

HCV QUEST

Global Patient Survey

Country-Specific Report

Hungary





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

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

“The biggest barrier I have faced in the fight against viral hepatitis is... I feel stigmatized, since people consider me as a potential hazard, as they are not well informed, even physicians”

“The biggest barrier I have faced in the fight against viral hepatitis is... the ignorance of side effects by the treating physician. Ignoring complications of the therapy”

“The biggest barrier I have faced in the fight against viral hepatitis is... I got excluded at work. I keep my disease in secret. I’ve had a boyfriend for a year now, but I wouldn’t dare to tell him”

Public awareness of hepatitis C – a priority to encourage early diagnosis and increased patient understanding

Almost **two thirds** of respondents did not know what hepatitis C was before diagnosis



Awareness of hepatitis C before diagnosis among HCV Quest respondents. (Country data based on 223 responses)

Survey findings

- The low public awareness of hepatitis C (35%) in Hungary is in line with the figures from Russia (37%) and Romania (36%)
- Individuals who had heard about hepatitis C generally received information through the media (TV, radio, newspapers) (42%) or via a medical professional (28%)
- Government campaigns were less successful, reaching less than 3% of respondents
- Around 30% of individuals were prompted to get tested for hepatitis C after receiving relevant information

FAST FACTS

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

Around 68,000 adults (0.8%) in Hungary 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 of hepatitis C in Hungary needs to be raised

Raised public awareness and education are essential to prompt early diagnosis, to improve patient understanding, to highlight the impact of hepatitis C on an individual's life and to educate about disease prevention.

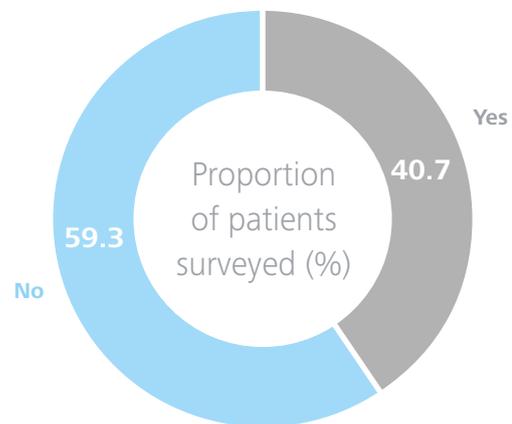
1. Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2015;385:117–71.
2. Gower E et al. Global epidemiology and genotype distribution of the hepatitis C 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.



Physician awareness of hepatitis C symptoms is key for timely diagnosis and referral

Just **41%** of respondents were offered a test for hepatitis C after discussing their symptoms with a medical professional

Country data based on 189 responses



Survey findings



- Most individuals (76%) diagnosed by a family doctor are quickly referred to a specialist (within 3 months)
- Only 20% of patients had no liver damage at diagnosis

What does this mean?

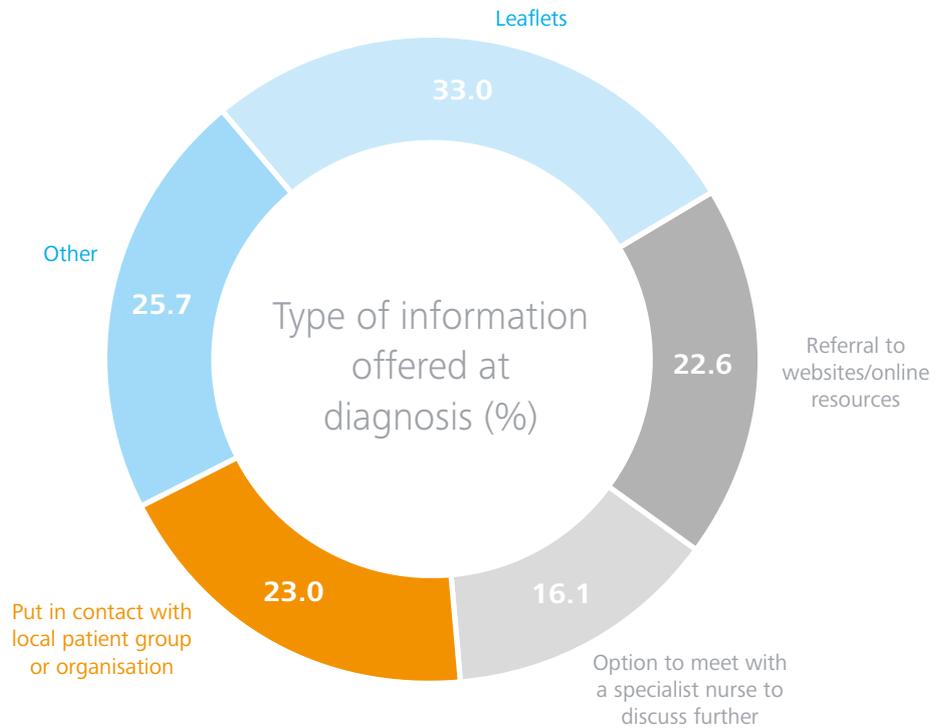
Increasing physician awareness needs to go hand-in-hand with increasing public awareness

