

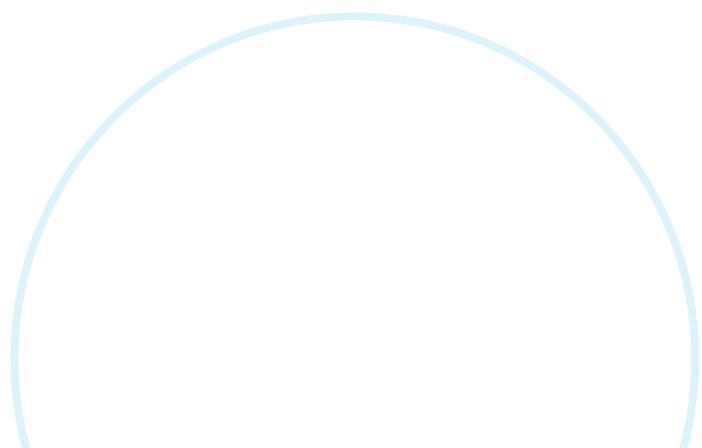
# HCV QUEST

Global patient survey

Country-Specific Report

Spain





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



"The lack of treatments, and what there are have a low success rate and significant side effects"

"The new treatment cannot be prescribed to all patients, apparently because it is too expensive and this is not fair, our lives are at stake"

"The fact that the new treatments are not approved in Spain due to a lack of investment in health"

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

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

# HCV Quest Country-Specific Report

## Public and physician awareness of hepatitis C is low

Only **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 50 responses

Only **1 in 3** respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor



Percentage of HCV Quest respondents. Country data based on 50 responses

## Survey findings



- Just 26% of respondents in Spain knew what HCV was before they were tested for the disease, and only 12% said that their prior knowledge of hepatitis C prompted them to seek testing
- The majority of respondents were tested as part of a routine health screen; only 22% took a test because it was recommended by their doctor
- Almost 70% of respondents who told their doctor about hepatitis C symptoms were not offered a hepatitis C test
- Almost one third of respondents had fibrosis of the liver when they were diagnosed with hepatitis C, and 12% said they didn't know the state of their liver at diagnosis

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)

### FAST FACTS

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

Around 688,000 adults (1.7%) in Spain 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?

#### Awareness of hepatitis C is unacceptably low

It is unacceptable that in Spain today we are seeing such low levels of public and physician awareness about hepatitis C. Failure to identify hepatitis C in affected individuals profoundly impacts long-term health, as we can see from the liver damage that many people sustain before they are diagnosed.

People who are informed about the risks of getting hepatitis C can take steps to protect themselves. Those who are diagnosed early can begin appropriate treatment and make lifestyle changes to help reduce the impact of the disease on their health, and healthcare systems that support timely diagnosis of hepatitis C are faced with fewer cases of cirrhosis, cancers and other serious complications of the disease, which are very expensive to treat.

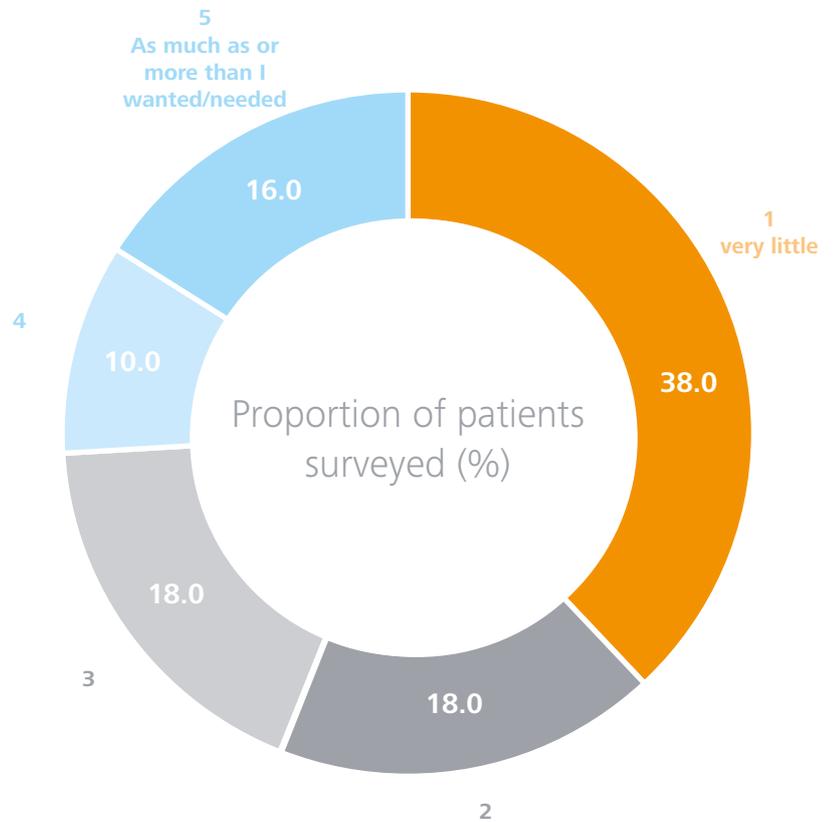
Put simply, increasing public awareness lowers the human and economic cost of hepatitis C. Government must make this investment now, to reduce a long-term burden on Spain.



