

# HCV QUEST

Global Patient Survey

Key findings



"I feel stigmatized,  
since people consider  
me as a potential hazard, as  
they are not well informed,  
even physicians."

**We asked  
people who are  
living with hepatitis C  
around the world about  
their experiences.  
This report gives their  
response.**

"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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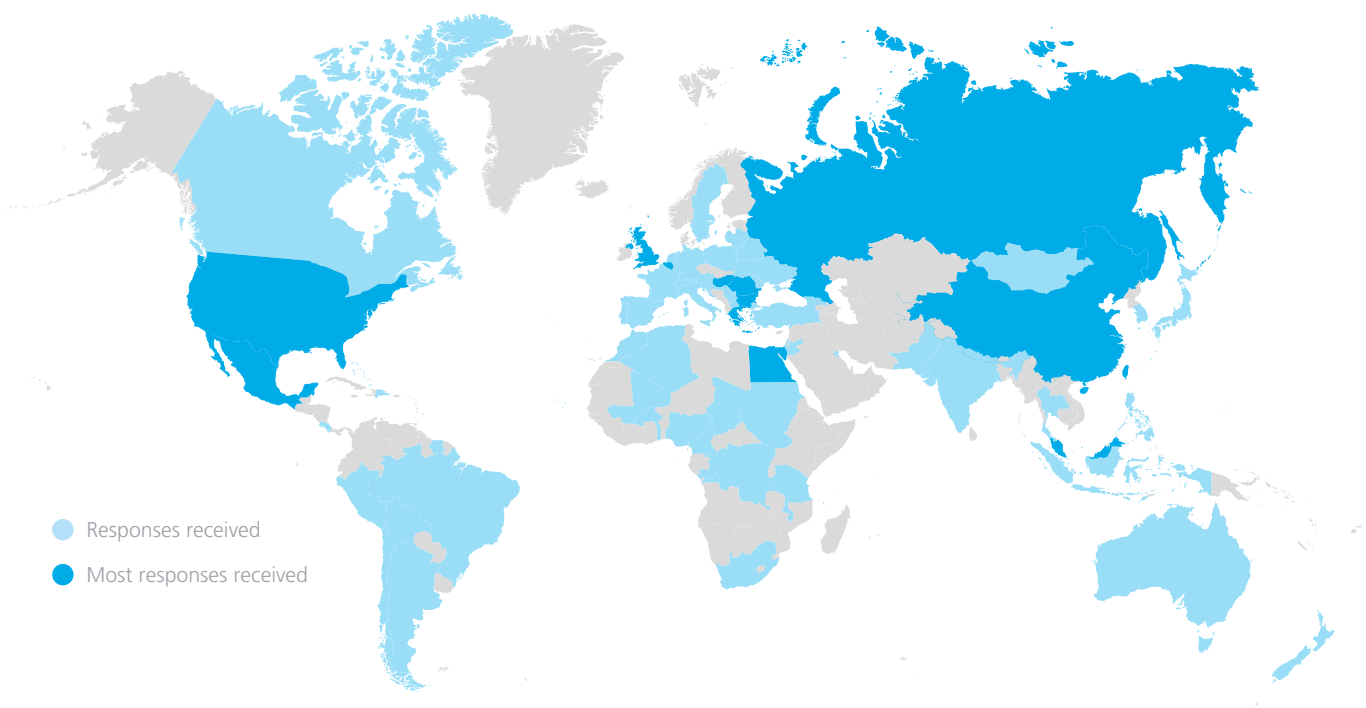
## Introduction from Charles Gore, President, World Hepatitis Alliance

Almost all the information and data available about hepatitis C has come exclusively from clinicians, from epidemiologists and from the pharmaceutical industry. So little information has come from the people living with, and too often dying from, this virus. To address this unacceptable imbalance and ensure the patient voice is truly heard, we created the HCV Quest Global Patient Survey. We surveyed almost 4,000 people from 73 countries on how living with hepatitis C impacts all aspects of their lifestyle, how much they knew before they were diagnosed and their experience of diagnosis, care and treatment.

There was a truly global response. Although there are of course variations from country to country, the key messages are remarkably consistent. At a time when the world is beginning to wake up to the severity of the situation and governments are starting to consider how to address hepatitis C, there is a clear imperative for them to take note of these messages and act accordingly.

What HCV Quest clearly reveals is that not enough is being done by governments to raise awareness, that physicians persistently miss opportunities to diagnose people, that living with hepatitis C and undergoing interferon-based treatment has a greater than appreciated impact on a person's physical, psychological and emotional health, that the impact is too often unappreciated by healthcare professionals in particular and that in general not enough is being done to inform and support patients across the world. Most concerning of all, healthcare professionals are not referring patients to groups that exist to address these very issues. How on earth are we going to prevent new infections, encourage people to get tested and assist people through treatment if adequate information and support is not accessible to those who need it most?

HCV Quest, because it is global and because of the number of respondents, is sending some very clear messages to governments everywhere about the many wasted opportunities – to use World Hepatitis Day to inform those at risk, to diagnose people much earlier because so often they do present with some symptoms and to make better use of patient groups to take some of the burden from the health system. Finally it is telling them that they must do more to ensure that people with hepatitis C have access to interferon-free treatment. They must in fact give them back their lives.





## HCV Quest – around the world in 6 months

- The HCV Quest Survey was developed by the World Hepatitis Alliance (WHA), with help from the European Association for the Study of the Liver (EASL), and translated into 35 languages
- The survey was available online in all languages from July to December 2014, and was also sent in hard copy to patient groups and physicians around the world to distribute
- The survey was promoted via the WHA website and dedicated Twitter and Facebook pages, which generated hundreds of followers
- Responses were translated and analysed, including many thousands of free-text responses sharing insights into the reality of life with hepatitis C
- Every effort has been made to represent survey data faithfully. Where percentages are given, footnotes provide the number of responses per question
- The WHA acknowledges limitations of this type of survey, such as:
  - Access to the internet (online survey)
  - Source of survey
    - People who learned about or were sent the survey via a patient organisation may be better informed than those without contact with a patient group
    - People whose physicians provided access to the survey in their clinics (online or hard copy) may have reported better relationships or more frequent access to healthcare and support than would be represented by a cross-section of all patients
- Throughout the survey, ‘physicians’ refers to family doctors, general practitioners (GPs), and non-specialist doctors. Nurses and specialists/consultant physicians are referenced as such.

