


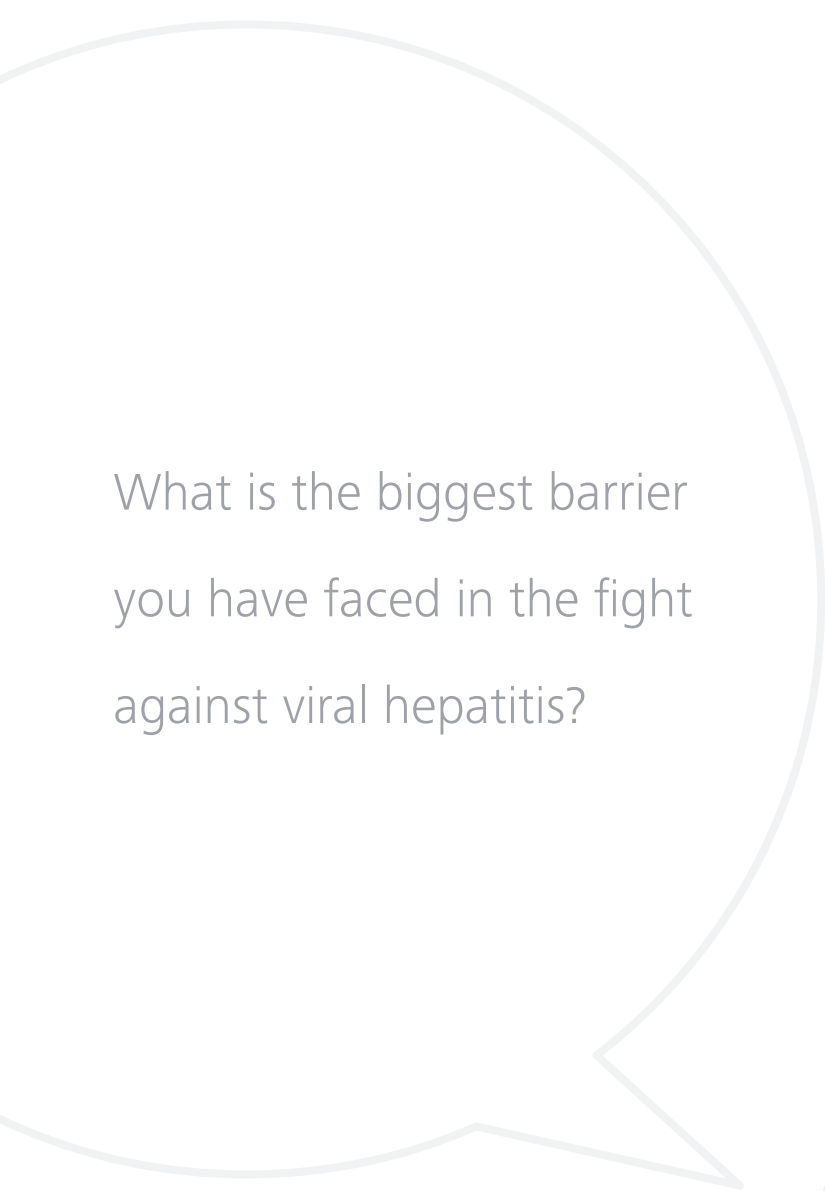

# HCV QUEST

Global Patient Survey

Country-Specific Report

Poland





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



“Long waiting list, failure to get treatment in my town, travelling for therapy (500 km one way), side effects of treatment”

“No widespread access to specialists and advanced therapies”

“Complete lack of understanding about my disease among the general public”

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

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

# HCV Quest Country-Specific Report

## Public and physician awareness of hepatitis C is low

**Fewer than 1 in 5** respondents knew what hepatitis C was before their diagnosis



17.3%

Awareness of hepatitis C before diagnosis among HCV Quest respondents. Country data based on 52 responses

**Fewer than half** of all respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor



47.1%

Percentage of HCV Quest respondents. Country data based on 51 responses

## Survey findings



- Across the European region used for comparison, Poland had the lowest level of public awareness of hepatitis C before diagnosis
- People who knew about hepatitis C prior to diagnosis heard mainly through news or other media, such as TV, radio and newspapers (67%), medical professionals (33%) or patient organisations (11%). None of the respondents got their information on hepatitis C from government awareness campaign
- Of the 67% of respondents who had hepatitis C symptoms at the time of diagnosis, less than half (47%) were offered a hepatitis C test when they reported these symptoms to their doctor

### FAST FACTS

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

Around 279,000 adults (0.9%) in Poland 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?

#### More must be done to raise public and physician awareness

Polish respondents to HCV Quest gave a shocking insight into the lack of public and healthcare professional knowledge of hepatitis C.

