

# HCV QUEST

Global Patient Survey

Country-Specific Report

Russia







“The biggest barrier I have faced in the fight against viral hepatitis is... incompetence of doctors, lack of government programs and as a consequence unwillingness of doctors to detect and treat HCV”

“The biggest barrier I have faced in the fight against viral hepatitis is... fear of infecting others. Failure to fulfil the plans in life and family, primarily because of hepatitis”

“The biggest barrier I have faced in the fight against viral hepatitis is... I have no drugs for therapy, my colleagues turned away from me (I was fired from a job), my husband divorced me. I do not know what to do”

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

For the purposes of this report, Russia 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, Hungary, Israel, Poland, Romania, Spain and the United Kingdom.

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

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



Awareness of hepatitis C before diagnosis among HCV Quest respondents (based on 310 responses)

### Survey findings



- The low public awareness of hepatitis C in Russia (37%) is in line with other Eastern European countries – Bulgaria (42%), Hungary (35%) and Romania (36%). This is above the wider regional average of 30%
- Individuals who had heard about hepatitis C generally received information through the media (TV, radio, newspapers) (47%)
- Government campaigns reached less than 5% of respondents
- Just 24% of individuals were prompted to get tested for hepatitis C based on their knowledge on the disease

### FAST FACTS

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

Around 5 million adults (4.1%) in Russia 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 Russia needs to be raised

Raised public awareness and education are essential to prompt early diagnosis, improve patient understanding, 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](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.

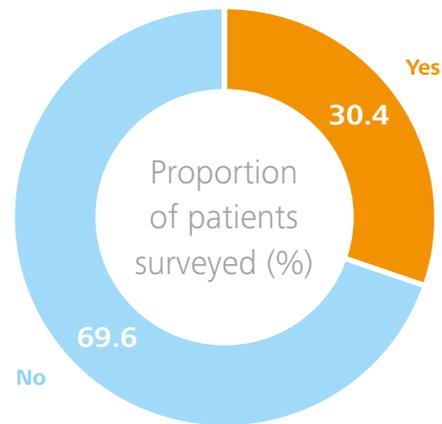


## Physician awareness of hepatitis C symptoms is key to timely diagnosis and referral

Physicians in Russia may not be aware of key symptoms for hepatitis C

Just **30%** of respondents were offered a test for hepatitis C after discussing their symptoms with a medical professional

Country data based on 306 responses



### Survey findings



- Once diagnosed, most individuals (67%) are referred to a specialist within 3 months
- 30% of respondents had sustained liver damage (fibrosis or cirrhosis) by the time they were diagnosed
- 77% changed their lifestyle after diagnosis and of those who have changed, 75% have reduced or stopped their alcohol consumption and 54% have changed their diet

#### What does this mean?

#### Increasing awareness among healthcare professionals needs to go hand-in-hand with increasing public awareness

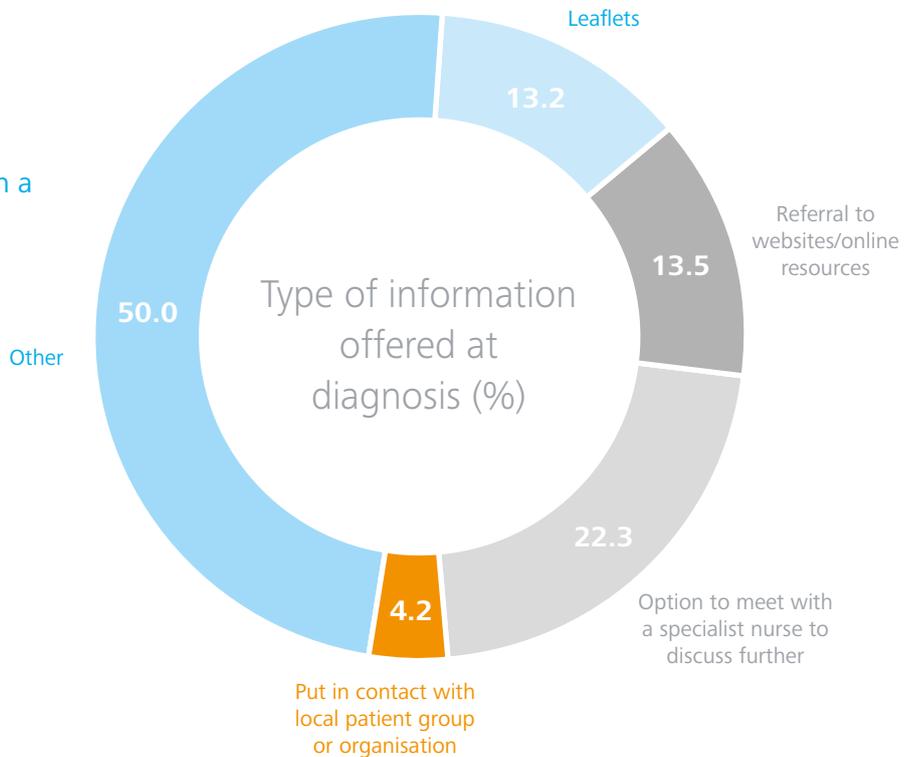
If people with hepatitis C are to benefit from rapid referral to a specialist, it is key that their healthcare professional be aware of the symptoms of hepatitis C. While the condition may be difficult to recognize, the introduction of screening (among high-risk individuals) may offer a useful tool.

