

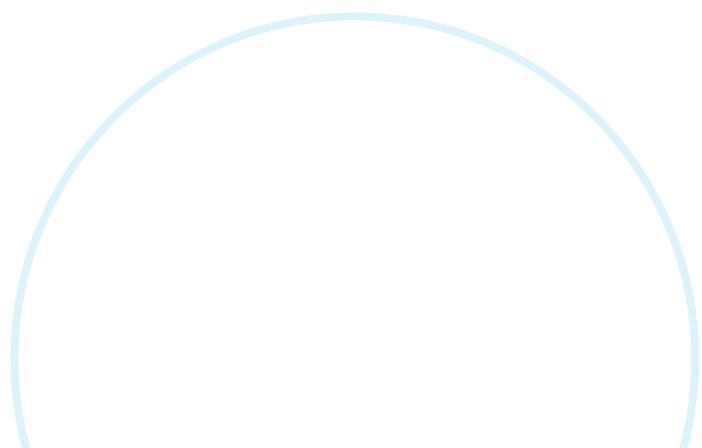
# HCV QUEST

Global Patient Survey

Country-Specific Report

France





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



“The symptoms of the disease: being permanently exhausted, which for two years has prevented me from living and working normally”

“The ignorance and attitude of certain doctors, failure to acknowledge the difficulties of living with gastro and explaining hepatitis!”

“The vagueness of the doctors’ and experts’ answers”

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

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

# HCV Quest Country-Specific Report

## Public and physician awareness of hepatitis C is low

Less than **1 in 4** people knew what hepatitis C was before their diagnosis



Awareness of hepatitis C before diagnosis among HCV Quest respondents. Country data based on 84 responses

Less than **1 in 4** respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor



Percentage of HCV Quest respondents. Country data based on 82 responses

### Survey findings



- Only 13% of respondents said that their prior knowledge of hepatitis C prompted them to seek testing and, of these, only 5% received information about the disease from a government campaign
- The majority of respondents (48%) were tested as part of a routine health screen; only 15% took a test because their doctor suggested it
- Almost 80% of respondents who told their doctor about hepatitis C symptoms were not offered a hepatitis C test
- Almost half (48%) of all respondents had fibrosis of the liver when they were diagnosed with hepatitis C. 13% had either cirrhosis without complications or decompensated cirrhosis with symptoms (e.g. jaundice, bleeding, ascites or encephalopathy), and 12% said they didn't know the state of their liver at diagnosis

### FAST FACTS

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

Around 303,000 adults (0.6%) in France 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?

#### Patient and physician awareness in unacceptably low in France

Despite a series of government action plans since 1999 that have included awareness campaigns, the public is still not adequately aware of the risks of hepatitis C. For that reason, people are not equipped with the knowledge and information to seek help and few are offered a test if they do report symptoms.

Almost half of those who responded to the survey said they already had liver fibrosis by the time of their diagnosis – damage caused by their untreated hepatitis C. This proportion could be reduced with government-supported public information campaigns and prompt testing when symptoms of hepatitis C are reported.

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: 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/>

