

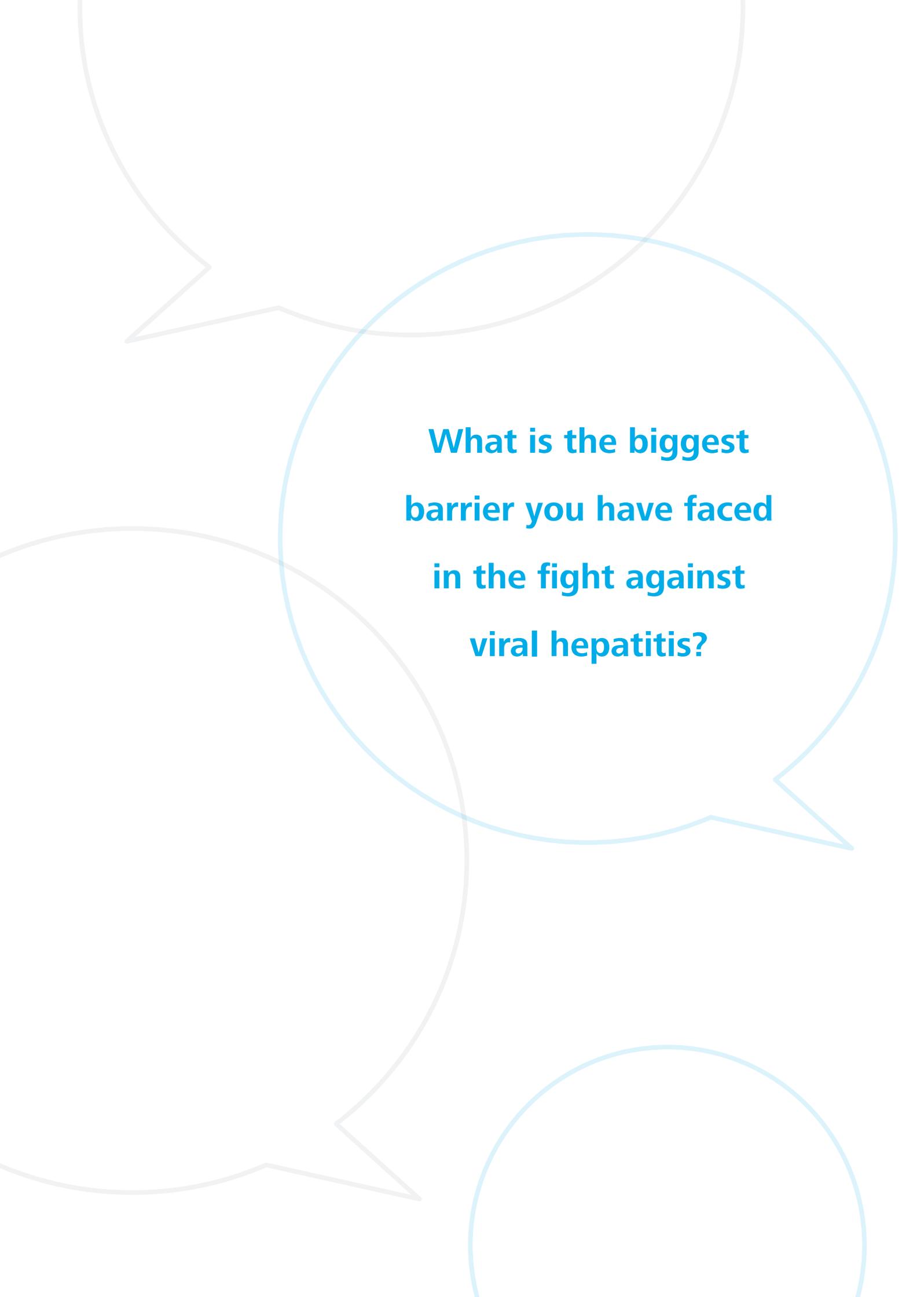
# HCV QUEST

Global Patient Survey

Country-Specific Report

Israel





**What is the biggest  
barrier you have faced  
in the fight against  
viral hepatitis?**



“Not enough emotional support and understanding of the treatment complexity”

“Finding a dentist that will accept me for treatment”

“Prejudice - ignorance of the general public - ignorance of the family doctor”

## ABOUT HCV QUEST

**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 43 people from Israel, with insights into the experiences they shared and pertinent comparisons with regional findings.