Diagnosis by itself is an important first step which gives individuals the opportunity to adopt positive lifestyle changes.

## High impact of hepatitis C, low awareness of support available from patient organisations

Just **4%** of individuals with hepatitis C are put into contact with a patient organisation after diagnosis

Country data based on 310 responses



### Survey findings



- A high proportion of respondents said that living with hepatitis C had a significant or very significant impact on their physical (36%), emotional (42%) and/or mental/psychological (57%) well-being
- 57% said having hepatitis C had an impact on their work life
- Very few Russians responding to the survey (8%) belonged to a patient group
- One-third of Russians were “not at all satisfied” with the help/advice they received after diagnosis

### What does this mean?

**We need to raise the profile of patient support organizations in Russia, and ensure that healthcare professionals are fully aware of what help and advice is available to people with hepatitis C**

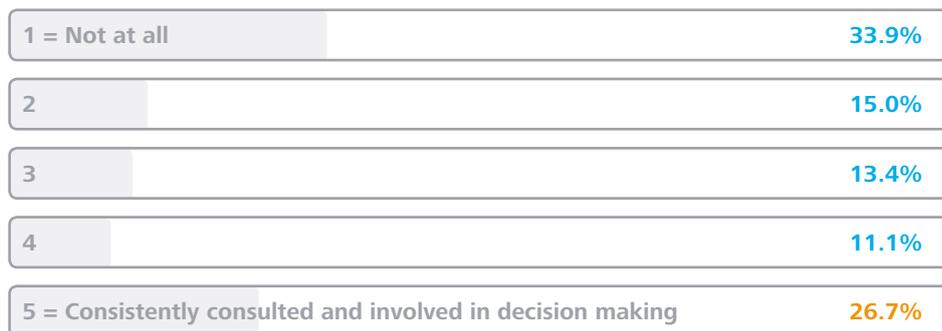
The impact of living with hepatitis C is significant and affects many facets of personal, social and professional life - so it is critical that individuals are connected with the patient organisations that can offer support.



## Patient empowerment and involvement in treatment decisions

When asked about how involved they felt in decisions about treatment options, just **27%** of Russian respondents said that they felt “consistently consulted and involved”

**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)



Patient involvement in treatment decisions (based on 307 respondents)

### Survey findings



- Most respondents felt that treatment discussions are the responsibility of both the individual and the doctor and should be discussed between them (74%), with either the person living with hepatitis C making the final decision (37%) or the doctor (37%)
- 65% of respondents had agreed a treatment plan with their healthcare professionals
- Few respondents (26%) felt the impact of hepatitis C was “completely understood” by their physician and of those who have received interferon-based treatment, 43% were not sufficiently prepared for the side-effects
- Patients gave variable assessments of the standard of communication from their healthcare professionals, with 17% feeling it is “totally unsatisfactory” and 37% receiving only “very little” information at the time of their diagnosis.

#### What does this mean?

**Individuals living with hepatitis C want to be actively involved in decision making around their treatment and care plan, but they need improved communication and co-operation with their healthcare teams to make this possible**

Allowing patients to be as involved as they want to be is likely to promote good co-operation around the management of hepatitis C. Equally, it is also vital that individuals are provided with all the information they need to feel informed about their health and treatment options and to contribute appropriately in conversations with their healthcare professionals.

# Driving change in your country to transform the lives of people with hepatitis C

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### 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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“This is the most important thing in life for me, the quality and length of life depends on it, I am constantly thinking about my illness and I am afraid to die”

“Cure would allow me to live a full life and I am not afraid to start a family. I am 24 now and I am afraid to have children”

“Cure for me is a way to the light, the next step that I have to make to a normal life”





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World Hepatitis  
**Alliance**