

HCV QUEST

Global Patient Survey

Country-Specific Report

Romania





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 107 people from Romania, with insights into the experiences they shared and pertinent comparisons with regional findings.

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

“The biggest barrier I have faced in the fight against viral hepatitis is... I cannot have access to all drugs available in other countries, I am scared that I could die, I fear that I will not be able to find work”

“The biggest barrier I have faced in the fight against viral hepatitis is... The fact that no psychologist was there to help me and that I had to wait for a better treatment”

“The biggest barrier I have faced in the fight against viral hepatitis is... Lack of communication at all levels. There should be more medical visits for patients”

Low public awareness of hepatitis C – a hidden burden for patients

Almost **two thirds** of respondents did not know what hepatitis C was before diagnosis



Country data based on 101 responses

Survey findings



- Individuals who had heard about hepatitis C generally received information from a medical professional (42%) or through the media (TV, radio, newspapers) (39%)
- Government campaigns were not successful, reaching none of the respondents
- Only 10% of respondents said they were given as much information as (or more than) they wanted/needed at diagnosis
- Few individuals with hepatitis C feel comfortable sharing their diagnosis with family and friends. Less than 24% of respondents said they had told their close family members, only 7% had told friends. 53% had told no one at all, easily the highest rate in Europe

FAST FACTS

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

Around 595,000 adults (3.2%) in Romania 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]

What does this mean?

Public awareness of hepatitis C in Romania needs to be raised. Current public education activities by the Romanian government are not successful and more investment is needed to support public understanding of hepatitis C

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.

Stigma is a significant issue, with over half of respondents keeping silent about their diagnosis. Governments must do more to combat this.

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. 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 infection. Geneva, Switzerland, 2014. Available at: 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.



Physician awareness of hepatitis C symptoms is key to timely diagnosis and referral

Physicians in Romania respond more proactively to hepatitis C symptoms than physicians in other European countries

If you told your doctor about these symptoms, were you offered a hepatitis C test?

Yes	53.5%	No
-----	-------	----

Doctors (%) referring patients with symptoms of hepatitis C (top 5 in Eastern Europe)
Country data based on 71 responses

If you were diagnosed by a family doctor (non-specialist), how much later were you referred to see a specialist? Alternatively, if you were diagnosed by a specialist, please indicate this below.

Never	0%
-------	----

Within 3 months	90.5%
-----------------	-------

Within 1 year	9.5%
---------------	------

Within 3 years	0%
----------------	----

Longer than years	0%
-------------------	----

I don't know	0%
--------------	----

Patients (%) first seen by a family doctor and referred to a specialist within 3 months (top 5 in Europe)
Country data based on 21 responses

Survey findings



- Many more patients in Romania with symptoms suggestive of hepatitis C are offered a hepatitis C test than in the other European countries used for comparison
- Almost two thirds of those with hepatitis C in Romania had some liver disease at diagnosis
- The levels of help and advice given at diagnosis are variable across Romania, however, 41% are given the opportunity to meet with a specialist nurse and 43% are directed to the internet for further information
- Two thirds of respondents felt that their physician "understood" or "fully understood" the impact of hepatitis C on their life
- More than two thirds of respondents changed their lifestyle after diagnosis

What does this mean?