“If I was offered a treatment immediately after diagnosis, it would be more likely for me to recover, and now I have had hepatitis for 16 years.”

“To be healed is my dream for a self-confident and happy life.”

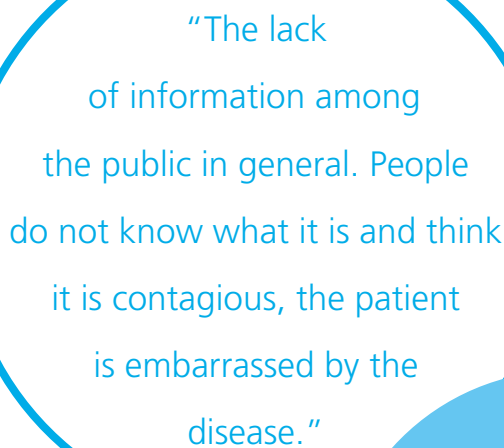
HCV Quest was sponsored by AbbVie in support of the WHA. All content has been developed and approved by the WHA.

## What does it mean to live with hepatitis C?

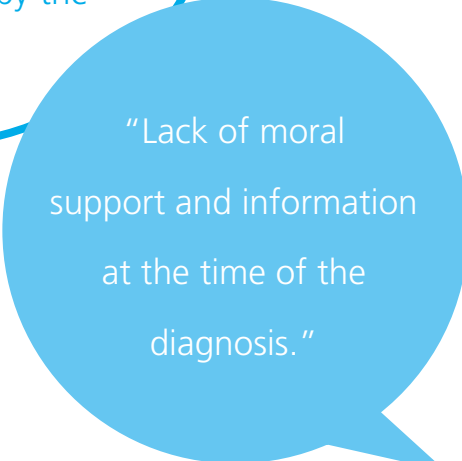
*The HCV Quest survey was designed to shine a spotlight on the experiences of patients around the world and to use insights from people living with the disease to drive awareness of the true burden of hepatitis C.*

*The concerns of people living with hepatitis C and the barriers they face are common across continents and cultures, even with the wide variations between healthcare systems, governments and the socioeconomic circumstances in which they live.*

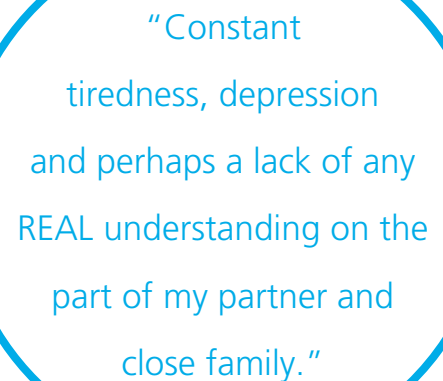
We asked people living with hepatitis C to identify the biggest barriers they have experienced in their fight against viral hepatitis.



“The lack of information among the public in general. People do not know what it is and think it is contagious, the patient is embarrassed by the disease.”



“Lack of moral support and information at the time of the diagnosis.”



“Constant tiredness, depression and perhaps a lack of any REAL understanding on the part of my partner and close family.”

These responses highlight aspects of the true burden of hepatitis C, and the pressing need for coordinated efforts by governments, healthcare providers and patient groups to improve support for people living with the disease.



“The loss of self-esteem, confidence, drive and energy to be able to execute the activities required of a high demand, complicated job.”

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

Cost Depression Lack  
Disease Financial Expensive  
Medicine New Work  
**Treatment**  
Fear Side effects  
Time Drugs Health  
**Interferon**

## Public awareness of hepatitis C: A global priority to drive referrals, diagnosis and support

Hepatitis C is one of the most common causes of liver disease worldwide. [1] Despite the worldwide impact of this chronic disease, its public profile is much lower than other diseases of comparable severity. To help measure global and regional levels of public awareness, HCV Quest explored what people knew about hepatitis C before their diagnosis.

Nearly **7/10** people did not know what HCV was before their diagnosis (Global data based on 3780 responses)



Awareness of hepatitis C before diagnosis among HCV Quest respondents

### Survey findings



**While overall awareness of hepatitis C was low, there were some variations:**

**Pakistan:** around half of respondents to our survey had heard of hepatitis C before their diagnosis

**Brazil:** only 13% were aware of hepatitis C before diagnosis.

**Italy:** two thirds of respondents said they knew about hepatitis C before their diagnosis; the only country where awareness was relatively high.

### FAST FACTS

80–150 million people are living with chronic hepatitis C infection [2]

There is currently no vaccine for hepatitis C [2,3]

In 2013, 700,000 people died from hepatitis C-related disease; [1] the World Health Organization estimates that there has been a substantial increase in deaths related to hepatitis C over the past 20 years [1]

### What does this mean?

**Public awareness of hepatitis C is unacceptably low**

If we are to strengthen measures for prevention and control of hepatitis C, we need to drive radical change in public perception and understanding by finally recognising hepatitis C as a global health priority.

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 2013. Lancet 2015;385:117–71.

