“The biggest barrier I have faced in the fight against viral hepatitis is... no recognition, lack of help. Being left to my own devices with a treatment that causes major anxiety and depression”

“The biggest barrier I have faced in the fight against viral hepatitis is... depression. Inability to stop working, disastrous close family relationships and health status”

“The biggest barrier I have faced in the fight against viral hepatitis is... waiting for treatment”
Hepatitis C is one of the most common causes of liver disease worldwide [1]

Around 69,000 adults (0.9%) in Belgium 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]

**HCV Quest Country-Specific Report**

Public awareness and understanding about hepatitis C needs to improve

**Survey findings**

- Belgium had the lowest awareness of hepatitis C prior to diagnosis in Europe — equal with Poland (17.3% aware); this compares with a regional average of 26%, with the highest level of awareness in Greece (52.8%)
- Only 4.3% had heard about hepatitis C from government campaigns, even lower than the global average of 4.8%
- In Belgium, only 38% (vs. 29% across the region) of responders felt that in general people had been ‘very understanding’ about their hepatitis C, with 11% feeling they were ‘not understanding at all’
- People’s perception of healthcare professionals’ empathy and understanding seemed to be even lower, with few Belgian responders feeling that their nurses (26%) and physicians (36%) ‘completely’ understood the full impact their disease on their lives
- Many people felt their nurse (14%) or physician (9%) did not understand this at all
- Encouragingly, 21% of respondents were put in touch with a patient group on diagnosis, which is almost twice the global average and well above the regional average of 14%.

4 in 5 said they didn’t know what hepatitis C was before their diagnosis

**FAST FACTS**

- General awareness of hepatitis C is unacceptably low

The government is not doing enough to fulfil its commitment to World Health Assembly Resolution 63.18 to use World Hepatitis Day each year to raise awareness.

Stronger awareness and recognition of hepatitis C is a global health priority and is urgently needed to drive change in public and healthcare perceptions, acceptance and understanding of the disease and ultimately to help prevent, diagnose and treat hepatitis C infection in a timely way.

2. Gower E et al. Global epidemiology and genotype distribution of the hepatitis C virus infection. J Hepatol 2014; 61: S45-S57
Early diagnosis: timely testing and referral requires physician awareness of risk and symptoms

Physician awareness of symptoms is low

<table>
<thead>
<tr>
<th>Belgium</th>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes 34.9%</td>
<td>Yes 29%</td>
</tr>
</tbody>
</table>

On reporting symptoms of hepatitis C, only 35% of respondents were offered a test (based on 106 responses)

Belgian respondents reported high levels of liver damage sustained before diagnosis

<table>
<thead>
<tr>
<th>Belgium</th>
<th>Regional</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = No damage 33%</td>
<td>1 = No damage 33%</td>
</tr>
<tr>
<td>2 = Fibrosis 45%</td>
<td>2 = Fibrosis 34%</td>
</tr>
<tr>
<td>3 = Cirrhosis without complications 11%</td>
<td>3 = Cirrhosis without complications 8%</td>
</tr>
<tr>
<td>4 = Decompensated cirrhosis 2%</td>
<td>4 = Decompensated cirrhosis 2%</td>
</tr>
<tr>
<td>5 = Liver cancer 1%</td>
<td>5 = Liver cancer 0.2%</td>
</tr>
<tr>
<td>6 = I don’t know 12%</td>
<td>6 = I don’t know 16%</td>
</tr>
</tbody>
</table>

Belgian respondents had suffered more liver damage than the average across the region before their diagnosis (based on 123 responses)

Survey findings

- Only 35% of people said they had been offered a test for hepatitis after reporting symptoms of the disease to their doctor
- At the time of diagnosis, almost 60% of responders believe they had symptoms of hepatitis C
- Belgians had below-average liver health at the time of their diagnosis, compared with other European nations
- 5% of respondents only discovered they had hepatitis C when they were admitted to hospital with liver-related illness
- Once aware that they had hepatitis C, 65% changed their lifestyle and three quarters stopped or reduced alcohol consumption
- More positively, once diagnosis was made, 67% of Belgian respondents who were diagnosed by their family doctor were referred to a specialist within 3 months, only slightly below the European average (71%)

What does this mean?

