

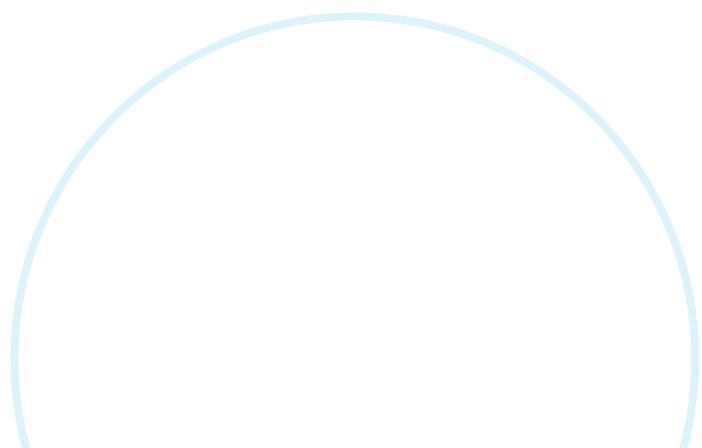
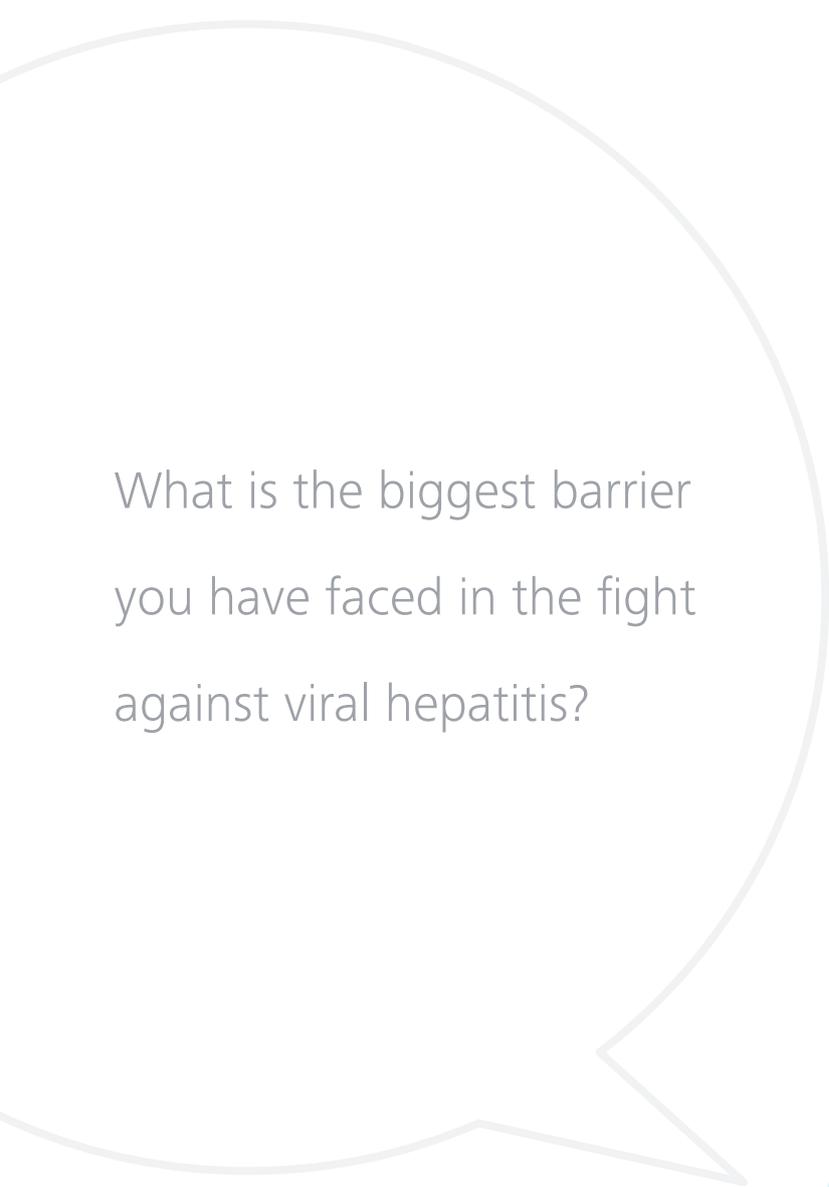
HCV QUEST

Global Patient Survey

Country-Specific Report

Austria





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



“People around me fail to understand”

“Discrimination, being stigmatised as a drug addict. But I’m not a junkie”

“Getting rid of the thought that this may result in hepatic cancer”

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

For the purposes of this report, Austria is defined as part of the World Health Organization (WHO) Europe region and has been contrasted against other nations in this region, including Belarus, Belgium, Bulgaria, France, Greece, Hungary, Israel, Poland, Romania, Russia, Spain and the United Kingdom.