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

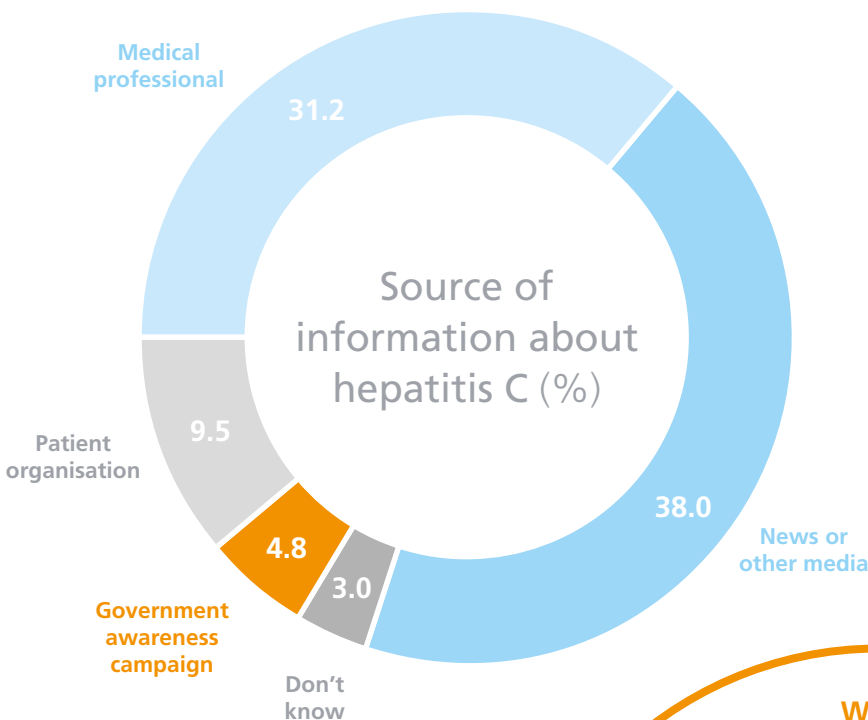
3. World Health Organization (WHO). Guidelines for the screening, care and treatment of persons with hepatitis C infection. Geneva, Switzerland, 2014. Available at: [http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755\\_eng.pdf?ua=1&ua=1.26](http://apps.who.int/iris/bitstream/10665/111747/1/9789241548755_eng.pdf?ua=1&ua=1.26) for 240 causes of death, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. Lancet 2015;385:117–71.





## Government awareness campaigns are not a key source of hepatitis C awareness

Almost **7/10** respondents got their knowledge from the media or from healthcare professionals



**WORLD HEALTH ASSEMBLY  
RESOLUTION WHA63.18**

RESOLVES that 28 July or such other day or days as individual Member States decide shall be designated as World Hepatitis Day in order to provide an opportunity for education and greater understanding of viral hepatitis as a global public health problem, and to stimulate the strengthening of preventive and control measures of this disease in Member States.

*Adopted by all  
WHO Member States*

Only **5%** identified Government awareness campaigns as a source of information

Sources of information about hepatitis C identified by HCV Quest respondents (n=1181)

### What does this mean?

#### Governments must do more to raise the profile of hepatitis C

Fewer than 5 in every 100 people who had heard of hepatitis C when they were diagnosed found their information from government awareness campaigns.

This statistic reveals that governments are failing to uphold their commitment to raising awareness about hepatitis as agreed in World Health Assembly Resolution 63.18, which highlighted the importance of education to drive public awareness of hepatitis C as a global public health problem as long ago as 2010.

Governments have a responsibility to respond to this call to action. They must not forget it, and we must not fail to remind them that inaction costs lives

## Timely diagnosis of hepatitis C: Physician awareness of symptoms is essential

Hepatitis C infection can be difficult to recognise. Many people do not appear to be unwell for years. While screening or testing can detect the disease, the reality is that hepatitis C is often only detected when people have gone on to develop serious or indeed end-stage liver disease.

### Not all people receive best practice care for hepatitis C

**43%**  
(n=3473)

... Were offered a test after describing symptoms of hepatitis C to their physician

Top 5 (for testing for hepatitis C)		Bottom 5 (for testing for hepatitis C)	
1. China	69.0% (n=710)	1. Togo	0.0% (n=10)
2. Malaysia	66.1% (n=112)	2. Netherlands	10.0% (n=10)
3. Egypt	63.7% (n=342)	3. Belarus	16.3% (n=49)
4. Romania	53.5% (n=71)	3. United Kingdom	16.3% (n=129)
5. Pakistan	50.0% (n=16)	5. Israel	16.7% (n=42)

**65%**  
(n=737)

... Are referred to a specialist within 3 months of diagnosis

Top 5 (for referring within 3 months)		Bottom 5 (for referring within 3 months)	
1. Romania	90.5% (n=21)	1. Canada	35.3% (n=17)
2. United Kingdom	72.7% (n=55)	2. Malaysia	50.0% (n=38)
2. Germany	72.7% (n=11)	2. Japan	50.0% (n=20)
4. China	70.6% (n=51)	2. Egypt	50.0% (n=10)
5. Hungary	70.3% (n=37)	5. Australia	50.8% (n=61)



## Survey findings



- Worldwide, almost half of our respondents (47%) considered that they had symptoms that they now believe were due to hepatitis C at the time of their diagnosis.
- Testing rates varied considerably by country\*:

There was a positive picture from parts the Western Pacific. In China, 69% of people were offered a test after reporting symptoms of hepatitis C and in Malaysia this was 66%. However, people in Australia reported a rate of only 25%.

In Europe, too, there were wide discrepancies. 54% of respondents in Romania said they had been offered a test versus 47% in Poland, 30% in Russia, 22% in France and 21% in Austria. North America did little better, with reported rates of only 30% in the USA and 27% in Canada.

Shockingly, just 16% of people reporting hepatitis C symptoms in the UK were offered a test, and this falls even lower in the Netherlands to 1 out of 10 respondents.

In Africa, not a single respondent in Togo said they had been offered a test.

- Globally, 65% of respondents who were diagnosed by a non-specialist physician reported that they were referred to a specialist within 3 months of diagnosis. However, 12% of respondents said that they were referred after 3 years or were never referred.
- Although most people (38%) had no liver damage at the time of diagnosis with hepatitis C, 15% had cirrhosis (with and without complications).

### FAST FACTS

As many as 80% of people don't appear to be unwell at the time of HCV infection [1]

Signs and symptoms can include fever, poor appetite, nausea and vomiting, changes in the colour of their urine and faeces, and jaundice [1, 2]

### What does this mean?

#### Physicians are unaware of key symptoms of hepatitis C

Fewer than half of the HCV Quest respondents who visited their physician with symptoms suggesting hepatitis C said that they were offered a test for hepatitis C. Many reported significant delays in referral to a specialist.

This is important. Healthcare systems around the world may differ in how soon people with hepatitis C can be seen by a specialist – but the ability of physicians to recognise key symptoms and refer promptly should be universal.

Better education of physicians would lead to earlier diagnosis and referrals, resulting in more prompt treatment and care for those affected by the disease. We know that earlier intervention is critical to effective treatment, and would also likely reduce the overall costs involved.