Physicians could make a difference through earlier detection and prompt referral

Doctors only recommended testing to a third of people who presented with symptoms of hepatitis C. While two thirds were referred to a specialist within 3 months of diagnosis, by this time many had liver damage (fibrosis or cirrhosis).

The story is similar across Europe – early detection and referral should be universal. Better education of physicians and routine screening, particularly in high-risk people, is needed.

Diagnosis itself can have a positive and empowering effect, with many people changing their lifestyle to protect their liver. This emphasises the importance of finding people who have yet to be diagnosed and helping them to look after their long-term health.
HCV Quest Country-Specific Report

Hepatitis C has a huge impact on people’s lives

Around half of Belgian respondents feel hepatitis C has a significant impact on their physical, emotional or mental health.

Survey findings

- In Belgium, roughly 25% of people described the impact of hepatitis C as ‘very significant’ across all aspects of their lives (physical, emotional, psychological and mental wellbeing, and other); this was similar across the European region.
- The highest impact was felt on physical and psychological and mental health with more people rating this at 4 or 5 out of 5 for severity.
- Belgians were significantly more open that the European average when it came to talking about their diagnosis. Over 90% of Belgians had told their close family about their diagnosis, 68% had told friends and 43% had told colleagues – though 2% had told no one at all.
- One third of those surveyed from Belgium had told patient organisations about their diagnosis, above the regional average (29%). This may be partly because in Belgium, 20% of people are referred to patient groups at the time of their diagnosis, versus a regional average of just 14%. In several European countries this is much lower, e.g. Greece 2%, Russia 4%, UK 9%.
- More than 70% of Belgians felt having hepatitis C had impacted their work life, while only 7% felt it had affected their education.
- 18% said they believed they had suffered discrimination as a result of having hepatitis C. This was similar to the regional average of 21%, and 34% said they would be ‘uncomfortable’ to discuss their diagnosis with a boss or colleagues.

What does this mean?

A large proportion of people in Belgium and across the European region felt the disease and treatment had a significant or severe impact on their health, lifestyle and working life.

There is a clear need for support for those living with hepatitis C. Belgium scores comparatively well on sharing news of the diagnosis with friends and loved ones, but the specialist knowledge and support of patient groups can be a critical resource, so efforts should be made to continue increasing the proportion of patients referred at the time they are diagnosed.

With nearly 1 in 5 people feeling they have suffered discrimination as a result of hepatitis C, the government must act to ensure that robust legislation prohibits discrimination and can be enforced to send a strong message.
Better partnerships are needed to improve communication and joint decision making between patients and physicians

Healthcare professionals’ communication was rated as “exemplary” by 33% of respondents, but 10% had a “totally unsatisfactory” experience.

Survey findings

- 40% said they had never discussed the option of newer therapies with their healthcare professional.
- Of those whose healthcare professional decided they were not eligible for treatment, 72% were not comfortable with this decision.
- 85% of responders felt they should discuss treatment options with their doctor before a decision is made. 19% felt the final decision should be with the doctor, and 65% by the patient.
- By contrast, only 58% said they had been consistently consulted and involved in decision making.

What does this mean?

Healthcare systems are promoting partnership and dialogue between patients and physicians, and this is reflected in Belgium with more than a third of respondents rating communication from their healthcare professionals as exemplary.

However, 10% held the opposite view and said their experience had been “totally unsatisfactory”. Taken together with other responses, it is clear that communication around important issues such as treatment options is not ideal. This variation in reported standards of care suggests that more needs to be done to ensure the best standards in all parts of the country.

The large majority of people want to be involved in decisions around their treatment and care. Including people in discussions about their treatment and care is fundamental to good healthcare, and a good partnership between patients and physicians can result in benefits, such as improved adherence to medications, which may in turn mean that treatment is more effective.

It makes sense for patients and healthcare teams to work together – and we must find ways to do this better.
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

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

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 & 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
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

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 websites, 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
“Cure would mean… I could make plans instead of living from day to day”

“Cure would mean… Freedom and an immense victory”

“Cure would mean… Relief, freedom, no longer being constantly tired, opening up to the outside world, really finding myself”
HCV Quest was supported by sponsorship from AbbVie