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 110 people from Greece with insights into the experiences they shared and pertinent comparisons with regional and global findings.

For the purposes of this report, Greece 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, Bulgaria, France, Hungary, Israel, Poland, Romania, Russia, Spain and the United Kingdom.

“The biggest barrier I have faced in the fight against viral hepatitis is… the attitude of the doctors”

“The biggest barrier I have faced in the fight against viral hepatitis is… The anxiety of whether I’ll get well, discrimination at work and social discrimination”

“The biggest barrier I have faced in the fight against viral hepatitis is… the fact that I can’t speak openly about it”
Public awareness of hepatitis C – a priority to drive timely diagnosis and referral

53% of respondents from Greece knew about hepatitis C before diagnosis, but only 5% of them got this information from government awareness campaigns.

Sources of information about hepatitis C before diagnosis.
Country data based on 57 responses.

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Proportion of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government awareness campaign</td>
<td>5,3</td>
</tr>
<tr>
<td>Patient organisation</td>
<td>7,0</td>
</tr>
<tr>
<td>Medical professional</td>
<td>15,8</td>
</tr>
<tr>
<td>News or other media (TV, radio, newspapers etc.)</td>
<td>14,0</td>
</tr>
<tr>
<td>Other</td>
<td>57,9</td>
</tr>
<tr>
<td>I don’t know</td>
<td>1,8</td>
</tr>
</tbody>
</table>

Survey findings

• In contrast to many other European countries, awareness about hepatitis C was relatively high in Greece, with 53% of respondents saying they had knowledge about the disease before their diagnosis.

• Few Greeks had received information about hepatitis C through a conventional source (e.g. media [14%], medical professional [16%]); 58% quoted other, non-defined sources.

• Government campaigns were not successful, reaching just 5% of the respondents.

• Nevertheless, just 30% of individuals were prompted to get tested for hepatitis C after receiving relevant information, so more information about symptoms and risk factors may help patients to seek timely help.

• 73% were not offered a test when they reported symptoms to their doctor.

• Despite only 2% of patients being referred to patient groups by doctors at the time of diagnosis, a very high proportion of those who completed the HCV Quest survey (52%) were members of patients groups.

• 52% of those aware of patient groups operating in their community saw them as “Active: I see the organisation involved in supporting patients with hepatitis C.”

What does this mean?

Governments must take a lead role in providing high quality information about the risks and symptoms of hepatitis C and work together with effective patient groups.

Improved public awareness and education are essential to prompt early diagnosis, but equally so is awareness and education amongst doctors. Governments have a responsibility to protect their citizens from the risks associated with hepatitis C, but they don’t have to do it alone. Over 50% of those who took the HCV Quest survey were members of patient societies in Greece, despite only 2% being referred at the time of diagnosis. Clearly, patient groups are delivering a valuable and recognised service to patients in Greece. By working collaboratively with these groups, government can expand its reach to patients. The value of supportive interventions, such as new patient education materials, can also be enhanced through this kind of partnership.

FAST FACTS

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

- Around 178,000 adults (1.9%) in Greece 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].


Communication and trust between patients and their healthcare teams is an area of concern, particularly around treatment and living with hepatitis C

Slow referral times, sub-optimal communication, lack of confidence in asking questions and lack of patient involvement in decision making are seriously impacting the patient experience of care.

### Survey findings

- Referral times can be very slow – 17% of individuals who first discuss their diagnosis with a family doctor wait longer than 3 years to see a specialist.
- More than a third of respondents felt hepatitis C had a significant or very significant impact on their physical (42%), emotional (34%) and mental or psychological (37%) well-being.
- Just 55% of respondents had a treatment plan and, of these, only 42% were completely satisfied with it.
- Just under half of the patients surveyed did not feel they had access to a physician who is an authority on the condition.

### What does this mean?

The relationship between patients and healthcare teams needs considerable work.

Patients are reporting a lack of trust and communication with their healthcare teams. Too few patients are currently being included in decisions around their treatment, and many (14%) do not feel confident enough even to ask questions.

Serious thought and meaningful investment of time, training and consultation needs to be dedicated to improving the patient experience of their treatment journey.
Fear of stigma and discrimination in professional settings

While Hepatitis C is more openly discussed in Greece than in many European countries, it still carries a fear of stigma and discrimination in the workplace.

Survey findings

- More than 20% of Greek respondents had experienced discrimination at work or in education.
- Just 17% chose to disclose their diagnosis with colleagues.
- 43% of those for whom the question applied said they would be “uncomfortable” to discuss their hepatitis C with their boss and colleagues or with staff at their place of education.

What does this mean?

In many settings, including in family and social relationships, Greece appears less affected by shame and stigma around hepatitis C than other European nations. However, in professional and educational spheres, fear of discrimination including loss of prospects is a serious concern.

Governments need to be made aware of the scale of the problem and the impact of discrimination on individuals in professional and educational settings. It is vital for governments to outlaw discrimination through specific and enforceable anti-discrimination measures.
Patients are not satisfied with the level of their involvement in decisions about their treatment

When asked about how involved they felt in decisions about treatment options, 21% said they had not been involved at all.

How involved do you feel you have been in decisions around your treatment options? Please rate 1–5
(1 = Not at all; 5 = Consistently consulted and involved in decision making)

<table>
<thead>
<tr>
<th>Rating</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Not at all</td>
<td>20.8%</td>
</tr>
<tr>
<td>2</td>
<td>10.4%</td>
</tr>
<tr>
<td>3</td>
<td>13.2%</td>
</tr>
<tr>
<td>4</td>
<td>12.3%</td>
</tr>
<tr>
<td>5 = Consistently consulted and involved in decision making</td>
<td>43.4%</td>
</tr>
</tbody>
</table>

Score 1 “not at all” – score 5 “consistently consulted and involved

Survey findings

- Just 55% of respondents had agreed a treatment plan with their healthcare professionals.
- While 53% of respondents felt that the final decision about treatment ought to be theirs, not the doctor’s, 21% said they had not been consulted at all about their treatment.
- Communication between patients and healthcare professionals is of a variable standard across Greece, with 20% feeling it is “totally unsatisfactory”.

What does this mean?

Individuals living with hepatitis C want to be more actively involved in decision making around their treatment and care plan.

Patients are currently not given the opportunities they want to discuss their treatment with their healthcare teams. Healthcare professionals need to be more open to communicating with patients about their treatment and commit to improving levels of patient satisfaction, because communication between patients and their physicians, nurses and specialists builds trust and empowers patients.

Patient groups can be an excellent support to healthcare teams, by providing interim support to patients between clinical appointments. They can also help patients to understand medical terminology and provide them with the tools and encouragement they need to speak up in consultations, to demand a say in decisions about their treatment strategy.
HCV Quest Toolkit

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 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

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
“For me, a cure would mean... freedom from the stress regarding my health and transmitting hepatitis C to someone close to me”

“For me, a cure would mean... my psychology would change because I would be healthy. Now, I am afraid”

“For me, a cure would mean... I would be able to have a family and not be ashamed”
HCV Quest was supported by sponsorship from AbbVie