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

# HCV Quest Country-Specific Report

## Awareness of hepatitis C is low amongst the public and doctors

**4 out of every 5** respondents did not know what hepatitis C was before their diagnosis



Awareness of hepatitis C before diagnosis among HCV Quest respondents. Country data based on 43 responses

Less than **1 in 5** respondents were offered a hepatitis C test on reporting hepatitis C symptoms to their doctor



Percentage of HCV Quest respondents. Country data based on 42 responses

### Survey findings



- Just 21% of respondents said they knew what HCV was before they were tested for the disease
- Of those who knew what hepatitis C was before their diagnosis, one third said that their information had come from a medical professional, one third said their information had come from news or other media (TV, radio, newspapers etc.) and 11% said that their information had come from a patient organisation. None of the responders said they had received their information from the government
- Of those who reported symptoms related to hepatitis C to their doctor, only 17% were offered a test for HCV, one of the lowest rates in the European region

### FAST FACTS

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

Around 110,000 adults (2%) in Israel had hepatitis C in 2013, with a total of 80–150 million people living with the chronic condition worldwide [2,3]

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]

### What does this mean?

#### Public and physician awareness of hepatitis C in Israel is unacceptably low

The fact that only 17% of people reporting symptoms of hepatitis C were offered a test is extremely serious. It means that many people are likely to be suffering with hepatitis C, undiagnosed, and sustaining serious liver damage as a result.

The government and healthcare providers in Israel must act to improve public awareness of hepatitis C and physician knowledge and confidence in recognising signs and symptoms of the disease. This will improve management of those already affected and prevent more people from getting hepatitis C.

1. Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 2015;385:117–71.

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

3. World Health Organization (WHO). Hepatitis C. Fact Sheet N. 164. Geneva, Switzerland, 2014. Available at: <http://www.who.int/mediacentre/factsheets/fs164/en/>

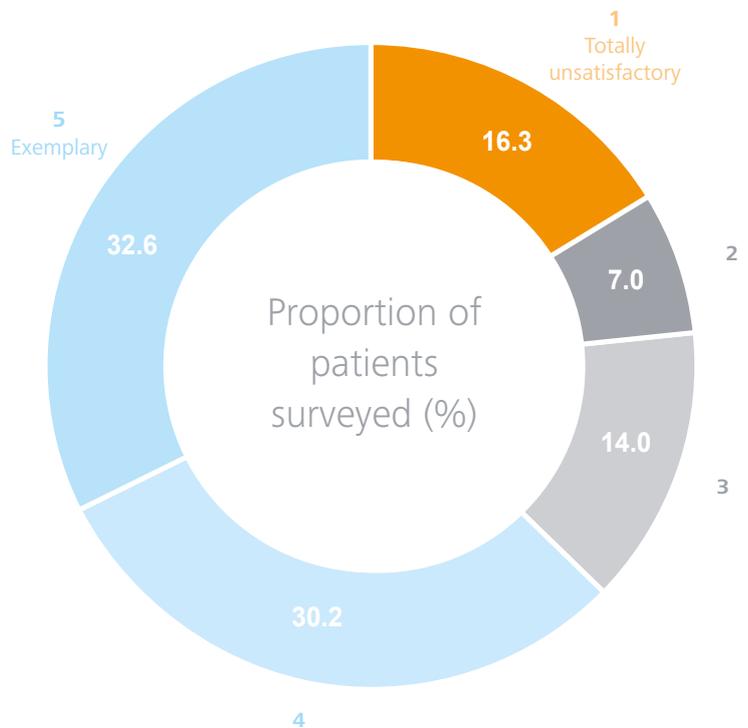
4. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: [http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755\\_eng.pdf?ua=1&ua=1.26](http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26)



## While trust in doctors is high, communication between patients and their healthcare teams could be improved

Almost **1 in 6** respondents rated communications with their healthcare team as **'totally unsatisfactory'**

Country data based on 43 responses



### Survey findings



- Around 40% of respondents in Israel felt that both nurses and physicians 'completely' understood the full impact of hepatitis C on their lives, which is significantly higher than the regional average (22% and 28%, respectively)
- However, while one third of respondents in Israel rate communications with their HCP as 'exemplary', 16% rated communications as 'totally unsatisfactory'
- A high percentage (72%) of respondents in Israel were 'completely satisfied' with their treatment plan, which was significantly higher than the regional average of 45%, and 84% said that they had access to a hepatitis C specialist or doctor that they could trust as an authority on the condition
- Among those who had been offered treatment but decided to defer it, a low percentage (40%) in Israel felt that they were being properly monitored by their specialist. This was significantly lower than the regional average (65%)

### What does this mean?

#### Patient relationships with healthcare professionals are positive but could be improved

Patients in Israel rate their relationships and interactions with their healthcare teams more positively than in many other countries in Europe.

Despite this, around 60% of patients do not feel that their nurses or physicians fully understand the impact of hepatitis C on their lives. In addition, while the majority of individuals with treatment plans in place are satisfied with them, only 40% of those who have deferred treatment feel they are being properly monitored.

Healthcare professionals need to demonstrate an understanding of the emotional pressures of living with hepatitis C. Optimising communications, including involving patients in the decisions around their treatment and maintaining contact between meetings, would help further increase patient confidence.