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

7 in 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 68 responses

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



Respondents offered a HCV test after reporting symptoms to their doctor. Country data based on 61 responses

Survey findings



- Just 31% of respondents knew what hepatitis C was before diagnosis and, of these, the vast majority (71%) had received their information from news or other media, such as television and newspapers; 19% received information from a patient organisation and 19% from a medical professional. None of the respondents had received information of hepatitis C from the government
- 55% of respondents said that they believe they had symptoms of hepatitis C at the time of their diagnosis. Of those who reported symptoms to their doctor, just 21% of patients were offered a hepatitis C test
- Austrian respondents to the HCV Quest survey had suffered more damage to their livers by the time of their diagnosis than elsewhere in Europe. 38% had fibrosis and 12% had cirrhosis without complications by the time they were diagnosed. Worryingly, 18% of people said they didn't know what condition their liver was in at this time
- 48% of respondents in Austria said they had received 'very little' information at the time of their diagnosis. This is a significantly more negative response than the European average, where 33% said they had received 'very little' information at the time of their diagnosis

FAST FACTS

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

Around 36,000 adults (0.5%) in Austria 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]

What does this mean?

Low levels of awareness risks lives

10% of respondents first found out they were living with hepatitis C when they were admitted to hospital with liver-related illness. This proportion could and must be reduced via government action to educate the public and physicians about hepatitis C risk factors and symptoms.

The Austrian government faces a clear imperative from patients to increase general awareness of hepatitis C – to protect the public and to support those affected by hepatitis C with proper information and signposting to the support they need.

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: 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



Many people living with hepatitis C feel they suffer because of stigma around the disease...

Nearly half of all respondents felt that they had been discriminated against because of their hepatitis C



46%

Respondents who had reported discrimination at work or in education, or that their prospects have been affected due to their hepatitis C status. Country data based on 56 responses.

...and physical, psychological and mental impacts of the disease affect work and relationships

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

**Would you say that your hepatitis C affects the following aspects of your life?
Please select all that apply and rate from 1-5, (1 = Little impact; 5 = Very significant impact)**

Very significant impact on physical health	31.7 %
Very significant impact on emotional health	33.9 %
Very significant impact on psychological and mental health	38.1 %

Responses based on country data (physical, n=63; emotional, n=59; psychological and mental health, n=63)

Survey findings



- 46% of respondents said they had suffered discrimination in work or education as a result of their hepatitis C, more than double the European average (21%)
- 56% of respondents said they would feel 'uncomfortable' talking to their boss, colleagues or staff at their school or university about their hepatitis C
- The most severe reported impact of hepatitis C was on psychological and mental health, including self-image, future plans or career decisions, anxiety or depression, where 38% of people said the effect on their life had been 'very significant'
- 60% of respondents felt that their work had been affected 'significantly' or 'to some degree' by their hepatitis C
- 28% of respondents said their hepatitis C had had a 'strong' or 'very strong' negative impact on their relationships with colleagues. 25% said the same of their relationships with friends, 14% with family relationships and 15% with partner relationships

What does this mean?

Hepatitis C affects all aspects of a person's life

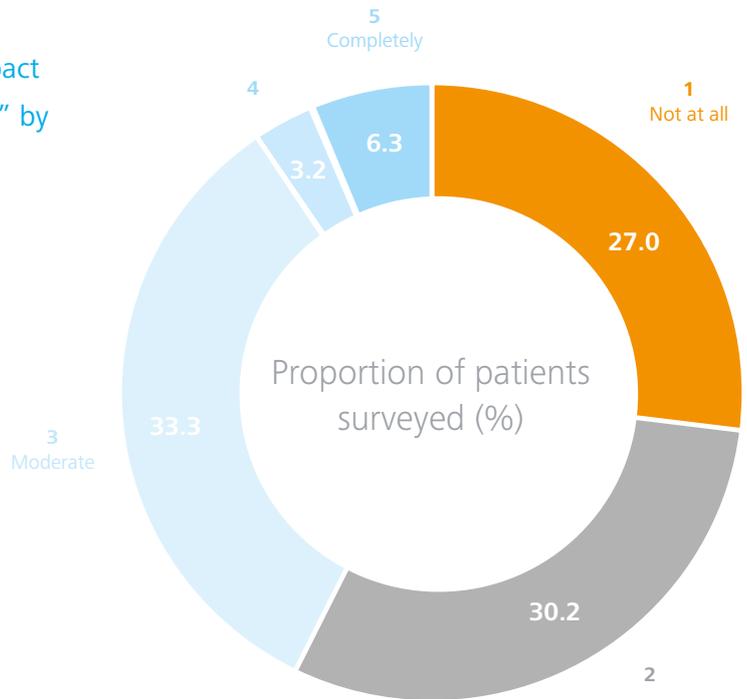
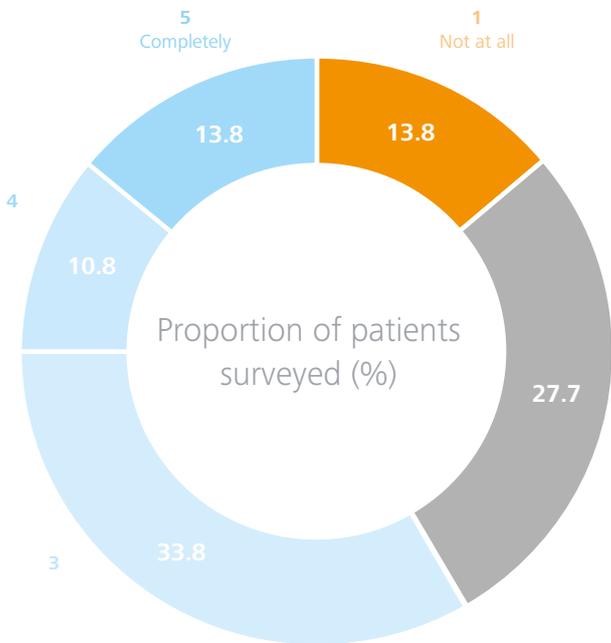
Austrian respondents to HCV Quest were clear: the psychological, emotional and physical impacts of hepatitis C are very significant. Their effects are felt in the workplace, education and in individuals' home lives and personal relationships.