It is unacceptable that even when patients reported hepatitis C symptoms, they were not offered a test for the disease in more than half of cases.

Lack of knowledge puts people at unnecessary risk. Immediate investment is required to educate the public and healthcare professionals about the risks and symptoms of hepatitis C. The Polish Government has a responsibility to respond to this call to action.

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/>

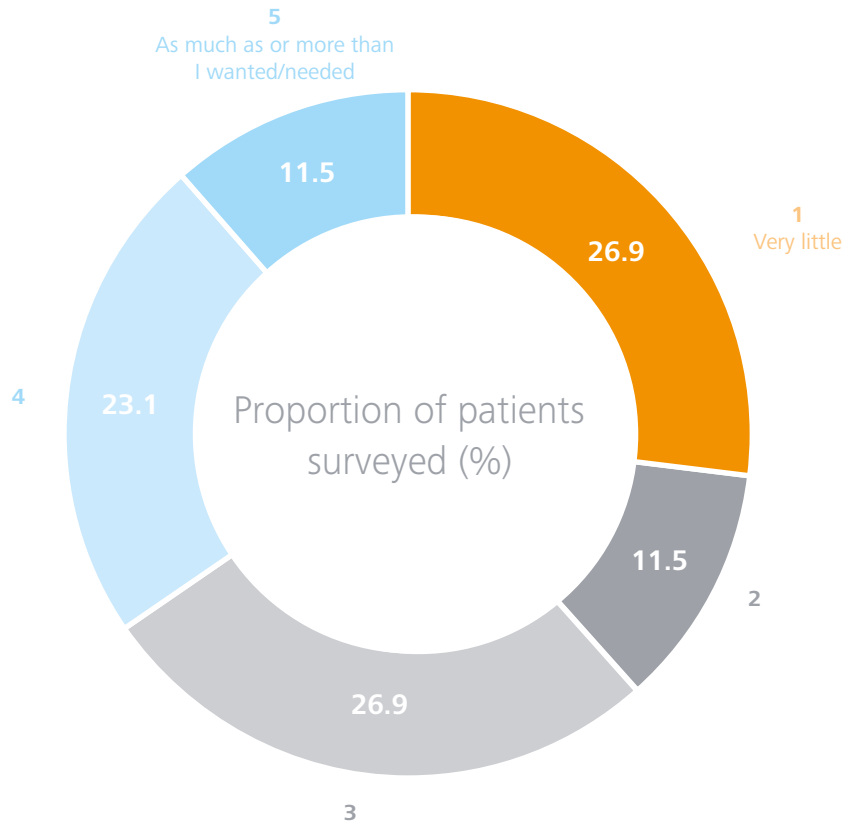
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: [http://apps.who.int/iris/bitstream/10665/1117471/9789241548755\\_eng.pdf?ua=1&ua=1.26](http://apps.who.int/iris/bitstream/10665/1117471/9789241548755_eng.pdf?ua=1&ua=1.26)



## Individuals with hepatitis C want more information about their condition, both at diagnosis and throughout their care

**Over 25%** of respondents felt that they were given **'very little'** information when they were diagnosed with hepatitis C

Country data based on 52 responses



### Survey findings



- Just 12% of respondents said that they received as much as or more information at the time of their diagnosis than they wanted/needed, which is much less than the regional average of 20%
- Only 8% of patients were given the option to meet with a specialist nurse to discuss their condition further and just 8% were put in contact with local patient group or organisation. 35% of people were given leaflets when they were diagnosed
- Almost all respondents (94%) said that they had looked for further sources of information since being diagnosed with hepatitis C. Most people (69%) found their information via specific websites, 57% had used search engines and 49% had visited patient organisation sites

