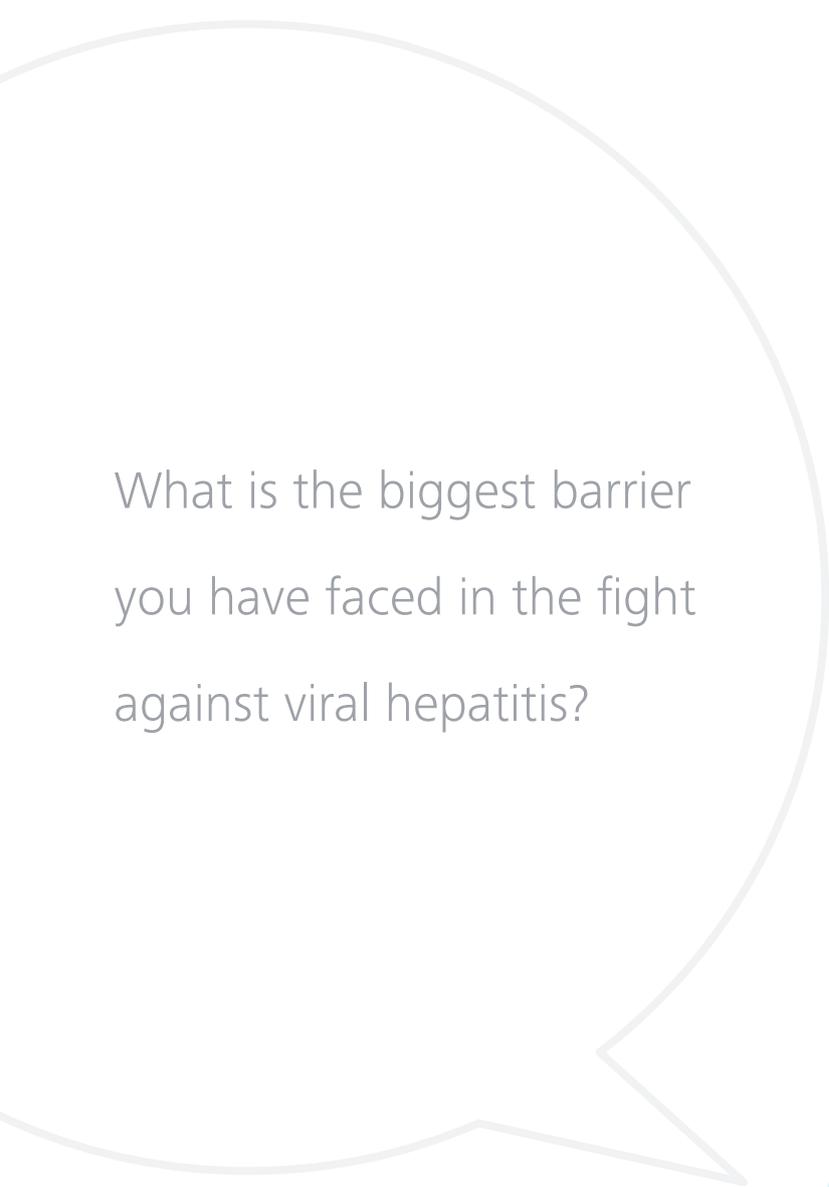
HCV QUEST

Global patient survey

Country-Specific Report

Argentina





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



“Sexual relations with my partner, which were limited or did not exist for fear of contracting the disease”

“Lack of information”

“The physical symptoms related to the side effects of the treatment. The emotional effects that it had on my life plans”

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

For the purposes of this report, Argentina 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 Brazil and Mexico.

Government awareness campaigns for hepatitis C are lacking, and public and physician awareness of the disease is low

4 in 5 respondents did not know what hepatitis C was before their diagnosis



Awareness of hepatitis C before diagnosis among HCV Quest respondent. Country data based on 38 responses

Just **1 in 3** respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor



Percentage of HCV Quest respondent. Country data based on 34 responses

FAST FACTS

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

Around 471,000 adults (1.5%) in Argentina 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



- Only 18% of respondents were aware of what hepatitis C was prior to diagnosis
- Among those who knew, none said that their information had come from government campaigns or medical professionals, and only one had heard through the news or other media (TV, radio, newspaper, etc.)
- Just 35% of respondents were offered a hepatitis C test on reporting symptoms to their doctor
- Respondents reported that they had suffered damage to their livers by the time of their diagnosis, with 40% reporting fibrosis and 11% reporting cirrhosis

What does this mean?

Public and physician awareness of hepatitis C is unacceptably low

High quality public awareness campaigns and proper education for healthcare professionals about hepatitis C, including risk factors and symptoms, are needed to protect people at risk from hepatitis C and to reduce the economic impact of the disease.