## Individuals with hepatitis C lack support and information at diagnosis

Nearly **40%** of respondents said **'very little'** information was made available to them through their doctor when they were diagnosed

Country data based on 50 responses



### Survey findings



- At the time of diagnosis, just 8% of respondents were put in contact with a local patient group or organisation, 8% were given the option to meet with a specialist nurse to discuss further and 6% were referred to online resources. 22% of respondents were offered information leaflets
- Only 16% of respondents felt that they received as much as or more information than they wanted/needed at the time of diagnosis
- Over 50% were 'not satisfied' or 'not at all satisfied' with the level of help and advice they received, and only 14% said that they were 'very satisfied'
- Since diagnosis, nearly all respondents (92%) in Spain had looked for further information. The main sources of information used were specific websites (63%), search engines (61%) and patient organisation sites (61%)

#### What does this mean?

##### People living with hepatitis C want more information and support

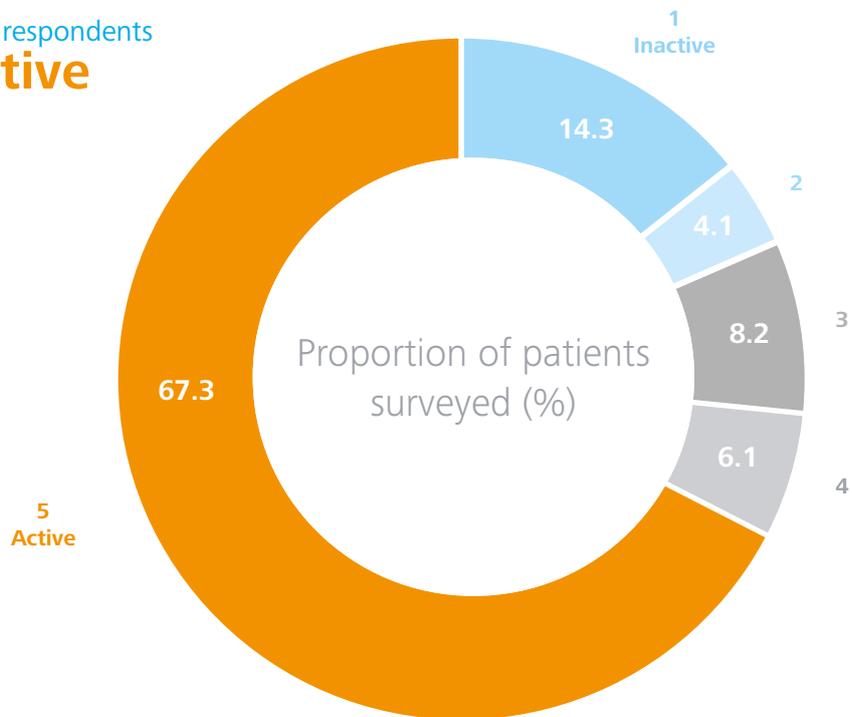
It's clear from these findings that many patients receive minimal information about hepatitis C from their healthcare team when they are diagnosed. This is very disappointing, especially when, as these data show, patients themselves are keen to access the resources and support already available in Spain from national patient groups.

Healthcare teams need to prioritise signposting patients to patient groups, which can provide support outside the clinical environment for people coming to terms with a hepatitis C diagnosis. Patient groups can be the difference between isolation and support, information and community.

## Spanish respondents have the best perception of their national patient organisations in Europe and rely on them for support

Over **two thirds** of Spanish respondents saw their local patient groups as **active and supportive**

Country data based on 49 responses



### Survey findings



- Following their hepatitis C diagnosis, 61% of respondents who had looked for further information about the disease had used patient organisation websites. This percentage was far greater than the European average of 42%
- A high percentage (52% compared with the European average of 28%) said they had told patient organisations about their hepatitis C
- Over 60% of respondents were currently members of patient organisations. This is significantly higher than the regional average (44%)

#### What does this mean?

##### Patient organisations can offer invaluable information and support

With so little information and support being made available to patients by their healthcare teams, the role of patient organisations is critical in Spain.

People living with hepatitis C are proactively seeking out the resources on offer from patient groups, and this relationship appears to be working well, with a very high proportion of respondents saying that they are now members of patient groups.

Healthcare teams don't usually see people more than a few times each year, which makes the ongoing support from patient groups invaluable to people living with the daily impact of the disease.



## Hepatitis C has a significant impact on the individual's health and relationships, and limits their ability to work or study

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	36.7 %
Very significant impact on emotional health	33.3 %
Very significant impact on psychological and mental health	40.8 %

Responses based on country data (physical, n=49; emotional, n=48; psychological and mental health, n=48)

### Survey findings



- Nearly two thirds of respondents said that hepatitis C has negatively affected the way or the amount they are able to work, and over a quarter (26%) said that having hepatitis C has affected their education
- Nearly a quarter of respondents reported suffering discrimination at work or in education because of their condition
- Almost 85% of respondents said they had changed their lifestyle because of hepatitis C
- Just 64% of respondents said they had told their close family about their hepatitis C, compared to the European average of 81%
- 16% reported a 'very strong negative impact' on relationships with partners, which was almost double the European average of 9%

#### What does this mean?

#### Hepatitis C has a profound impact on a person's life

These findings make it absolutely clear that hepatitis C is a disease that affects multiple aspects of the individual's life. The profound impact on psychological, emotional and physical health reported by so many patients affects individuals' confidence, personal relationships, education and careers.

It is time that governments understood that the impact of hepatitis C is social and economic, as well as personal.

The costs of failing to treat hepatitis C are too great.

# 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?

"It would mean a great deal. It is difficult to live with the thought that your liver is a bomb waiting to explode"

"It would be a new lease of life"

"Although marked time is irreversible, certain worries would no longer haunt me"





HCV Quest was supported by sponsorship from AbbVie

World Hepatitis  
**Alliance**