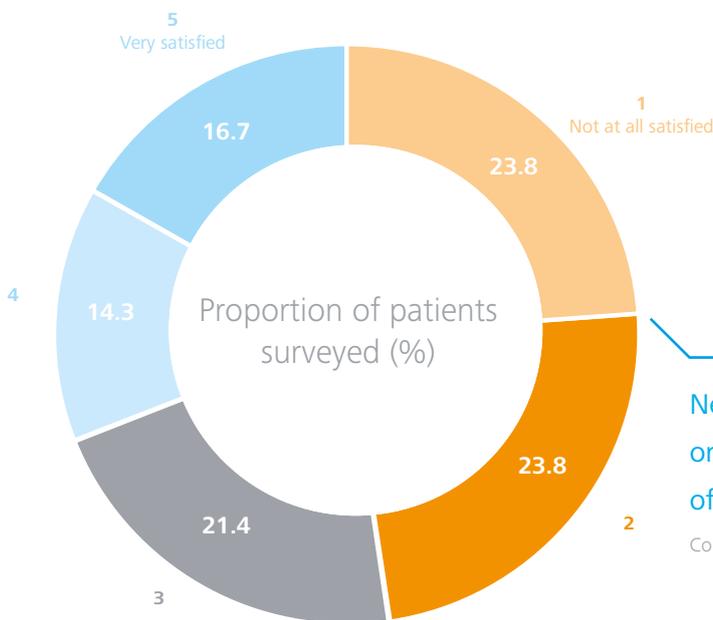
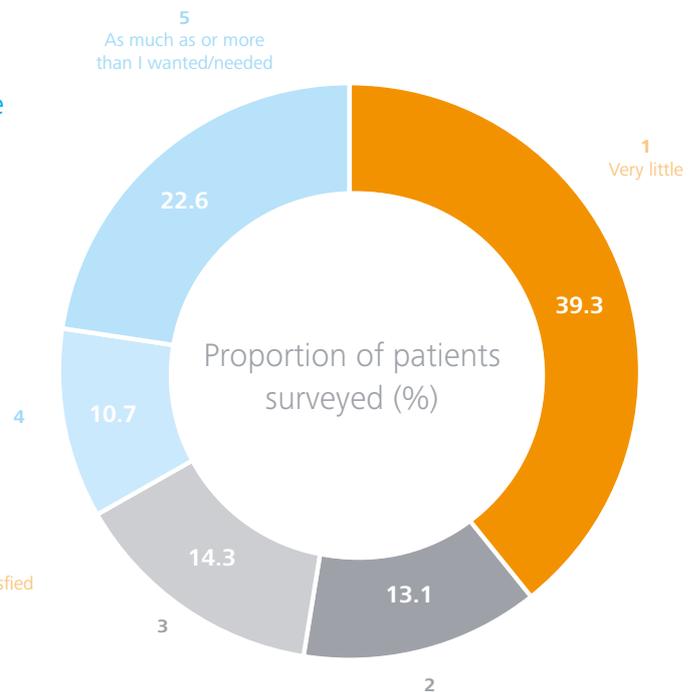
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: [http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755\\_eng.pdf?ua=1&ua=1.26](http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26)



## Individuals with hepatitis C are not getting the information and support they need

Nearly **40%** of respondents felt that they were given 'very little' information about hepatitis C when they were diagnosed

Country data based on 84 responses



Nearly **50%** of respondents were 'not satisfied' or 'not at all satisfied' with the level of help and advice they received at diagnosis

Country data based on 84 responses

### Survey findings



- At the time of diagnosis, just 12% of respondents were put in contact with a local patient group or organisation, 13% were given the option to meet with a specialist nurse to discuss further and 6% were referred to online resources. 31% of respondents were offered information leaflets
- Since diagnosis, nearly all respondents (94%) in France had looked for further information. Most people (71%) found their information on specific websites, patient organisation websites (58%) and via search engines (42%)

### What does this mean?

#### People living with hepatitis C need more information to feel satisfied with their level of care

Since 40% of respondents received almost no information about their disease when they were diagnosed, it is not surprising that patient satisfaction is low. This is desperately sad because patients without information about hepatitis C have a much lower chance of accessing the right help, making the right lifestyle choices and asking their physicians the right questions.

Leaflets can play an important role in providing some information to patients, but they cannot cater to individuals' needs and questions. With few patients being given the opportunity to meet with a specialist nurse, it is essential that healthcare teams refer patients to the support, resources and expertise available via patient groups.

## Hepatitis C has a significant impact on health and relationships – and stigma causes additional suffering

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	21.5 %
Very significant impact on emotional health	13.0 %
Very significant impact on psychological and mental health	25.6 %

Responses based on country data (physical, n=79; emotional, n=77; psychological and mental health, n=78)

### Survey findings



- Overall, the majority of respondents felt that hepatitis C had impacted their personal and professional relationships; approximately two thirds reported a negative impact on relationships with colleagues, friends, family and partners
- Nearly one third (31%) of respondents said they would feel uncomfortable talking about their hepatitis C to their boss or colleagues, and only 35% had told colleagues of their hepatitis C status
- Over 70% of respondents said that hepatitis C has negatively affected the way or the amount they are able to work
- Nearly 20% of respondents reported suffering discrimination at work or in education because of their condition

#### What does this mean?

##### Hepatitis C affects all aspects of a person's life

These findings highlight the profound impact of hepatitis C on multiple aspects of health and wellbeing, with the effect on psychological health especially striking.