It is really disturbing to note that not a single respondent had known about hepatitis C because of government hepatitis C awareness campaigns, or been made aware of the virus by their doctor, before they were diagnosed.

Without a much more responsible approach to hepatitis by government and healthcare professionals, people remain at grave risk.

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/>

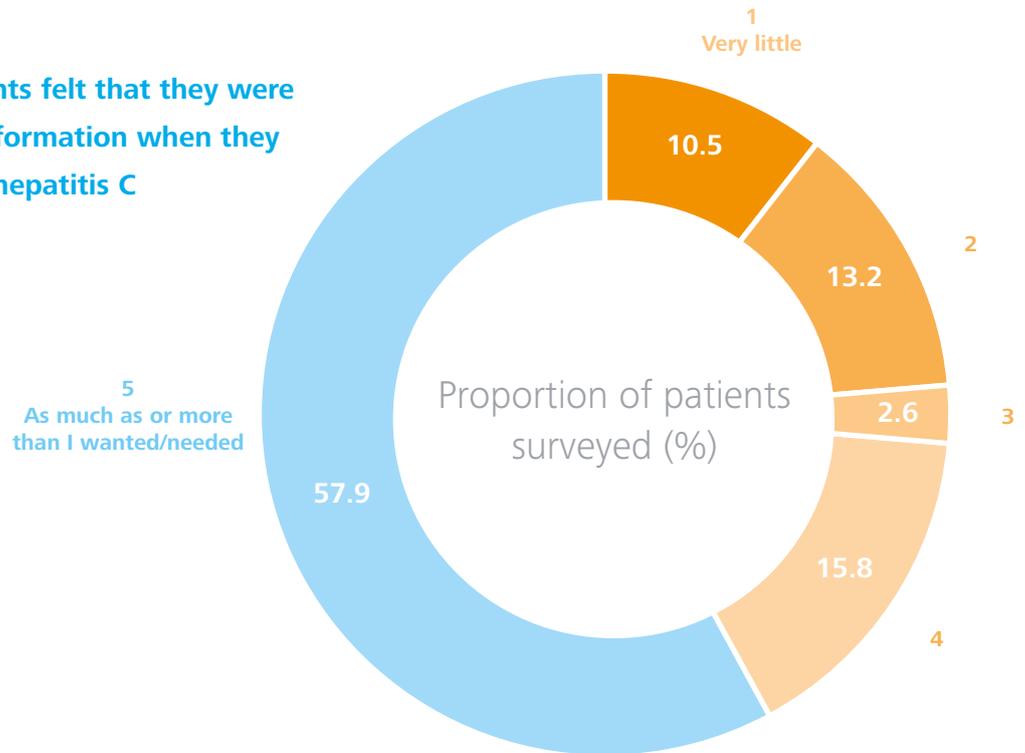
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26



Individuals with hepatitis C want more information about their condition

40% of respondents felt that they were not given sufficient information when they were diagnosed with hepatitis C

Country data based on 38 responses



Survey findings



- More than 40% of patients in Argentina wanted more information about their condition than they received at the time of their diagnosis
- While 50% of respondents from Argentina said they were 'very satisfied' with the level of help and advice they received when they were diagnosed, which compares favourably to Brazil (24%) and Mexico (33%), over one-quarter of respondents were not satisfied (ratings of 1–2 out of 5)
- 87% of respondents said that they had looked for further sources of information since being diagnosed with hepatitis C. Most people (76%) found their information via search engines, 58% had visited specific websites and 24% had visited patient organisation sites

What does this mean?

People living with hepatitis C need more information

Respondents in Argentina are more satisfied with the information and support they receive than elsewhere in the Americas region, but it is extremely disappointing that, despite this, more than 40% of patients did not feel they had all the information they needed when they were diagnosed.

As there is no guarantee of the accuracy of information found via search engines, governments must ensure that adequate high quality information is offered to patients, with the opportunity for discussion with the healthcare team wherever possible, to help reduce anxiety and empower patients to lead a healthy life with hepatitis C.

Proper signposting to patient groups provides patients with an additional source of resources and on-going support, and complements the work of clinical teams.

Individuals with hepatitis C are suffering, but they are more open about their condition compared with other countries in the region

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 | 31.6% |
| Very significant impact on emotional health | 24.3% |
| Very significant impact on psychological and mental health | 26.3% |

Responses based on country data (physical, n=38; emotional, n=37; psychological and mental health, n=38)

Survey findings



- Over 60% of respondents said that hepatitis C has negatively affected the way or the amount they are able to work and nearly one third felt that hepatitis C had negatively affected their education
- Many respondents felt that hepatitis C had impacted their personal and professional relationships to some degree. Over one third reported a negative impact on partner relationships, nearly 30% reported a negative impact on relationships with colleagues, 25% reported a negative impact on family relationships and just under 20% reported a negative impact on friendships
- However, just 3% of respondents in Argentina believed that they had suffered discrimination at work or in education as a result of their hepatitis, compared with 18% in Mexico and 19% in Brazil
- 58% of respondents said they had told their colleagues about their hepatitis C, compared with 22% in Brazil and 25% in Mexico, and 76% told their friends about their hepatitis C, compared with 45% in both Brazil and Mexico

What does this mean?

