What is the biggest barrier you have faced in the fight against viral hepatitis?
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 summarizes responses of 232 people from the United States of America (USA), with insights into the experiences they shared and pertinent comparisons with regional and global findings.

For the purposes of this report, the USA responses have been contrasted against responses from other countries with similar socio-economic profiles, such as France, Australia and the United Kingdom (UK).

“I tried the interferon, but could not continue due to severe side-effects. I have been bedridden for years, unable to work. I get very depressed at times as I feel my future is unknown”

“Ignorance, fear and prejudice. I’ve lost 2 jobs after telling my boss which I did due to treatment”

“People do not understand. I look fine on the outside. They don’t understand tiredness”
Government campaigns are not supporting public awareness of hepatitis C

Just 37% of respondents knew what hepatitis C was before diagnosis and, of these, only 1% received this information from a government awareness campaign.

Country data based on 85 responses

Survey findings

- Little information about hepatitis C is currently made available to patients at the time of diagnosis. Just 14% of respondents said they received as much information as they wanted or needed and 36% were ‘not at all satisfied’ with the help and advice they received.
- Only 1% of respondents in the USA said they learned about hepatitis C through government awareness campaigns, with most receiving information through a medical professional (44%), news and media (24%), patient organizations (9%) or other, non-defined sources (47%).
- Healthcare professionals’ awareness of symptoms of hepatitis C also appears low. At diagnosis, 52% of respondents said they had symptoms suggestive of hepatitis C, but only 30% were offered a test on reporting symptoms.
- Less than two thirds of survey respondents were referred to an appropriate specialist within 3 months of their diagnosis and 11% waited more than 3 years to be referred.

What does this mean?

Improving public and physician awareness of hepatitis C and its symptoms is an urgent priority for the USA

Public awareness could drive earlier diagnosis by helping individuals understand the risk factors and symptoms of hepatitis C, and the available support when infection is suspected. Equally, physicians need to offer immediate testing to people showing symptoms of hepatitis C and specialist referral, to reduce the long-term health impact of the disease.

Governments have a clear responsibility to protect their citizens and make them aware of the risks associated with hepatitis C, but they don’t have to do it alone. By working collaboratively with patient groups, governments can maximize the benefit to patients and expand the reach of patient and physician education campaigns.
USA patients believe strongly in joint decision making and regular communication around treatment plans

The vast majority of respondents who did not have a treatment plan at the time of the survey said they thought this would be helpful to them

Survey findings

• Almost all responders (97%) felt that treatment decisions should be discussed between the patient and their doctor, with 80% feeling that the final decision should be with the patient
• 27% rarely see their doctor to discuss their ongoing care and treatment (once a year or less)
• While 49% felt they had been ‘consistently consulted and involved in decision-making’, 10% said they felt ‘not at all’ involved
• Of those who had been advised that they were ineligible for current treatment options (26%), 71% said they were dissatisfied with this decision
• Of the 68% of respondents who had an agreed treatment plan, only 49% were completely satisfied with it

Country data based on 57 responses

What does this mean?

Healthcare teams should support and encourage the wish of their patients to agree a treatment plan, and ensure this remains helpful to the patient

It is imperative that patients understand the current state of their health, what proactive steps they can take at home to reduce the risk of further liver damage (such as healthy lifestyle decisions) and what the next steps may be for them in terms of therapeutic treatment of their hepatitis C. This helps to reduce feelings of anxiety, powerlessness and dread around the disease, putting patients in an empowered position.

Treatment plans are most effective when they are regularly revisited with the patient, to ensure they are still comfortable with the decisions made.

FAST FACTS

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

Around 3,347,000 adults (1.3%) in the USA had hepatitis C in 2013 [2], with a total of 80–150 million people living with the chronic condition worldwide [3]

In the USA in 2012 the estimated number deaths from hepatitis C (18,650) [4] overtook the estimated number of deaths in people with HIV/AIDS diagnosis (13,712) [5]

Deaths related to hepatitis C are increasing and 700,000 died worldwide in 2013 [1]

There is currently no vaccine for hepatitis C [3,6]

2. Gower E et al. Global epidemiology and genotype distribution of the hepatitis C virus infection. J Hepatol 2014; 61: S45-S57
Patients want help and resources from patient organizations – but healthcare teams are not supporting referrals

Just 9% of individuals with hepatitis C are put into contact with a patient organization after diagnosis

Survey findings

- Around 50% of respondents said they were not aware of any patient support organizations or unaware of their activities in their communities
- Roughly 25% of those who took the HCV Quest survey said they were part of a patient group, and the same proportion said they saw patient groups actively engaged in helping patients in their communities
- 42% of respondents said they have looked at patient organization websites as a source of information since their diagnosis

What does this mean?

Patients want and deserve more access to patient group support

Just 9% of HCV Quest respondents were put in touch with a patient group at the time of diagnosis. However, it is clear that patients value and actively seek these resources, as 42% said they have looked at patient group websites since their diagnosis.

This mismatch represents a huge missed opportunity. Healthcare teams should be actively connecting individuals with hepatitis C with the information, advice and emotional support that patient organizations can offer.

Patient groups can provide a range of on-going support to patients, such as helping them to come to terms with their diagnosis and providing tools and information that can empower patients to take an active part in discussions around their treatment. This can also reduce some of the burden of support on healthcare professionals.
Hepatitis C has a huge impact, but patients often feel this is not understood by their healthcare teams and this was symptomatic of poor communication

Patients **do not** always feel their healthcare teams **understand** the impact of hepatitis C on their lives

**Survey findings**

- Over half of respondents felt that hepatitis C had a significant or very significant negative impact on their physical (61%), emotional (51%) or mental and psychological (69%) wellbeing
- Over three quarters (76%) said hepatitis C had a negative impact on their work life
- 23% said they had suffered discrimination in education or employment as a result of having hepatitis C
- While 32% of patients say their communication with their healthcare teams in person, in writing or over the telephone is ‘exemplary’, 15% describe it as ‘totally unsatisfactory’
- Of those who were not currently receiving treatment, just 56% felt they were being properly monitored. This compares unfavorably with Australia (60%), France (91%) and the UK (69%)

What **does this mean?**

**Hepatitis C has a major impact on many aspects of people’s lives and this has to be appreciated, especially by healthcare teams.**

In general, the relationship between patients and healthcare teams needs to be strengthened

Strong relationships of trust and mutual respect between healthcare teams and patients are crucial for optimal patient support and opportunities for recovery.

Patients who feel comfortable to ask their questions during consultations trust their doctors as authorities on their condition, and patients who sense that their healthcare teams understand the wider impacts of hepatitis C on their lives are more likely to communicate openly. This may be key to identifying patients who are suffering psychological or emotional impacts of the disease and important to ensure appropriate referrals for support.

State and federal government has a responsibility to ensure that there is no discrimination against people as a result of living with hepatitis C. It must do more.
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 give me my life back, so I could do more than be tired and sick most of the time”
“Having a life that loses the feeling of being diseased, and having freedom from fear of impending death”

“A cure would take the weight of the world off my shoulders and enable me to be free of the stress and financial burden of self-treating”
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