

HCV QUEST

Global Patient Survey

Country-Specific Report

Belarus





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



“Complete indifference and ignorance of doctors”

“Lack of accuracy of information about the disease. Lack of testing for diagnosis. Disrespect”

“Unavailability of medicines”

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

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

Public awareness of hepatitis C is low and doctors are failing to recognise the symptoms of the disease

4 in 5 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 49 responses

Fewer than **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 49 responses

Survey findings



- Across the European region used for comparison, Belarus had the third lowest level of public awareness of hepatitis C, with only 20% of respondents aware of what hepatitis C was prior to diagnosis
- People who knew about hepatitis C prior to diagnosis heard mainly through news or other media, such as TV, radio and newspapers (40%), medical professionals (20%) or patient organisations (20%). None of the respondents got their information on hepatitis C from government awareness campaign
- Only 16% of respondents were offered a hepatitis C test on reporting symptoms to their doctor. This was the lowest reported level in Europe

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

FAST FACTS

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

Around 100,000 adults (1.3%) in Belarus 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?

Public and physician awareness of hepatitis C is unacceptably low

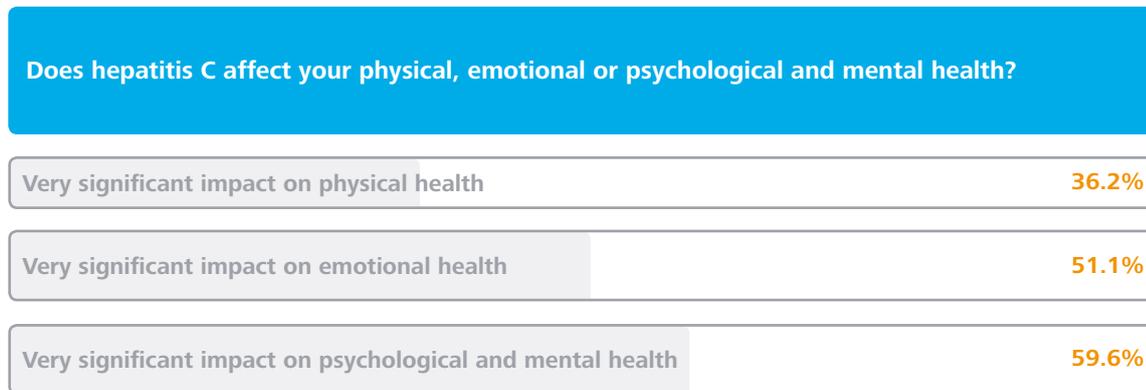
The fact that only 16% of people reporting symptoms of hepatitis C in Belarus were offered a test is extremely serious. It means that many people are likely to be suffering with hepatitis C, undiagnosed, and sustaining serious liver damage as a result.

The government and healthcare professionals in Belarus must act to improve public awareness and physician familiarity with the disease and its symptoms, to protect those already affected and to prevent more people from getting hepatitis C.



Patients are suffering with hepatitis C

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



Responses based on country data (physical, n=47; emotional, n=45; psychological and mental health, n=47)

Survey findings



- A large number of respondents felt that their hepatitis C has a very significant impact on their physical (36%), emotional (51%) and psychological (60%) wellbeing
- Of the respondents taking any medicines related to hepatitis C (other than those directly treating hepatitis C), 46% were taking immune-boosting medication, 36% were taking pain medication and 23% were taking anti-depressants
- Over 60% said hepatitis C had a negative impact on their work life
- Over half (51%) of respondents said they would feel uncomfortable talking about their hepatitis C to their boss or colleagues, and only 10% had told colleagues of their hepatitis C status
- Just under 1 in 5 (18.4%) felt they had been discriminated against at work or in education as a result of their hepatitis C

What does this mean?

Hepatitis C impacts all aspects of a person's life

These findings show the true scale of the impact of hepatitis C on individuals' lives. The physical, emotional and psychological pain of people living with the disease is clear and profound.

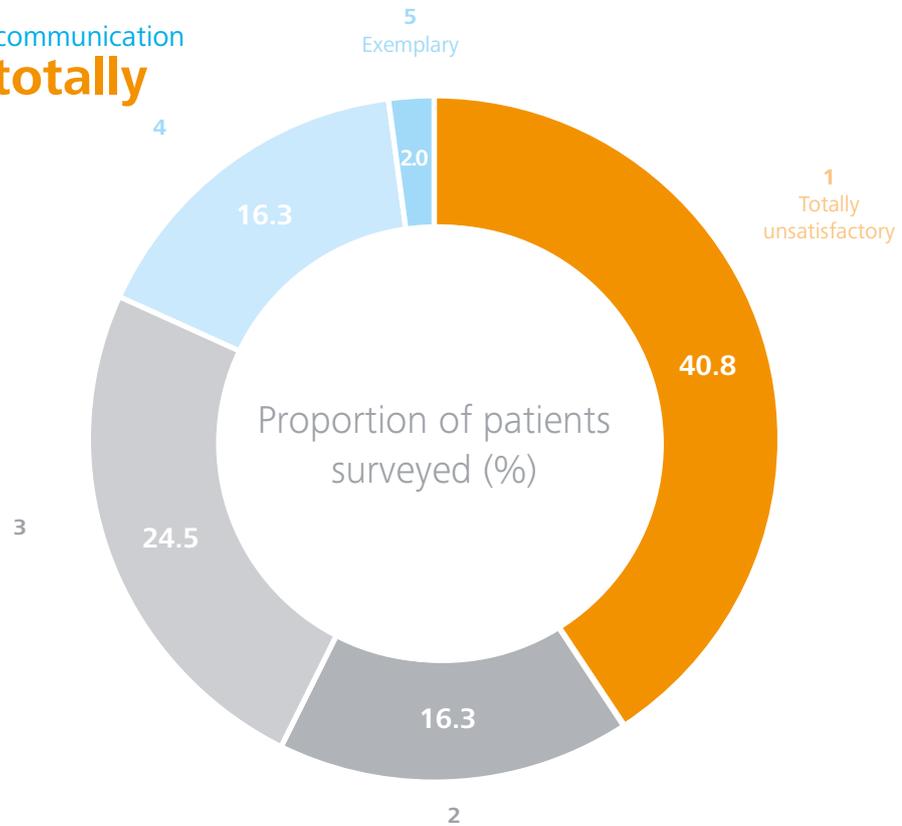
These data also show that people are often unwilling to disclose their hepatitis C, and why – a high proportion (nearly one fifth) felt that they had already experienced discrimination because of their illness.

