What is the biggest barrier you have faced in the fight against viral hepatitis?
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 people from the United Kingdom, with insights into the experiences they shared and pertinent comparisons with regional findings.

For the purposes of this report, the United Kingdom 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 Spain.

“I feel severely unwell and find it hard to cope with everyday life in all its aspects.”

“Others think it’s your fault you got the virus & they don’t understand that it can cause debilitating symptoms that affect your whole life.”

“I rarely get to see the consultant and would like greater access to discuss future treatments.”

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.
Public awareness is low and doctors are failing to recognise the symptoms of hepatitis C

Only 1 in 6 people were offered a hepatitis test after describing their symptoms to their doctor

Survey findings

- 23% of respondents were diagnosed after routine screening – fewer than the European average (31%)
- 62% of patients diagnosed with hepatitis C in the UK believe that they were exhibiting symptoms of the disease at the time of diagnosis compared with 44% of patients across Europe, yet only 16% were diagnosed after their doctor recommended a test
- Public awareness of hepatitis C is extremely low in the UK, with only 30% of survey respondents saying they were aware of hepatitis C prior to diagnosis and just 10% saying they were prompted to get tested based on their knowledge of the disease
- Government awareness campaigns are failing in the UK, with zero survey participants reporting they had been made aware of hepatitis C through such campaigns.

FAST FACTS

- Hepatitis C is one of the most common causes of liver disease worldwide [1]
- Around 307,000 adults (0.6%) in the UK 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]; in the UK annual deaths have quadrupled in the last 16 years
- There is currently no vaccine for hepatitis C [3,4]

What does this mean?

Healthcare professionals in the UK are failing to identify the symptoms of hepatitis C early

Almost two thirds of patients diagnosed with hepatitis C in the UK believe they were already experiencing symptoms of the disease, yet the proportion referred for testing was low. If at-risk people have low awareness and do not actively seek testing, this puts extra emphasis on the need for their healthcare professionals to identify the symptoms as early as possible.

The government should vastly improve its efforts to raise awareness of hepatitis C and improve education on the associated risks and symptoms in order to inform the public and encourage healthcare professionals to refer people for testing.

2. Gower E et al. Global epidemiology and genotype distribution of the hepatitis C virus infection. J Hepatol 2014; 61: S45-S57
Patient support

Healthcare teams have a greater role to play in patient support at diagnosis

More than 1 in 3 patients with hepatitis C in the UK were not at all satisfied with the level of help and advice they received at the time of diagnosis

Country data based on 129 responses

Survey findings

• Over half of people in the UK considered that little (12%) or very little (48%) information had been made available to them through their doctor at the time of their diagnosis. Other European countries reported better availability of information (‘very little information’ average across the region was 31%), except Belarus (61%) and Austria (48%)

• In contrast, following diagnosis, British people are the highest users of online resources in Europe, with websites (86%) and search engines (70%) being the main sources, and NHS (57%) and patient organisation (58%) sites commonly visited

• 39% of patients were provided with information leaflets at the time of diagnosis, but very few were referred to patient organisations for support (9%)

• However, the proportion referred to discuss their disease with specialist nurses (36%) is one of the highest rates in Europe, with only Romania (41%) reporting higher rates.

What does this mean?

Patients in the UK rely on online searches rather than healthcare professionals for information on hepatitis C

A high proportion of patients in the UK are not satisfied with the support and information they receive at the time of their diagnosis and seek more information via online sources. This is despite a relatively high proportion of patients in the UK having the opportunity to speak with a specialist nurse.

Furthermore, rather than direct engagement with specific government and patient organisation websites, patients are often finding their information via search engines, which may not be the best source of balanced, accurate data. Healthcare teams are wasting a valuable resource by failing to signpost newly-diagnosed patients to the best available sources of information and support.

Governments have a responsibility to ensure that clear, high-quality information is readily available in the public domain, and that it reaches people when they need it. Governments and healthcare teams can also draw on the expertise of patient organisations in the UK to provide supplementary information, support and advice for people diagnosed with hepatitis C. It is inappropriate and unnecessary for patients to be left in the dark.
Hepatitis C infection has a major impact on patients’ lives

More than half of patients in the UK report hepatitis C having a significant or very significant impact on their life and health

Survey findings

• The impact on physical health and psychological health on people in the UK was the second highest reported across Europe. 43% of respondents reported ‘very significant’ impact on their physical health and overall wellbeing, 31% on their emotional health and close relationships and 52% on their mental or psychological health.

• Likewise, half of people with hepatitis C in the UK believe that their disease has had a ‘significant’ impact on their ability to work (50%), which is the highest proportion in Europe (versus a regional average of countries at 29%).

• In addition, 23% of people in the UK report having suffered discrimination at work or in education as a result of their diagnosis.

What does this mean?

Many patients are significantly affected by hepatitis C and its impact on daily life

The majority of patients with hepatitis C in the UK report a significant impact of hepatitis C on their physical, emotional and/or mental health. Over half of respondents said that hepatitis C impacted on the way or amount they are able to work, which indicates that hepatitis C infection is having a greater impact on the day-to-day lives of patients in the UK than in any other European country surveyed.

Patient organisations can provide support, advice and information to people with hepatitis C to help reduce the impact of the disease on their lives, so it is tragic that healthcare teams do not refer patients to them.
Patient support

Interferon treatment and symptoms – a challenge for patients

Many patients take other medicines alongside their treatment for hepatitis C to help manage comorbidities and symptoms

Survey findings

- Of all European nations, British people were most affected by the side-effects of interferon therapy. 64% said they had not felt sufficiently prepared, versus 41% across Europe
- 40% reported taking herbal medicines mostly because of information suggesting they would relieve symptoms (68%) or slow/stop progression of liver disease (53%); but 40% have not received any information about the effects they may have on their liver
- In the UK, many patients (71%) have discussed newer, interferon-free treatment options with their healthcare professional, although this is lower than in some other European countries, including Austria (79%), France (79%) and Spain (90%)

What does this mean?

Treatment for hepatitis C can be complex and challenging for patients, but newer therapies may reduce the burden on patients and healthcare systems

Treatment for patients with hepatitis C is not limited to suppressing the virus itself and many patients may often require additional treatment for other physical and psychological symptoms, such as pain and depression. As a result of the low success rate and difficult side effects of interferon-based treatment, a high proportion of patients also seek alternative treatment options, such as herbal therapies, and may do so without fully understanding the overall consequences for their liver health.

Newer therapy options offer a much improved success rate, reduced side-effects and the prospect of life without hepatitis C for many. Access to such treatments should be a health priority, based on the potential benefit to patients and to long-term health economics, with fewer people suffering severe liver damage as a result of hepatitis C.
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 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

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 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
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?

“A cure would change my life entirely and allow me to get on with the years I have left.”
“A total transformation, an end to symptoms of chronic fatigue and depression, the ability to work, form intimate relationships... a full life”

“I would give anything to walk away from this thing. It impacts on my entire being. I would feel liberated and able to pursue so many things”
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