\* Data grouped according to WHO regions <http://www.who.int/about/regions/en/>. The number of respondents (n) for listed countries were, Australia (n=92), Austria (n=61), Canada (n=22), China (n=710), France (n=82), Malaysia (n=112), Netherlands (n=10), Poland (n=51), Romania (n=71), Russia (n=306), Togo (n=10), UK (n=129), and USA (n=226).

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

2. 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)

## Shame and stigma around hepatitis C: Heavy burdens carried by millions

People living with hepatitis C often experience feelings of shame and stigma sometimes because of negative perceptions about how the infection is acquired. While hepatitis C is associated with a culture of drug use in some countries, the reality is that it can be acquired in many ways, including routine medical procedures such as blood transfusions or because of inadequate sterilisation of syringes and needles. [1]

Patients are reluctant to share their diagnosis of hepatitis C (Global data based on 3811 responses\*)

Close family	67.5%	Colleagues	21.4%
Wider family	30.6%	Social media	5.5%
Family friends	20.9%	Patient organisations	16.0%
Friends	35.6%	None of the above	20.1%

\* Respondents could select more than one option

### Survey findings



#### Not disclosing HCV infection was very common in some countries:

In **China**, 75% of 810 respondents reported that they have not told anyone that they have hepatitis C. This is interesting given that more than 65% of people from China reported that their diagnosis had affected relationships.

#### What does this mean?

##### What does it mean to deal with a serious health condition like hepatitis C alone?

Through this survey, people living with hepatitis C have reminded us what we already know too well – that the disease is associated with high levels of stigma worldwide.

Shockingly, almost one third of HCV Quest respondents (32%) said that they had not told close family about their diagnosis, and 1 in 5 respondents had not told anyone.

The burden of living with a disease as serious as hepatitis C can be extremely hard to bear alone. If the cost of confiding in others is too high, this tells us that stigma surrounding the disease is extremely powerful, and that it is likely to be costing people with hepatitis C the support they need and deserve.

Unfortunately, the silence of people affected by hepatitis C can be a form of self-stigmatisation. Open communication allows us to address misconceptions and stereotypes. It also opens up the possibility to reach for much-needed support from friends, family and patient support organisations.

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



## Physical, emotional, psychological: The real impact of hepatitis C

Hepatitis C can seriously affect physical wellbeing, relationships and self-esteem.

### A diagnosis of hepatitis C had an impact on physical, emotional and psychological well being

#### Physical impact



Respondents (n=3580) were asked to rate the impact of hepatitis C on their overall physical health and well being based on a 5-point scale. Shading indicates the 44.1% of respondents who rated the physical impact as 4 or 5.

#### Emotional impact



Respondents (n=3507) were asked to rate the emotional impact of hepatitis C, such as the impact on their romantic and family relationships, based on a 5-point scale. Shading indicates the 37% of respondents who rated the emotional impact as 4 or 5.

#### Psychological impact



Respondents (n=3549) were asked to rate the psychological impact of hepatitis C, such as their self image, future plans, career decisions and feelings of anxiety or depression, based on a 5-point scale. Shading indicates the 49.5% of respondents who rated the psychological impact as 4 or 5.

#### IMPACT KEY

- Significant/very significant
- Little to moderate

## Survey findings



Worldwide, over 44% of respondents said that hepatitis C had a significant effect on their **overall health and wellbeing**.

- In some countries (including Australia, Germany and Japan), well over 60% of people living with hepatitis C said that the disease had a significant or very significant impact on their physical wellbeing.

Around 20% of survey respondents described their diagnosis of hepatitis C as **emotionally stressful**, while around 40% reported that it affected emotional aspects of their life, such as **relationships**.

Almost half of all respondents said that having hepatitis C had a **marked effect on their psychological and mental health**.

### What does this mean?

#### Hepatitis C affects all aspects of a person's life

One in 5 people reported a negative impact of hepatitis C on relationships with friends, partners and colleagues. These are distressing data, offering us a window into the unquantifiable damage caused by this disease.

Importantly, many people living with hepatitis C feel that their healthcare teams do not fully understand its impact on their lives. While around 25% of respondents said that their nurses understood the full impact of hepatitis C, more than 20% felt that their nurses didn't have any understanding at all. The picture is more positive with physicians, with over 35% of respondents saying they felt their physician understood the impact completely.

Healthcare professionals need to demonstrate an understanding of the emotional pressures that can lead to real psychological distress, and do more to signpost people living with hepatitis C to help when they need it.

## Damaged prospects: Educational and work opportunities are affected by hepatitis C

For many people, even those who receive treatment, hepatitis C follows a long course, often lasting for many years. This can mean living with the disease during education and while working. HCV Quest explored perceptions of the impact of hepatitis C on working lives and education.

Living with hepatitis C can have a negative impact on education and work prospects (Global data)

Impact on education (n=1685)	Impact on work (n=3386)
No impact 23.6%	No impact 24.4%
Some impact 12.8%	Some impact 32.0%
Significant impact 7.8%	Significant impact 32.4%

### Survey findings



Worldwide, 20% of respondents said that hepatitis C had affected their education to some degree.

A total of 64% of respondents said that hepatitis C had affected their work; for around half of these respondents the impact was reported to be significant.

Nearly a quarter (24%) of respondents said they'd experienced discrimination at work or in education, or that their prospects had been affected by their hepatitis C, with rates reaching higher than 35% for people from **Austria**, **Germany** and **China**.

### What does this mean?

#### People perceive missed opportunities and discrimination linked with hepatitis C

Around 1 in 4 people reported that hepatitis C had affected their educational or work prospects. This makes for difficult reading.

Perhaps even more alarmingly, almost a quarter of respondents worldwide said that they have experienced discrimination at work or in education because of their condition.

This is a strong and provocative piece of research. This level of discrimination and disadvantage must be addressed – in the home, in the classroom, in the factory, corporate meeting room and everywhere in between.