Adding to the burden of the disease, the proportion of people reporting that they have been discriminated against in work or education is disturbingly high, at 20%. We know that social stigma silences people living with hepatitis C, preventing them from getting the support they deserve.

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.

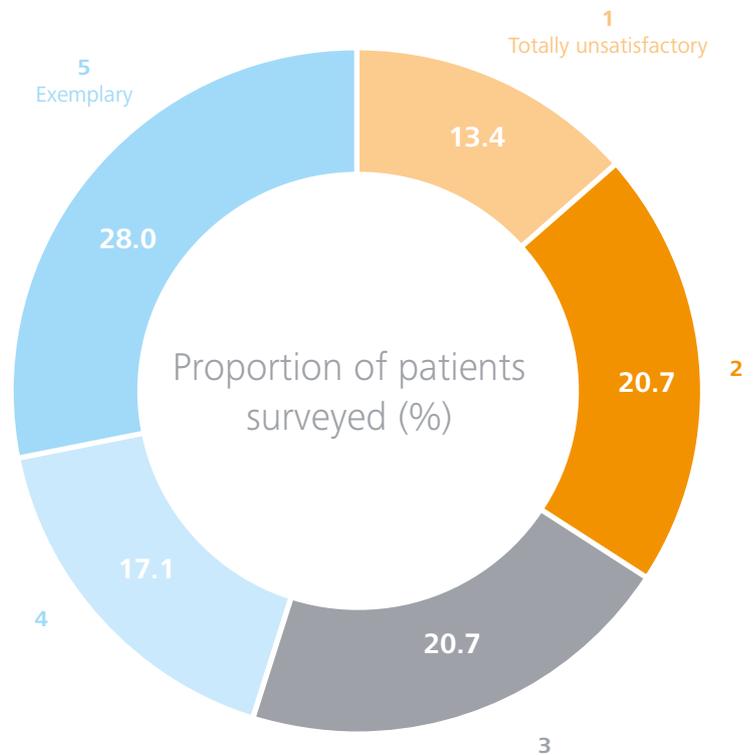
Furthermore, governments need to understand that the wide-ranging impact of hepatitis C on individuals' personal and working lives is a serious socioeconomic issue, and that new treatments represent the opportunity to lift this terrible burden.



## Patient relationships with their healthcare teams could be improved

Over one third of respondents rated communications with their healthcare team as **'unsatisfactory'** or **'totally unsatisfactory'**

Country data based on 82 responses



### Survey findings



- The majority of respondents (86%) had access to a specialist or doctor who they trusted as an authority on hepatitis C, and approximately 80% saw their doctor at least twice a year
- However, a significant percentage of respondents felt that their nurses (37%) and physicians (42%) did not understand the full impact of hepatitis C on their life (ratings of 1–2 out of 5). Additionally, 45% of respondents did not feel confident to ask questions during consultations with their doctor, 68% felt the same way during consultations with their nurse and 32% during consultations with their hepatitis C specialist
- Of the respondents who had been advised that they were not eligible for current treatment options, over 80% were not comfortable with the decision

#### What does this mean?

##### The impact of hepatitis C is not fully understood by healthcare professionals

While the majority of respondents felt confident in their specialist or doctor's expertise in hepatitis C, they don't feel that its impact on their lives is really understood, and they don't feel comfortable to ask questions in their consultations.

Communication between patients and healthcare teams in France must be a focus for improvement, to empower patients and ensure that decisions about their treatment take their wishes properly into account. Healthcare professionals need to also demonstrate that they have an understanding of the emotional pressures that can lead to real psychological distress, and do more to signpost people living with hepatitis C to help when they need it.

# 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?

“Get an ordinary life back / Not live with fear of liver cancer / Stop knowing that I’m infected”

“Free in my head and being like everyone else”

“The best present you could give me, to no longer have a sword hanging over my head, to be sure of seeing my grandchildren grow up”





HCV Quest was supported by sponsorship from AbbVie

World Hepatitis  
**Alliance**