If people with hepatitis C are to benefit from rapid referral to a specialist, it is critical that their doctor is aware of the symptoms of hepatitis C. While the condition may be difficult to recognize, the introduction of screening (among high-risk individuals) may offer a useful tool.

Hepatitis C has a major impact on people's lives and patient organisations play an active role in supporting those affected

Around **one fifth** of individuals with hepatitis C are put into contact with a patient organisation after diagnosis

Country data based on 230 responses



Survey findings



- 71% said that hepatitis had an impact on their work life
- Between a third and a half of respondents said that hepatitis had a significant or very significant impact on their physical (39%), emotional (38%) and mental/psychological (48%) well-being
- Of those respondents aware of patient organisations, one-third said that they played an active role in supporting people with hepatitis C

What does this mean?

Hepatitis C has an important impact on those with the disease and patient organisations have a key role in supporting them

Increasing awareness of patient support organizations, including referrals from healthcare professionals, will help to provide a greater number of individuals diagnosed with hepatitis C with a source of information, advice and emotional support. Hopefully, this will encourage individuals to feel more confident discussing their diagnosis with family members and friends. It may also help them to collaborate more confidently during discussions about their condition with their healthcare professional and to take on a more active role during consultations.



Active involvement in decision making about treatment

Almost **60%** of Hungarian respondents said that they felt “consistently consulted and involved” in decisions about treatment options

How involved do you feel you have been in decisions around your treatment options? Please rate 1–5
(1 = Not at all; 5 = Consistently consulted and involved in decision making)

1 = Not at all	6.3%
2	4.9%
3	10.8%
4	21.1%
5 = Consistently consulted and involved in decision making	57.0%

Country data based on 223 respondents

Survey findings



- Slightly more than 46% of individuals with hepatitis C felt that discussions about their treatment plan should be shared between the doctor and the individual but that the final decision ought to be the individual's
- More than 9/10 respondents had agreed a treatment plan with their doctor and 70% were satisfied with this
- Healthcare professional-patient communication is of a high standard, with 52% of respondents saying it was “exemplary”

What does this mean?

Patients reported that their healthcare teams are doing well in including them in discussions around their treatment options, keeping them consistently consulted in 57% of cases, versus the regional average of 43%. In the region, only Belgium achieved a higher patient satisfaction score in this area (58% consistently consulted).

Patients appreciate the good communication skills of their healthcare teams. Hungary's response, saying that 52% of patients had 'exemplary' communication from their healthcare professionals, was unbeaten in Europe except by Bulgaria, where 68% gave the same rating. This compares strongly against Austria, with just 20%, Romania and Spain with 28% and Belarus, with just 2%.

Other nations may be able to learn from Hungary's examples of patient inclusion in decision-making and healthcare team communication skills.

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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“For me, a cure would mean...
Everything! Life and the ability
to reach future goals in life (job,
family)”

“For me, a cure would mean...
I would regain my physical and
mental strength and vitality. I would
be the person I used to be”

“For me, a cure would
mean... My fear of
transmitting the disease to my
loved ones would disappear”



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World Hepatitis
Alliance