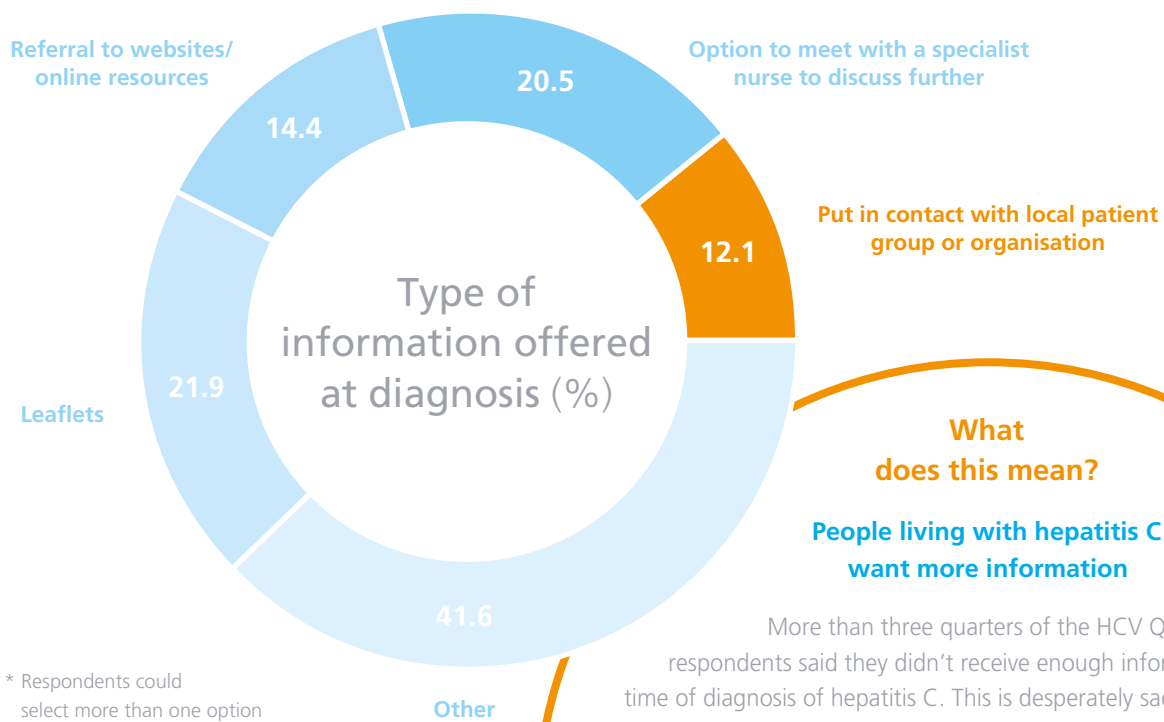
Governments, industry heads, employers and teachers must be made aware of their role in preventing stigma and discrimination from taking hold. Governments need to provide the incentives and resources for them to do so, and as patient groups, we can equip them with the information and support they need to do it effectively.



## Beyond medicine: Patient organisations have a key information and support role to play

Information has benefits for people with hepatitis C, ensuring greater knowledge of the disease and driving behaviours, including testing and willingness to start and maintain treatment. [1] We asked people to tell us about the information they received and their level of satisfaction with the information and support provided.

Only **12%** are put in contact with a local patient group or organisation at the time of hepatitis C diagnosis (Global data based on 3812 responses\*)



\* Respondents could select more than one option

*“I was given nothing. I had to look for information myself”*

*“The infectious diseases doctor explained when he saw me at the appointment but I didn’t know how serious it was, or I didn’t understand”*

*“I looked for a patient association myself”*

*“I was given no information, he said, goodbye and good luck, in an email, with the lab results”*

### What does this mean?

#### People living with hepatitis C want more information

More than three quarters of the HCV Quest respondents said they didn’t receive enough information at the time of diagnosis of hepatitis C. This is desperately sad because patients without information about hepatitis C have a much lower chance of accessing the right help, making the right lifestyle choices and asking the right questions of their physicians.

There is so much in the public domain, from printed resources to links to websites or referrals to supportive patient groups. Whatever the context and budget, there is no reason to leave patients in the dark about their health and their future in this way.

As patient groups, we should challenge ourselves to consider which communities we can identify which are not receiving information, particularly where access to the internet is limited. What can we, individually or together, do to improve this shocking statistic?

1. Shah HA and Abu-Amara M. Education provides significant benefits to patients with hepatitis B virus or hepatitis C virus infection: a systematic review. Clin Gastroenterol Hepatol 2013;11:922-33.

# HCV Quest Global Patient Survey

## Many patients are not aware of hepatitis C patient organisations (Global data based on 2974 responses)



Shading indicates the proportion of patients who were not aware of hepatitis C patient organisations in their country

## Patients who are aware of hepatitis C patient organisations rate them highly (Global data based on 2045 responses)



Respondents were asked to rate the level of support offered by their patient organisation, where 5 is the highest rating, 'Active: I see the organisation involved in supporting patients with hepatitis C'

## Survey findings



Almost one third of respondents (31%) said that they were not aware of any patient organisations offering information and support about hepatitis C.

Awareness varied by country:

- In **Germany** and **Bulgaria**, over 40% of respondents told us that they were unaware of patient organisations
- In **Russia** and the **Ukraine**, over half of respondents didn't know about hepatitis C patient organisations.

## FAST FACTS

Around the world there are a large number of patient organisations operating globally, regionally, at country and local level to provide information and support to people with hepatitis C

### What does this mean?

**Patient organisations can offer invaluable information and support... so why don't people know about them?**

Patient organisations can offer a lifeline to people with hepatitis C. They can be the difference between isolation and support, information and community.

Around one third of people with hepatitis C aren't aware of hepatitis C patient organisations, and only 12% of respondents were told about patient organisations by their healthcare teams at the time of diagnosis. This is concerning and may reflect a lack of knowledge about appropriate information and support resources by healthcare professionals.

What it definitely means is that the resources of patient groups are needed by people currently outside our reach. Every person who knows about a patient group has the potential to benefit themselves and their communities by sharing and applying knowledge and support.

Furthermore, the responses clearly indicate that there is a need for healthcare professionals to inform people of patient groups at the time of diagnosis. Patient groups are a valuable resource that could benefit healthcare teams by providing people with hepatitis C with more information and more time.

We need to challenge ourselves to be smart about the way we are reaching out to people living with hepatitis C and ensure these methods work for their different age groups, circumstances and personal preferences.