## Living with hepatitis C is challenging, but patients in Israel seem more open about their disease

A high number of respondents felt that hepatitis C had a **very significant impact** on their physical, emotional and psychological wellbeing

### Does hepatitis C affect your physical, emotional or psychological and mental health?

Very significant impact on physical health	26.3%
Very significant impact on emotional health	36.1%
Very significant impact on psychological and mental health	32.4%

Responses based on country data (physical, n=38; emotional, n=36; psychological and mental health, n=34)

### Survey findings



- Of those respondents who felt that hepatitis C had impacted on their lives, approximately one third of all respondents described a 'very significant' impact on their psychological, mental and emotional health. 26% also said that there had been a 'very significant' impact on their physical health and wellbeing
- All respondents had told someone about their hepatitis C, and over 95% had told their close family
- Overall, the majority of patients felt that hepatitis C had not impacted their personal or professional relationships. 71% reported no impact on relationships with colleagues, 73% reported no impact on friendships, 78% reported no impact on family relationships and 73% said that their relationships with partners were not impacted
- Just 7% reported suffering any discrimination, one of the lowest rates across Europe, and almost half (49%) said they had not changed their lifestyle at all because of their hepatitis C

#### What does this mean?

**Hepatitis C affects all aspect of a person's life but the ability to speak openly about their disease greatly benefits patients**

One in three people rated the impact of hepatitis C on their psychological, emotional and physical health as 'very significant'. This is compelling evidence of the true, wide-ranging nature of the burden of hepatitis C and its potential to disrupt every aspect of an individual's life.

Social attitudes towards the disease seem more accepting in Israel than in other countries in Europe, as evidenced by the high proportion of respondents who decide to talk about their hepatitis C and the relatively low perceived discrimination and impact on relationships.

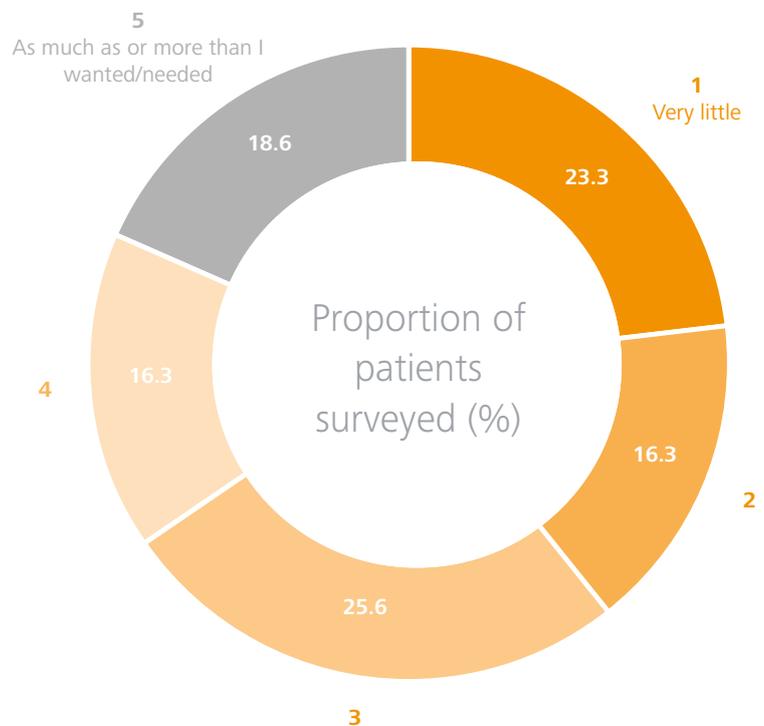
The ability to speak openly about hepatitis C empowers patients to seek support when they need it and to build vibrant patient communities that benefit individuals with hepatitis C, their healthcare team and the wider community.



## Patient organisations play a key role in providing people living with hepatitis C with the information and support they need

More than **80%** of respondents felt that they were given **insufficient information** when they were diagnosed with hepatitis C

Country data based on 43 responses



### Survey findings



- Over 80% of respondents felt that insufficient information was made available to them through their doctor at the time of diagnosis and only 19% said that they received as much as or more than they wanted or needed
- Almost 2 out of 5 (39.6%) were not satisfied with the information they were given when diagnosed
- Only 14% were put in touch with a patient group when they were diagnosed, but almost double that proportion (27.9%) then used patient organisation websites for further information
- The majority of respondents were aware of at least one patient organisation and 58% were members of a patient organisation, significantly above the regional average of 44%

#### What does this mean?

##### Patient organisations can offer invaluable information and support

Most respondents felt unsatisfied with the information they were provided with at the time they were diagnosed, and a disappointingly low number were signposted to the existing, excellent support available through patient groups in Israel.

Patient groups can be the difference between isolation and support, information and community. Healthcare teams could serve their patients much better by connecting them with supportive patient organisations at the time of diagnosis, complementing clinical care and treatment with ongoing support, information and community.

# Driving change in your country to transform the lives of people with hepatitis C

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### 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
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### 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
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### 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
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### 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
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### **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
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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?

"I hope the next  
generation of drugs  
will annihilate the virus.  
I am ready for the next  
round"

"Relief, victory, joy,  
freedom"

"Returning to normal  
life without thinking  
of the future condition  
of my liver"





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World Hepatitis  
**Alliance**