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 388 people from Egypt, with insights into the experiences they shared and pertinent comparisons with global findings.

For the purposes of this report, Egypt is defined as part of the World Health Organization (WHO) Eastern Mediterranean Region. Responses have been contrasted against trends identified in the global survey, as there was low participation in the survey from other nations in this region.

The situation in Egypt regarding treatment options may have changed dramatically since the time of the survey, due to the launch of the Egyptian government-funded treatment programme, which has provided many patients in Egypt with access to newer therapies.

“The biggest barrier I have faced in the fight against viral hepatitis is... Waiting for the new medication and fear of health deterioration”

“The biggest barrier I have faced in the fight against viral hepatitis is... the analysis procedure and medication costs”

“The biggest barrier I have faced in the fight against viral hepatitis is... Depression”
The major impact of hepatitis C, the importance of continuing diagnosis and dissatisfaction with treatment decisions

At diagnosis, a significant proportion of individuals with hepatitis C have some liver damage

The state of respondents’ liver health at the time of diagnosis

<table>
<thead>
<tr>
<th>Liver Health Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No damage</td>
<td>34.1%</td>
</tr>
<tr>
<td>Fibrosis</td>
<td>20.7%</td>
</tr>
<tr>
<td>Cirrhosis without complications</td>
<td>6.5%</td>
</tr>
<tr>
<td>Decompensated cirrhosis*</td>
<td>24.8%</td>
</tr>
<tr>
<td>Liver cancer</td>
<td>2.1%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>10.3%</td>
</tr>
</tbody>
</table>

*Decompensated cirrhosis with symptoms such as jaundice, bleeding, ascites or encephalopathy

Based on 387 respondents

FAST FACTS

- Hepatitis C is one of the most common causes of liver disease worldwide [1]
- Around 8 million adults (15%) in Egypt 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]
- Egypt has very high cirrhosis mortality from hepatitis C among men and women [4]
- There is currently no vaccine for hepatitis C [3,5]
- A new government treatment programme was launched in Egypt in October 2014 to tackle the high prevalence rate of hepatitis C [6, 7]

In October 2014, the Egyptian Ministry of Health released the executive summary of the new national action plan to address the high hepatitis C prevalence rate – titled “Action Plan for the Prevention, Care, and Treatment of Hepatitis C 2014-2018” [7]

Survey findings

- Just over a fifth of those with hepatitis C had fibrosis at diagnosis, while one quarter had decompensated (progressive) cirrhosis, which presents with liver symptoms such as jaundice, bleeding and build-up of fluid in the abdomen
- Around one third of respondents (34%) had no damage to the liver at diagnosis, slightly lower than the global figure (38%)
- Around 58% of respondents reported having symptoms suggestive of hepatitis C infection at the time of diagnosis, compared with 47% globally. Typical symptoms might include: fever, nausea, vomiting or poor appetite
- Following diagnosis, nearly 80% of patients made lifestyle changes

What does this mean?

An early and timely diagnosis of hepatitis C is essential if more people are to be protected from liver damage and death

This is particularly important given the Egyptian government’s recently launched treatment programme, which can ensure that those most in need are prioritised for treatment

Even with the government’s huge investment in treatment, demand is much greater than current capacity. Nevertheless, diagnosis must remain a priority. Knowledge of their condition equips patients to make relevant lifestyle changes to protect their health, and to educate themselves about treatment options.
Patient support

**Hepatitis C has a major impact on people’s life**

83% of respondents said hepatitis C had impacted on their work life

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I do not feel that my hepatitis C has affected my work</td>
<td>17.0%</td>
</tr>
<tr>
<td>Yes, I feel it has affected my work to some degree</td>
<td>27.3%</td>
</tr>
<tr>
<td>Yes, I feel it has affected my work significantly</td>
<td>55.7%</td>
</tr>
</tbody>
</table>

Living with hepatitis C can have a negative impact on work (based on 359 responses)

**Survey findings**

- 27% of respondents said hepatitis C had affected their work to some degree and 56% said it had done so significantly (vs. 32% globally)
- More than a third said that hepatitis had affected them physically (35%) or mentally/psychologically (39%) either significantly or very significantly
- In comparison, only 19% said hepatitis C had affected them emotionally and over half said it had had no impact on their relationships with friends, family and partners. 95% had told their close family, one of the highest rates in the world

**What does this mean?**

Hepatitis C has a major impact on people’s ability to work

Although respondents in Egypt are reporting that hepatitis C has less of an effect on their personal relationships than patients in many other countries, it does have an important impact on people’s physical and mental well-being.

The impact of the disease on people’s ability to work is very substantial, even though 90% report not having felt subject to discrimination. This may suggest that the physical, emotional or psychological impacts of the disease have also had repercussions in people’s professional lives.

The decision of whether or not to offer treatment to patients has historically been complex

Survey findings

- At the time of the survey, one third of diagnosed individuals had been advised that they were not eligible for current treatment options and 80% of these individuals were not comfortable with this decision.
- Over 50% of respondents in Egypt did not have an agreed treatment plan with their healthcare professional, and of those who did, only 1 in 10 respondents said they were completely satisfied.

What does this mean?

More patient information about treatment is needed to ensure better patient satisfaction.

At the time of the survey, 75% of respondents had discussed new treatment options with their doctors. However, many patients were advised that they were not eligible for current treatment options, the vast majority of whom were not satisfied with this decision.

The situation may be very different now with the launch of the government-funded treatment programme in October 2014. However, people living with hepatitis C may continue to have diverse experiences of treatment and will need support and education to understand their treatment options in this new situation.
Who should make decisions about treatment?

Survey findings

- More than 50% of respondents said decision making about treatment options ought to be a joint process between themselves and their doctor, with the final decision being the responsibility of the doctor.
- Over 40% of respondents said they thought the doctor should advise the patient on treatment, without patient input in making this decision.
- Many patients felt they had not been sufficiently involved in decisions about their treatment, with 15% saying they had not been consulted at all and a further 25% rating the amount they had been involved at 2 out of 5.

What does this mean?

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

Allowing people to be as involved as they want to be is likely to promote good cooperation around the management of hepatitis C. It is vital that we provide those living with hepatitis C with all the information they need, so they can feel confident to contribute to conversations with their healthcare professionals about their treatment.

With many more patients now having access to treatment in Egypt, it remains essential to have good communication between physicians and patients, to help patients understand how to be adherent to therapies and maximise their chance of cure.
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
“For me, cure would mean… Better family and work life”

“For me, cure would mean… Extreme mental relief”

“For me, cure would mean… Feeling normal and being able to do whatever I want”
HCV Quest was supported by sponsorship from AbbVie