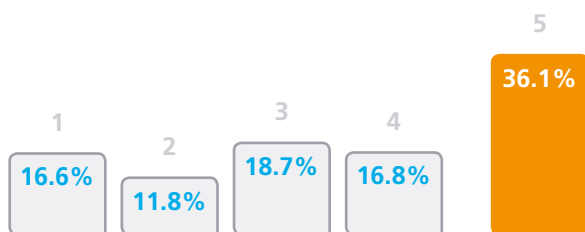
## Treatment decisions: People living with hepatitis C want to be actively involved

The degree to which people want to contribute to decisions about healthcare is an individual choice. Some people want to be actively involved. Others want to be informed but ultimately want decisions to be made by a specialist or expert. There is no right answer. However, understanding perspectives about decision making can help to ensure that discussions and consultations take account of the individuals' preference. HCV Quest asked people living with hepatitis C about their current and preferred involvement in treatment decision-making.

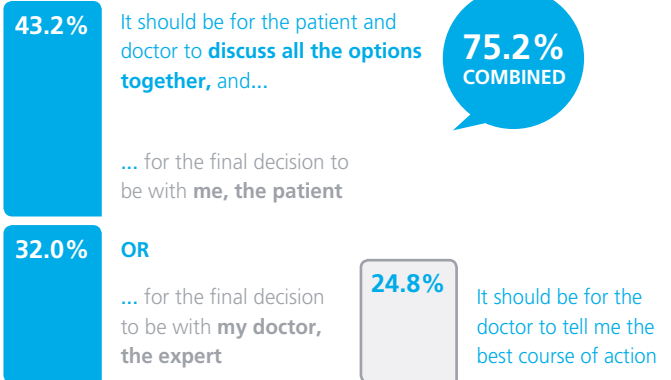
The majority of patients feel that they should be involved in decisions regarding their treatment, yet only the minority are regularly consulted

### Patients' involvement in treatment decision making (Global data based on 3726 responses)

1 = Not at all  
5 = Consistently consulted and involved in decision making



### Who should make decisions about the treatment strategy (Global data based on 3768 responses)



### Survey findings



It is reassuring that overall, only 17% of respondents said they had not been involved in making decisions about their treatment; however, the picture varies around the world.

- In **Italy**, almost 42% of 12 respondents said that they were not involved in treatment decisions.
- By contrast, in **Argentina, Brazil, Japan, Mexico** and **South Korea**, over 60% of 293 respondents said they were consistently consulted over treatment decisions.

### What does this mean?

#### My health, my treatment... whose decision?

Our survey suggests that the large majority of people with hepatitis C (over three quarters of respondents) believe that they should be involved in decisions around their treatment and care.

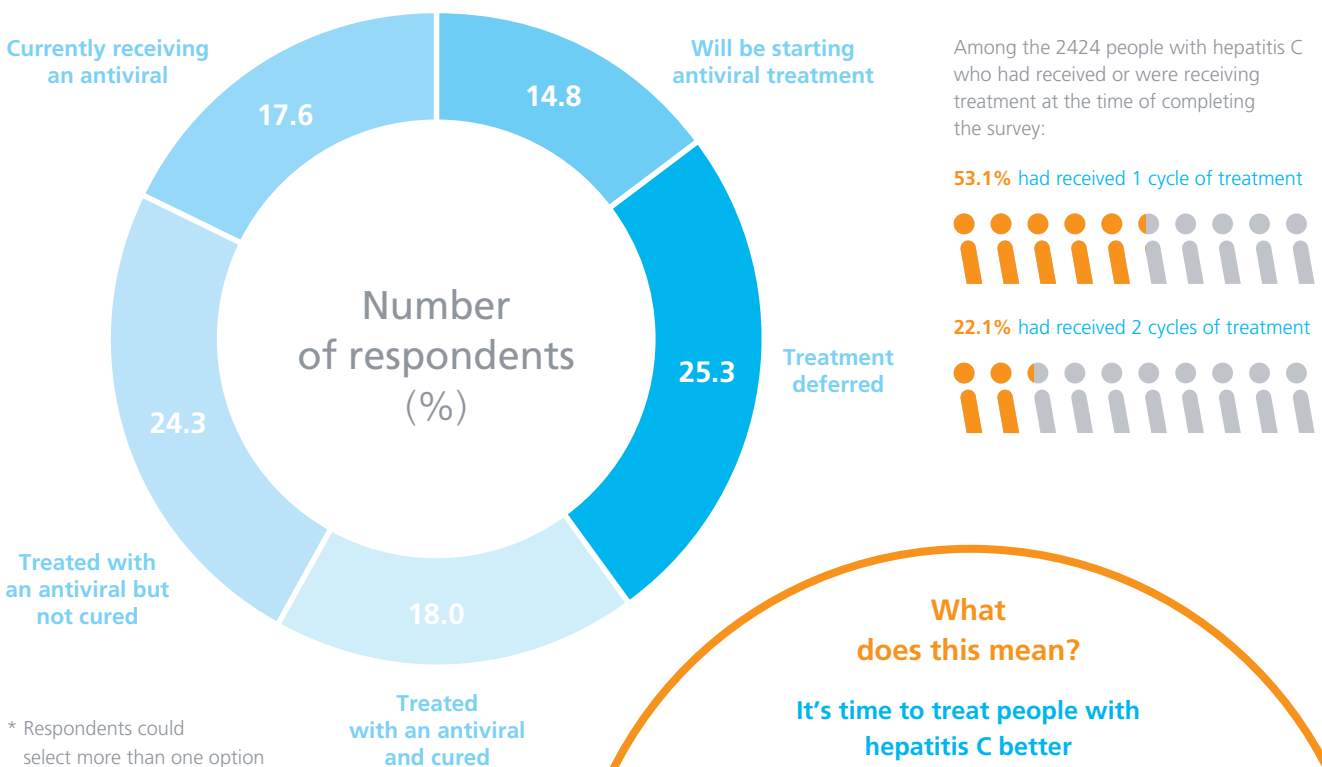
People living with hepatitis C want a participatory role. We know that healthcare systems that promote partnership and dialogue between patients and physicians result in benefits such as improved adherence to medications, which may in turn mean that treatment is more effective.

