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 summarises responses of 93 people from Australia, with insights into the experiences they shared and pertinent comparisons with regional findings.

For the purposes of this report, Australia is defined as part of the World Health Organization (WHO) Western Pacific Region, and has been contrasted against responses from other nations with similar economic situations, such as France, the United Kingdom (UK), and the United States of America (USA).

“My doctor doesn’t know anything about hep c and seems totally uninterested. I went to a liver clinic, the specialist told me nothing”

“The interferon-based treatment is so hard and debilitating, seeing many of friends go through it has completely made me unwilling to do it”

“I get very depressed at times as I feel my future is unknown”
Public and physician awareness of hepatitis C is low

More than 3 in 5 respondents did not know what hepatitis C was before their diagnosis.

Only 1 in 4 respondents were offered a hepatitis C test on reporting hepatitis C symptoms to the doctor.

Survey findings

- In Australia, only about 39% of those surveyed said they knew what hepatitis C was before their diagnosis. Awareness of hepatitis C is generally very low, with a global average of 31% awareness pre-diagnosis among HCV Quest respondents. Countries analysed for comparison had slightly poorer awareness than Australia, such as France (24%), UK (30%) and USA (37%).
- People who were informed about hepatitis C prior to diagnosis heard mainly through news and media, such as television and radio (22%), medical professionals (22%) or government campaign (11%). While government campaigns are more successful than the global average, there is still much work to be done to reach more people with high quality information about hepatitis C.
- Only a quarter of respondents were offered a hepatitis C test on reporting symptoms to their doctor.
- Just 60% of respondents diagnosed by their family doctor were referred to a specialist within 1 year – compared with UK (91%), France (75%) and USA (73%). However, a further 10% waited up to 3 years and 28% waited longer than 3 years or never saw a specialist.

What does this mean?

General awareness of hepatitis C is unacceptably low

The government is not doing enough to fulfil its commitment to World Health Assembly Resolution 63.18 to use World Hepatitis Day each year to raise awareness.

Increasing awareness among doctors is essential as many doctors are missing symptoms and opportunities for testing. Referrals into specialist care are an area of concern: the proportion of people who are never referred to a specialist in Australia (10%) is worse that the global average of 6% and compares poorly against countries like China and Japan in the same region, where everyone who had been diagnosed by a family doctor said they had been referred to specialist care for their hepatitis C.
Patient support

Diagnosis: patients are not adequately informed

Over 50% of respondents said ‘very little’ information was made available to them through their doctor when they were diagnosed.

Survey findings

• At the time of diagnosis, many respondents were offered information leaflets (35%) and given the option to meet with a specialist nurse to discuss further (26%). Only 9% were put in contact with local patient group or organisation, in line with findings in France (12%), UK (9%), and USA (9%)

• A third of the respondents were ‘not at all’ satisfied, and a further 17% were not satisfied (rating of 2 out of 5), with the level of help and advice they received when they were diagnosed. Only 15% said they had been very satisfied with the level of help and advice they received.

• Since diagnosis, nearly all respondents (99%) in Australia had looked for further information. The main sources of information used were specific websites (80%), search engines (71%), patient organisation sites (37%) and National Health Service (NHS) or government websites (36%)

• The majority (56%) of respondents in Australia felt they were not sufficiently prepared for the side-effects of their interferon-based treatment

• Nearly half of the respondents felt their healthcare professionals communicated well (ratings 4 or more out of 5) with them, with 19% having described communication as ‘exemplary’

What does this mean?

Access to information available through doctors at the time of diagnosis is poor in Australia

Almost all patients have looked for further information through websites and search engines. Although healthcare professionals’ communication with patients was mostly rated well, many respondents thought the level of help and advice they received was not satisfactory. Additionally, many felt they had not been sufficiently well prepared for the side effects of their interferon-based treatment.

Unfortunately, very few patients were put in touch with patient organisations by their healthcare teams. This is despite the wish for this support among patients, with more than a third of respondents saying they had proactively sought out patient groups online.

Patient organisations and local support groups can be a great source of reliable information. If doctors do not refer their patients to these groups, they are simply wasting this important resource.

FAST FACTS

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

Around 314,000 adults (1.7%) in Australia 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]
**Hepatitis C has a significant impact on people’s lives**

Over **90%** of respondents felt treatment has a moderate-to-severe impact on their lifestyle and general health.

Survey findings

- Many patients felt their hepatitis C had affected their work (46%) and education (13%) significantly. Only 22% felt it had not affected their education or work, which is low compared with UK (32%), France (33%) and USA (49%).
- About a fifth of respondents felt they had suffered discrimination at work or in education and over half said they would feel uncomfortable talking about their hepatitis C with their boss or colleagues or with staff at their school/university.
- 62% of respondents felt hepatitis C treatment had a severe impact on their lifestyle and/or general health (vs. the regional average of 40% at this severity) and only 5% felt it had little or no impact.
- Few respondents felt their physicians (22%) and nurses (23%) completely understand the full impact of hepatitis C has on their life.

**What does this mean?**

**Most respondents felt hepatitis C has affected their work or education**

Many admitted they were uncomfortable discussing the disease with work or school or university colleagues, and a significant proportion felt they had suffered discrimination because of their hepatitis C at work or in education.

Many respondents thought hepatitis C treatment had a severe impact on their lifestyle and health. However, very few patients felt their doctors and nurses fully understood the impact the condition has on their life.

Governments and healthcare payers should recognise the huge impact of both the disease and its treatment on relationships, lifestyle and health and working life, and the value of supporting people with hepatitis C as they take on this battle.

Patient groups can provide expertise and encouragement, which we know can support adherence to treatment and increase its success rate.
Patients want to be more involved in decision making

Australians believe it should be for the patient and doctor to discuss all the options together

Survey findings

• Many respondents (44%) in Australia do not have an agreed treatment plan with their healthcare professional – more than in the USA (32%), UK (25%) and 22% (France)

• 42% of respondents in Australia felt they have been consistently consulted and involved in decisions around their treatment options. However, 14% felt they had not been involved in decision making at all, compared with the 17% global average

• Very few (2%) respondents felt their doctor should choose the best course of action for their treatment alone; 79% felt the patient and doctors discuss all the options together with the final decision to be made by the patient, versus 25% who felt the final decision should be for their doctor

• Of the 29% of respondents who had been advised that they were not eligible for current treatment options, three quarters said they were not comfortable with this decision

What does this mean?

Many patients do not have an agreed treatment plan with their healthcare professional

The majority of patients would like to discuss their treatment options with their doctors. However, many felt they have not been consistently consulted or involved in that decision and some (14%) felt they had not been consulted at all.

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.
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?

“My world would be flipped to the right way up because I’m worried all the time and it seems like forever to get the treatments”
“If treatment was made available to me - I feel I could hopefully recommence my work life - or at least be able to expand my capabilities”

“A miracle, but not just for me, for my family. I would not have to worry anymore about anyone rejecting me out of fear of infection again”
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