Despite a certain openness about their disease, people with hepatitis C are still suffering

The perception of hepatitis C in the workplace in Argentina appears to be significantly more positive than elsewhere in the region. Although many more people tell colleagues that they have hepatitis C, and very few feel that they have been discriminated against in the workplace, a sizeable number of people are reporting a negative impact on relationships with friends, family and partners.

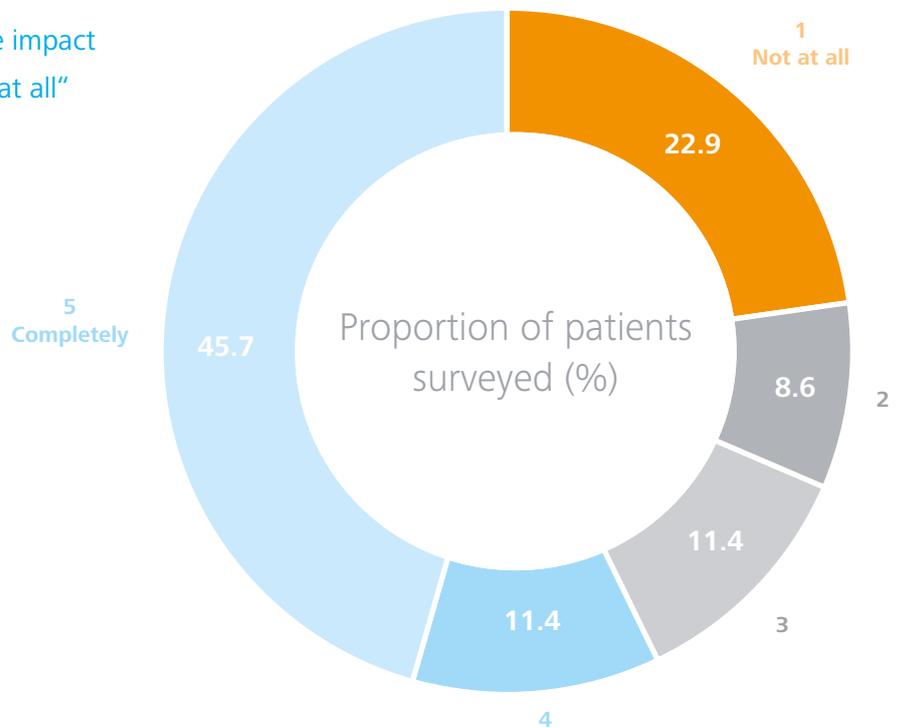
The fact that over 60% of respondents have said that the disease has affected the way or amount they could work is indicative of the physical, psychological and emotional impact of hepatitis C on the professional as well as the personal aspects of an individual's life.



While patients generally receive a good level of care, individuals often do not feel understood by their healthcare teams

23% of respondents felt that the impact of hepatitis C on their lives was “not at all” understood by their nurse

Country data based on 35 responses



Survey findings



- 100% of the patients surveyed said they felt they had access to a hepatitis C specialist or doctor that they trusted as an authority on the condition, more than 10% higher than in Brazil and Mexico
- 70% of respondents had agreed a treatment plan with their healthcare team; of these, 81% said they were ‘completely satisfied’ with it
- However, 1 in 6 felt they had not been involved at all in the decisions around their treatment options
- Additionally, less than half of all respondents said they felt their nurses understood the impact of hepatitis C on their lives ‘completely’, including aspects such as social impact or depression.

What does this mean?

More must be done by healthcare professionals to support their patients

It is encouraging to see that a relatively high proportion of respondents to our survey had a treatment plan already in place, and that most of them were happy with it. This can be a big boost to patients, helping them to feel empowered and more likely to adhere to treatments.

However, while patient trust in healthcare teams is very high, some respondents still reported that they did not feel involved in decisions around their treatment, and this should be a goal for improvement of care in Argentina. These discussions may also provide an opportunity for healthcare teams to listen to patients’ concerns and the specific challenges they face, allowing patients to feel better understood.

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?

“More peace of mind, better quality of life and more protection for me and my loved ones”

“Everything”

“A fuller life, with the possibilities of continuing to feel useful to society”



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World Hepatitis
Alliance