Including people in discussions about their treatment and care is fundamental to good healthcare. It makes sense for patients and the healthcare system – and we must find ways to do this better.

## Complex treatments: Experience of treatment is not all positive

Making decisions about treatment can be confusing – the treatment options are complex and side effects can be significant. For many individuals with hepatitis C, regular monitoring of their condition forms a key part of disease management to detect and diagnose early signs of chronic liver disease. HCV Quest asked people with hepatitis C who have had, or are currently receiving treatment, about their experiences.

### Patients' current treatment status (Global data based on 3812 responses\*)



### Survey findings



Around 18% of respondents had been treated with an antiviral and consider themselves cured.

A total of 37% of respondents who said that they had received interferon treatment reported that it had been successful.

**What does this mean?**

**It's time to treat people with hepatitis C better**

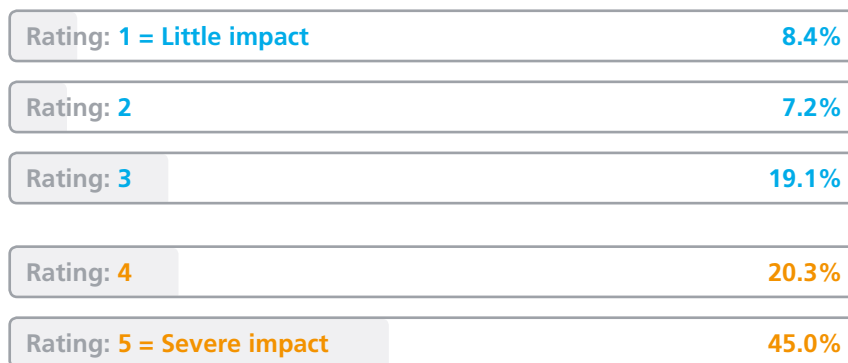
People living with hepatitis C around the world have very diverse treatment experiences. Some have undergone formal therapies using interferon or other medications; others have tried alternative medicine. No one option has so far offered a universal cure.

When discussing treatment experiences, people talk about expense, access problems and treatment-related sickness. Perhaps this is part of the reason why 35% of respondents had not received treatment at all.

We need to keep up our calls for affordable, accessible treatments that offer a better chance of clearing hepatitis C. This would transform millions of lives.



The majority of patients feel that treatment for hepatitis C has a considerable impact on their lifestyle and general health (Global data based on 2362 responses)



## FAST FACTS

When treatment is necessary for hepatitis C, the goal is sustained virological cure

Current treatment typically involves combination antiviral therapy with interferon and ribavirin [1], but alternative treatment options with higher cure rates and fewer side effects are emerging

## What does this mean?

### Treatment benefits from diverse forms of investment

Many people undergo treatment more than once, but almost 85% who had undergone treatment for hepatitis C reported that it had a moderate to severe impact on their lifestyle or health. For many, clearing hepatitis C is not an easy ride.

Some people are able to cope with treatment symptoms and side-effects, while others find they have to interrupt their course of treatment because of how sick they feel.

Where treatment courses may continue to be challenging, governments and healthcare payers should recognise the huge value of supporting people with hepatitis C as they take on this battle.

Patient groups can provide expertise and encouragement, which we know can increase adherence to treatment and increase its success rate. It's a partnership that really pays.

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

## Choosing to be monitored rather than starting on treatment

*For many individuals with hepatitis C, regular monitoring of their condition forms a key part of disease management. Monitoring is performed in order to detect and diagnose early signs of chronic liver disease. [1]*

### Survey findings



Over 60% of the 1733 respondents who had been offered treatment but were not being treated at the time of the survey believed they were being properly monitored.

However, this statistic suggests that almost 40% of respondents did not feel that their disease was being properly monitored.

### What does this mean?

#### If we don't monitor and support people with hepatitis C, we all lose

If 40% of people with hepatitis C feel their condition is not being properly monitored, we have a serious problem.

Better and more open communication with healthcare professionals, including physicians, nurses and broader support teams can help to give reassurance, and provide opportunities for people to ask questions, raise concerns or discuss symptoms they may be experiencing.

Perhaps of greater concern, these data may well be suggesting that, at least in some countries and regions, monitoring is simply not adequate and does not provide people living with hepatitis C with the support and help they need to deal with symptoms, physical, emotional or psychological – or to be able to participate fully in their education, home and working lives.

With the growing understanding among healthcare professionals about the broad and life-altering impact of hepatitis C, patients must not be left to wrestle with their condition alone, or we all lose out. The human, economic and social costs of allowing this disease to develop unchecked are simply too high.

"I am going through therapy. Cure means happiness for me."

"The virus is no longer active, but my liver was damaged so I need annual tests to prevent possible cancer."

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



## We have the opportunity to change lives... and we should take it

"I am full of  
confidence, and the  
future will be  
better."

*Despite the everyday challenges faced by people living with hepatitis C, many remain optimistic about their disease and are hopeful for their future.*

### We asked people what a cure would mean for them. This is what they told us.

*"I am going through therapy. Cure means happiness for me."*

*"The virus is no longer active, but my liver was damaged so I need annual tests to prevent possible cancer."*

*"It means LIVING!!! Fulfilling dreams and plans! Today I am only existing, having many limitations."*

*"A great deal. A huge load lifted mentally, and physically and emotionally."*

*"A total transformation, an end to symptoms of chronic fatigue and depression, the ability to work, form intimate relationships... a full life."*

*"I would regain my physical and mental strength and vitality. I would be the person I used to be."*

*"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."*

*"Not seeing the fear of contagion in people's eyes."*

"Living a  
normal life again, at  
last. Living again... after a  
15-year battle and  
3 different medications."

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 word cloud of responses to the question '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?'. The words are arranged in a circular shape, with 'Life' and 'Cure' being the largest and most prominent. Other significant words include 'Health', 'Treatment', 'Relief', 'New', 'Happiness', 'Family', 'Hope', 'Quality', 'Mental', 'Improvement', 'Better', 'Live', 'Liver', and 'Virus'.

