The biggest barrier I have faced in the fight against viral hepatitis is... the fear of saying I have hepatitis C.

The biggest barrier I have faced in the fight against viral hepatitis is... being treated in a city that’s 300km away from mine. The bureaucracy and the endless number of documents.

The biggest barrier I have faced in the fight against viral hepatitis is... the cumbersome procedure through which the treatment is approved.

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.

HCV Quest 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 the responses of 145 people from Bulgaria, with insights into the experiences they shared and pertinent comparisons with regional findings.

For the purposes of this report, Bulgaria 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, France, Greece, Hungary, Israel, Poland, Romania, Russia, Spain and the United Kingdom.
Low public and physician awareness of hepatitis C

Less than half of respondents knew what hepatitis C was before their diagnosis

Country data based on 145 responses

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

Around 67,000 adults (1.1%) in Bulgaria 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]

Survey findings

- In Bulgaria, 58% of respondents to the survey said they did not know what hepatitis C was prior to their diagnosis
- Low awareness of hepatitis C is a widespread problem – the HCV Quest survey reported that on average nearly 70% of global and European respondents did not know what hepatitis C was before their diagnosis
- People who were informed about hepatitis C before their diagnosis said they had heard mainly through news and media, such as television and radio (44%), their healthcare professional (20%), and patient organisations (12%). Very few respondents were made aware of hepatitis C via government campaigns (2%)
- Less than 20% of respondents were offered a hepatitis C test after reporting symptoms of the disease to their doctor
- A third of the respondents were diagnosed with hepatitis C through a routine health screen, 14% asked to be tested themselves, 12% were tested because their doctor suggested it and 12% were tested as part of a hepatitis C or blood-borne virus screen

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.

As a result, public awareness is low and the vast majority of physicians fail to recognise the symptoms of hepatitis C when described by a patient, with serious implications on how long patients wait to be diagnosed and receive appropriate care, treatment and support.
Diagnosis: patients are not adequately informed

Only **27%** received 'as much or more' information than they want or need at diagnosis

Amount of information offered at diagnosis (rating 1-5; 1=very little, 5=as much as or more than wanted/needed). Country data based on 143 responses

Survey findings

- 27% of respondents said they received as much or more information than they wanted or needed through their doctor at the time of diagnosis. However, 22% felt they had 'very little' and a further 13% felt they had 'little' information. On average, a third of respondents in the European region felt they had 'very little' access to information through their doctor.
- Information at diagnosis in Bulgaria is generally offered via websites (15%) or leaflets (12%), and only 3% of respondents were put in contact with local patient groups or organisations.
- More than half of respondents in Bulgaria were not aware of any hepatitis C patient organisation.
- 17% of respondents who have taken interferon-based treatment did not know if it was successful, and about a third said they were not sufficiently prepared for treatment side effects.
- Nearly 39% of respondents said they had taken herbal medicines for their hepatitis C, of which 28% were not given any information regarding their effect on the liver.

What does this mean?

Access to information available through doctors at the time of diagnosis varies in Bulgaria, but overall it is far from adequate. Unfortunately, very few patients are in touch with patient organisations.

Patient organisations and local support groups can be a great source of reliable information but doctors are simply wasting this important resource.
Hepatitis C has a significant impact on people’s lives

Hepatitis C affects patients’ lives in many ways

Survey findings

• Most respondents had told their close family about their diagnosis (88%)

• Between one third and one half of respondents in Bulgaria said that hepatitis C impacted significantly or very significantly on their physical health and sense of overall wellbeing (48%), emotional health (37%) and psychological and mental health (47%)

• 44% of respondents said having hepatitis C had affected their work to some degree (28%) or significantly (16%).

What does this mean?

Although a much greater proportion of Bulgarians had told their close family about their diagnosis than the global average, a significant proportion had not, indicating that stigma may still be an issue. This should be addressed through government awareness campaigns.

Many respondents said that hepatitis C had a ‘significant’ impact on physical, emotional and mental health, and also on work.

Governments and healthcare payers should recognise the huge impact of both the disease and its treatment on relationships, lifestyle, health and professional attainment, as well as the value of supporting people with hepatitis C as they take on this battle.
Patients want to be more involved in decision making

76% of respondents agree that it should be for the patient and doctor to discuss their treatment options together, though opinions differ on who should make the final decision.

Who should make decisions about the treatment strategy?

- It should be for the doctor to tell me the best course of action: 23.8%
- It should be for the patient and doctor to discuss all the options together, and for the final decision to be with me, the patient: 26.6%
- It should be for the patient and doctor to discuss all the options together, and for the final decision to be with my doctor, the expert: 49.7%

How involved do you feel you have been in decisions around your treatment options?

- 1 = Not at all: 7.7%
- 2: 11.9%
- 3: 9.1%
- 4: 23.1%
- 5 = Consistently consulted and involved in decision making: 48.3%

Survey findings

- Nearly 50% of respondents felt they have not been consistently consulted and involved in decision making around their treatment options.
- Of the 79% of respondents who have a treatment plan in place, about 30% were not ‘completely satisfied’ with it.
- 50% of respondents felt that the patient and doctor should discuss all the treatment options together and for the final decisions to be made by the doctor, in their capacity as expert, versus 27% who preferred to make these decisions themselves.
- 27% of respondents were advised that they were not eligible for the current treatment options, of which the majority (88%) said they were not comfortable with this decision.
- Approximately 40% of respondents said they had never discussed the newest therapy options with their healthcare professionals, in line with the European average.

What does this mean?

Communication between patients and healthcare professionals needs to improve so that patients are more involved with treatment decisions.

Although nearly 70% of respondents reported being ‘completely satisfied’ with their treatment plan and 68% described communication with their healthcare professionals as ‘exemplary’, many felt they had not been consistently consulted around decisions and many people had never discussed newer therapy options.

Including patients in discussions about their treatment and care is fundamental to good healthcare. It makes sense for patients and the healthcare system – 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 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

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
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… the realization of a dream”

“Cure would mean… going back to the life of a normal father, husband and son. A new hope for a fulfilling life”

“Cure would mean… a radically different state of mental comfort”
HCV Quest was supported by sponsorship from AbbVie