It is alarming that almost half of respondents reported discrimination at work or in education as a result of their hepatitis C. This level of discrimination must be addressed and governments, industry heads, employers and teachers must be made aware of their role in preventing stigma and discrimination from taking hold. Governments need to provide the incentives and resources for them to do so, and as patient groups, we can equip them with the information and support they need to do it effectively.

Hepatitis C has a huge impact on patients' lives, but they do not feel understood by their healthcare teams

27% of respondents did not feel that the impact of hepatitis C on their lives was "at all understood" by their nurse

Country data based on 63 responses



14% of respondents did not feel that the impact of hepatitis C on their lives was "at all understood" by their physician

Country data based on 63 responses

Survey findings



- Just 6% of respondents to the survey from Austria said they felt their nurses understood the impact of hepatitis C on their lives 'completely', including aspects such as social impact or depression, and only 14% said this about their physicians
- While 20% rated the communication of their healthcare professionals in writing, in person or over the phone as 'exemplary', more than 20% rated this communication as just 1 or 2 out of 5, indicating totally unsatisfactory or poor communication
- Just 36% of patients in Austria said they felt they had been consistently consulted and involved in decision making around their treatment options, well below the average of 43% who felt this across the other countries in the European region

What does this mean?

Healthcare professionals must do more to demonstrate their understanding of the impact of hepatitis C

Patients who feel that their healthcare teams do not appreciate the impact of their disease on their lives may feel less motivated to attend appointments or to adhere to treatment, which can have a serious impact on their health.

Healthcare teams need to demonstrate an understanding of the emotional, psychological and physical impact of hepatitis C and do more to signpost people living with hepatitis C to help when they need it.



Patient organisations play a key role in providing hepatitis C patients with the help and resources they need

Half of all respondents looked to patient organisations for further information following their hepatitis C diagnosis

What sources of information have you looked at since your diagnosis to find out more about hepatitis C? Please select all that apply:

Specific websites	33.3 %
Search engines	38.6 %
Hospital website	3.5 %
National Health Service (NHS) or government website	1.8 %
Patient organisation site	49.1 %
WHO site	1.8 %
Other	33.3 %

Responses based on country data (n=57)

Survey findings



- 40% of respondents said they were put in touch with patient groups when they were diagnosed, making this the largest source of information offered at this time
- However, while the rate of referral to patient groups is positive and significantly higher than the European average (14%), it is likely that more patients want access to patient group support. Following their diagnosis with hepatitis C, nearly 50% of those surveyed had referred to patient organisation websites
- Additionally, 67% of respondents said that they were currently members of patient organisations; this is significantly higher than the European average (44%).

What does this mean?

Patient organisations play an important role in offering invaluable information and support

When patients are not given enough information about hepatitis C, they have a much lower chance of accessing the right help, making the right lifestyle choices and asking the right questions of their physicians. Patient groups are helping to fill the gap left by inadequate patient information in Austria. Healthcare teams must refer newly-diagnosed patients to patient organisations, who have the tools and expertise to inform and support patients over the longer term.

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 sense of life, happiness, not waking up anymore feeling anxious”

“Good health, start a family”

“Improved psychological robustness and, as a consequence, averting the permanent feeling of anxiety
‘What will happen to me?’”



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World Hepatitis
Alliance