Liver Family Happiness  
Hope New Relief  
Quality Life Cure Mental  
Health Improvement  
Better Live  
Treatment  
Everything Virus



## Join the fight against hepatitis C: use HCV Quest as your toolkit for change

*The HCV Quest data is a rich resource. You can draw on its findings to drive change in your area that will transform the lives of people affected by hepatitis C.*

*If we can increase awareness of hepatitis C, we will open the way for more people to seek early testing. If we can show policy makers the true burden of hepatitis C – physical, mental, emotional and economic, we can campaign effectively for increased access to more effective treatments. If we talk about hepatitis C, we can allow others to join the conversation, tackling stigma. Together, we can lift the global burden of hepatitis C*

**Here are some suggestions for how patient groups, advocates and civil society can use the data to enact change. Couple global figures with data specific to your country in your advocacy work.**

**1. “[The biggest barriers are] constant tiredness, depression and perhaps a lack of any REAL understanding on the part of my partner and close family”**

Living with hepatitis C means dealing with a debilitating disease which is poorly understood, often with insufficient access to information.

What can you do?

- Approach the media with data and quotations from the survey to highlight the debilitating effects of hepatitis C
- Post key facts and findings on your social media and or websites you use, encouraging others to share insights

**2. Fewer than 5% of respondents had heard of hepatitis C from government campaigns.**

Public awareness of hepatitis C is low – despite World Health Assembly Resolution WHA63.18.

What can you do?

- Hold governments accountable to WHA63.18, in which they committed to improve public awareness
- Offer to partner with governments for World Hepatitis Day

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# HCV Quest Global Patient Survey

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### **3. Fewer than 50% of respondents who visited their physician with symptoms of hepatitis C were offered a test.**

Timely diagnosis matters, and it depends on both public and physician awareness.

#### What can you do?

- Urge governments to improve awareness of and resources to tackle hepatitis C among healthcare professionals

### **4. 1 in 5 respondents had not told anyone about their hepatitis C.**

Shame and stigma are heavy burdens for people with hepatitis C.

#### What can you do?

- Use the data to highlight the devastating effect of stigma to governments and pressure them to tackle this through awareness campaigns
- Encourage patients to come forward and talk to the media and inspire the media to run sympathetic stories

### **5. Almost half of all respondents said that having hepatitis C had a marked effect on their psychological and mental health.**

Hepatitis C affects a person's physical, mental and emotional health.

#### What can you do?

- Set up a patient support group in your area and consider establishing a helpline

### **6. 1 in 4 respondents experienced discrimination at work or in education because of their condition.**

People living with hepatitis C find their education and work lives are impacted by the disease.

#### What can you do?

- Lobby governments to tackle discrimination through specific anti-discrimination legislation
- Become a member of WHA to learn from other members who have successfully tackled discrimination in the workplace in their countries
- Challenge pre-conceptions about hepatitis C, replacing prejudice with real data and insights and refuse to support negative attitudes to hepatitis C in your school or workplace





**7. Only 12% of respondents were told about patient organisations by their healthcare teams at the time of diagnosis.**

Patient organisations are under-used, but they have a key role to play in supporting people living with hepatitis C.

**What can you do?**

- Make sure doctors' surgeries and hospitals have patient group contact details and information
- Build relationships with healthcare professionals so they understand the value of referring patients to patient groups
- Help others to access available resources, including patient organisation websites and hubs, which can offer a wealth of much needed support and information

**8. Over three quarters of respondents believe that they should be involved in decisions around their treatment and care.**

People with hepatitis C want to be actively involved in decisions about their treatment.

**What can you do?**

- Work with physician and nurse associations to persuade them to see the value of a more balanced patient/healthcare professionals relationship

**9. A total of 47% of respondents who said that they had received interferon treatment reported that it had not been successful.**

Treatment is expensive, can be hard to tolerate and doesn't always result in clearing the virus.

**What can you do?**

- Lobby governments to increase access to new medicines – by providing better treatment options, we can grant more people the opportunity of cure

**10. "What would a cure mean to you?" "LIFE."**

People with hepatitis C say that cure would mean new life.

**What can you do?**

- Help governments and healthcare decision-makers where you are understand what it really means for a person to be free of hepatitis C – liberation from ill-health, fear and stigma and the freedom to move into a healthy, productive future.

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# HCV Quest Global Patient Survey

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## Thank you!

**A huge thank you from the World Hepatitis Alliance to all the people who gave of their time and completed the HCV Quest survey.**

Every contribution now forms part of a powerful tool to change the way the world views hepatitis C, which can now be harnessed by patients, patient groups and advocacy networks all around the world.

Thanks also go to the many hepatitis C and viral hepatitis patient support organisations and physicians who helped to share this survey through their networks, on social media and in healthcare settings, and who continue to support people living with hepatitis C every day.

Your tenacity, dedication and generosity in joining the HCV Quest made it possible to gain these insights, and we hope they will be valuable to you and your colleagues.

Country	No. of respondents	Country	No. of respondents	Country	No. of respondents
Algeria	2	Hungary	233	Russia	314
Argentina	38	India	2	Slovenia	1
Australia	93	Indonesia	5	South Africa	1
Austria	70	Israel	43	South Korea	18
Bahamas	2	Italy	12	Spain	52
Belarus	49	Japan	81	Sudan	1
Belgium	128	Jordan	1	Sweden	8
Bolivia	2	Kuwait	1	Switzerland	1
Brazil	65	Lithuania	8	Thailand	1
Bulgaria	150	Luxembourg	1	Togo	10
Burkina Faso	1	Macedonia	7	Turkey	1
Cameroon	2	Malaysia	131	Ukraine	26
Canada	22	Mali	2	United Kingdom	135
Cape Verde	1	Mexico	114	United States	232
Chad	2	Mongolia	2	Andorra	1
Chile	8	Morocco	1	Georgia	2
China	830	Nepal	2	Latvia	1
Congo, Democratic Republic	1	Netherlands	11	Malawi	1
Costa Rica	3	New Zealand	6	Moldova	3
Croatia	8	Nigeria	9	Romania	107
Dominican Republic	2	Pakistan	16	Serbia	3
Egypt	389	Peru	2	Surinam	1
France	84	Philippines	1	Tanzania (Zanzibar)	1
Germany	24	Poland	52		
Greece	110	Portugal	21		
				<b>Total</b>	<b>3771</b>