#### What does this mean?

#### People living with hepatitis C need more information

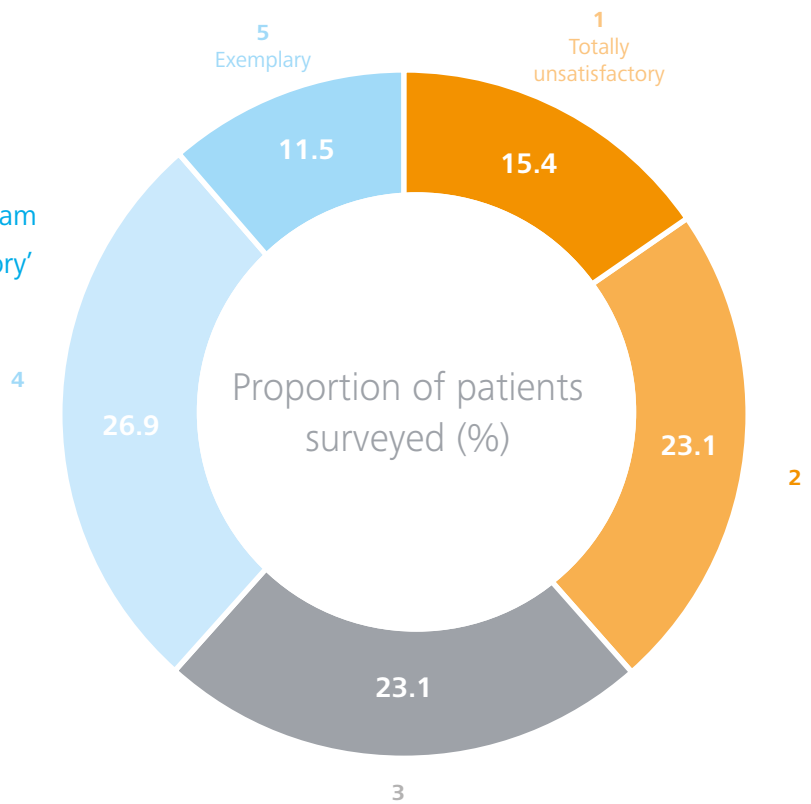
It's clear that patients want information about hepatitis C when they are diagnosed, so why are so few provided with as much as they need?

Healthcare teams should actively refer newly diagnosed patients to patient organisations, which can provide ongoing support and often have resources freely available online to help address questions and concerns, as well as offering access to an understanding and supportive community.

## Individuals with hepatitis C are not satisfied with their care

Nearly **40%** of respondents rated communications with their healthcare team as 'unsatisfactory' or 'totally unsatisfactory'

Country data based on 52 responses



### Survey findings



- A very low percentage of respondents in Poland felt that their nurses (10%) or physicians (17%) 'completely' understood the full impact of hepatitis C on their lives
- Over one third (37%) of respondents felt that they did not have access to a hepatitis C specialist or doctor who they trusted as an authority on their condition, above the European average (26%)
- Of the respondents who had agreed on a hepatitis C treatment plan with their healthcare professional (67%), just 24% were 'completely satisfied' with it
- A low percentage (42%) of respondents in Poland who had been offered treatment but decided not to be treated at this time felt that they were being properly monitored by their specialist, significantly lower than the regional average of 65%
- Of the respondents who were told that they were not eligible for current treatment options (40%), 88% were not comfortable with the decision

### What does this mean? Patients need a better level of care

Respondents in Poland reported a very negative perception of the care they receive.

Patients in Poland deserve better care and communication with their healthcare teams. They should feel that their concerns and preferences are taken properly into account. We know that healthcare systems that promote partnership and dialogue between patients and physicians result in benefits such as better adherence to treatment and better outcomes



## Living with hepatitis C is challenging, but individuals in Poland seem proactive and open about their condition

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	24.0%
Very significant impact on emotional health	14.9%
Very significant impact on psychological and mental health	34.7%

Responses based on country data (physical, n=50; emotional, n=47; psychological and mental health, n=49)

### Survey findings



- 75% of respondents said hepatitis C had a negative impact on their work life and 31% said hepatitis C affected their ability to study
- Over 20% of respondents reported suffering discrimination at work or in education because of their condition, and 23% said they would feel uncomfortable speaking to their boss, colleagues or staff at an educational institution about their hepatitis C
- However, 42% of respondents in Poland said that they felt that people had been generally very understanding of their hepatitis C, much higher than the regional average of 29%
- All respondents said they had told their close family about their hepatitis C, 71% had told their friends and 50% also told their colleagues
- Over 90% of respondents said they had made changes to their lifestyle because of having hepatitis C; of these, 83% had reduced their alcohol intake and 77% had changed their diet

#### What does this mean? Hepatitis C impacts all aspects of a person's life

While a relatively high proportion of respondents in Poland said they had told people about their hepatitis C, many felt they had been discriminated against because of their illness and a huge proportion felt that their work and education had been affected by the disease.

Governments must address the issue of discrimination by providing employers with incentives and resources to prevent stigma, and as patient groups, we can equip them with the information and support they need to do it effectively.

Governments also need to understand that hepatitis C affects both personal and professional areas of an individuals' life, and that new treatments represent an opportunity to reduce the burden of disease. This makes beating hepatitis a social and economic issue, not just a personal one.

# 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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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?

“Eliminating the ever-present fear about my life and health”

“I could live a normal life and could try for a baby, which I yearn for so much, and get back to my career”

“It would definitely mean an improvement in the comfort of life and an end to discrimination”





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World Hepatitis  
**Alliance**