Lack of information in the public domain contributes to stigma and lack of understanding around hepatitis C, creating an unnecessary burden for sufferers in both personal and professional areas of life and preventing them from asking for the support they need.

Patient relationships with their healthcare teams are generally very poor

2 in 5 respondents rated communication with their healthcare team as **'totally unsatisfactory'**

Country data based on 49 respondents



Survey findings



- The majority of respondents felt that their nurses (78%) and physicians (61%) do not understand the full impact of hepatitis C on their life (ratings of 1–2 out of 5)
- 80% of respondents felt they do not have access to a hepatitis C specialist or doctor who they trust as an authority on their condition. This is far above the regional (26%) and global (22%) averages
- 41% of respondents rate communications with their HCP as 'totally unsatisfactory' – the highest level of dissatisfaction within the region, compared with a regional average of 14%
- 51% of respondents do not have an agreed treatment plan with their healthcare professionals, much higher than the regional average of 28%

What does this mean?

Patients lack understanding and support from their healthcare teams

These findings suggest a very worrying situation for patients with hepatitis C in Belarus, who feel they are not understood, supported or, in many cases, even consulted in their treatment decisions.

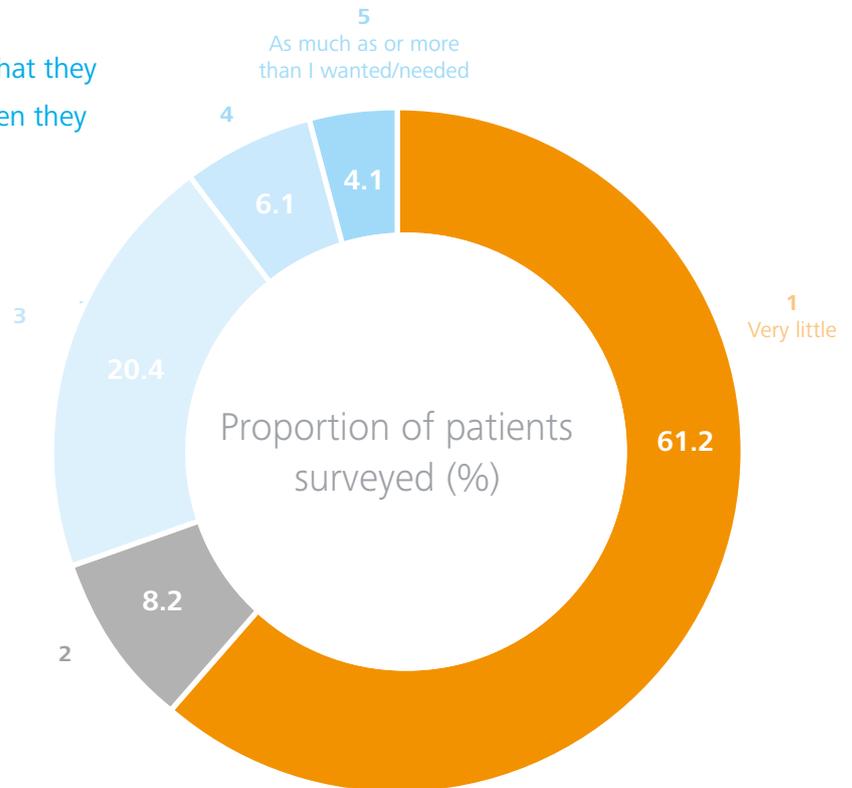
Improving the relationship and communications between healthcare teams and patients in Belarus needs to be an immediate priority to support the best possible outcomes for patients and bring the country in line with its European counterparts.



Patients want more information about hepatitis C...

3 out of 5 respondents felt that they were given 'very little' information when they were diagnosed with hepatitis C

Country data based on 49 responses



Survey findings



- 61% of respondents felt that 'very little' information was made available to them through their doctor at the time of diagnosis and only 4% said that they received as much as or more than they wanted/needed, versus the regional average of 20%
- However, every respondent 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, and 37% had visited patient organisation sites
- More than 8 out of every 10 respondents said they had made changes to their lifestyle because of having hepatitis C. 93% of respondents had reduced their alcohol intake and 67% had changed their diet

What does this mean?

People living with hepatitis C want more information

Patients in Belarus are taking a proactive approach to finding information and making positive lifestyle changes to manage their health.

It is also clear that patients value the support of patient groups. Despite not a single respondent being put in touch with a local patient organisation by their healthcare team, 37% of those surveyed had actively sought advice from these groups, and 45% had become members.

Healthcare teams can better support patients by signposting them to local groups, who can provide understanding, support and practical advice on living healthily with hepatitis C, to complement clinical treatment and care.

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

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?

“A full life, family, children. No risk of infecting others”

“Psychological sense of freedom – not being destroyed from within”

“It means living! Fulfilling dreams and plans! Today I am only existing, with many limitations”



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World Hepatitis
Alliance