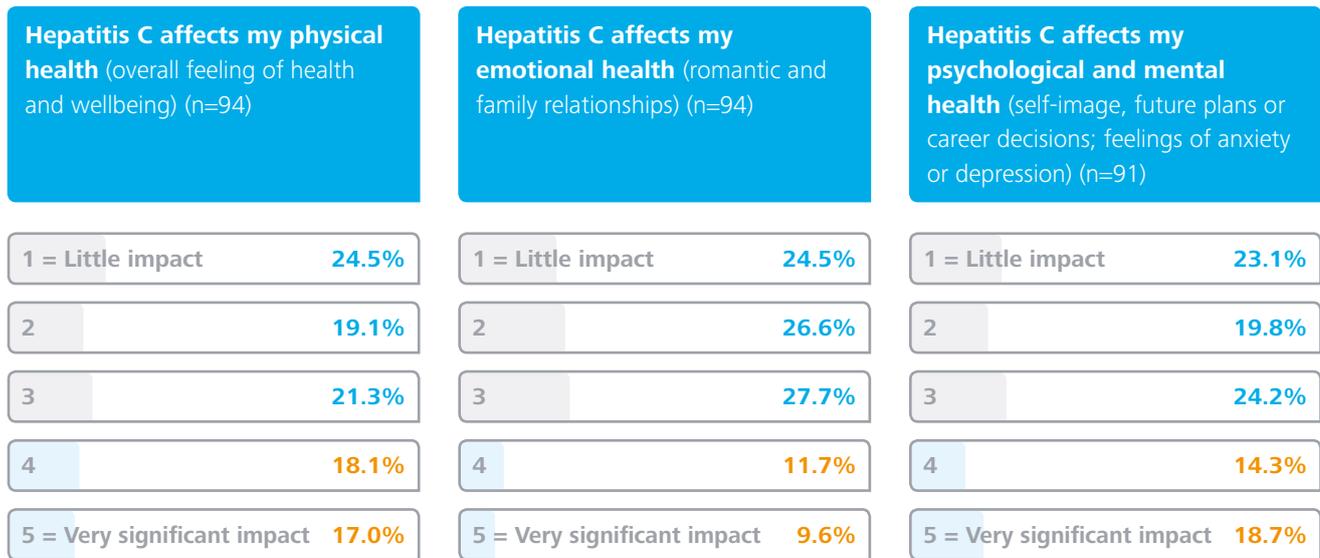
The relatively high level of awareness among healthcare professionals needs to go alongside increasing public awareness

Diagnosis is still late for many people and more emphasis needs to be put on early diagnosis, especially as most of those diagnosed make positive lifestyle changes as a result.

Living with hepatitis C – a severe impact on patients’ physical, emotional and psychological well being

Hepatitis C affects various aspects of an individual’s life, both personal and professional.

Patients’ **physical, emotional and mental health** is affected by living with hepatitis C



Data showing impacts rated as “significant” or “very significant”. 35% of patients selected this level of impact for their physical health; 22% for their emotional health (such as romantic and family relationships) and 33% for their mental health (including aspects such as self-esteem, anxiety and depression).

Survey findings



- Few individuals with hepatitis C (30%) are referred to a patient organisation after diagnosis
- A significant number of patients proactively search for information themselves on search engines (46%) or specific websites (25%)
- Most people with hepatitis C (87%) rated support from patient organisations highly
- Around 13% of respondents said their diagnosis had had a “strong” or “very strong” impact on the relationship with their partner. 14% rated the same level of impact on their family relationships and 11% on their relationships with friends.
- Two thirds of the respondents felt that hepatitis C had affected their work and/or education, either to “some degree” or “significantly”

What does this mean?

We need to capitalize on the relatively high profile of patient support organizations in Romania, and encourage more individuals to make use of the support they offer. This is particularly important given the significant negative impact that hepatitis C has on the lives of many

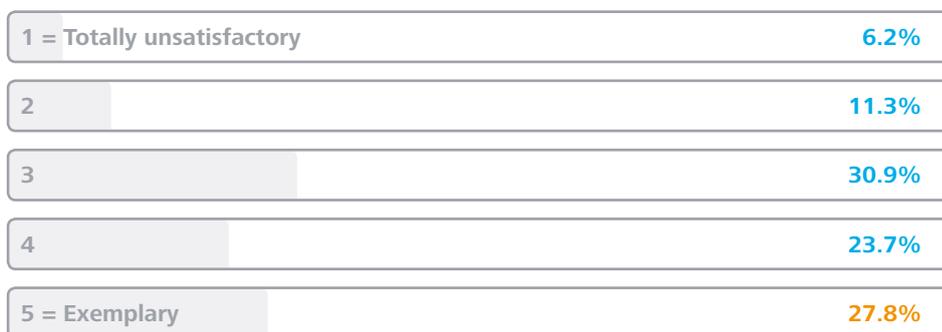
Many individuals are keen for knowledge and are proactive in finding information for themselves, from a variety of sources and around a variety of topics.



Healthcare professionals – Inconsistent levels of communication and shared decision making with patients

When asked how well healthcare professionals **communicated** with patients in writing, during consultations or over the phone respondents in Romania gave variable responses

Overall, how well do your healthcare professionals communicate with you, in writing, at consultations or over the phone? Please rate 1–5
(1 = Totally unsatisfactory; 5 = Exemplary)



Score 1 (totally unsatisfactory), score 5 (exemplary); based on 97 respondents.

Survey findings



- Communication between patients and healthcare professionals is variable throughout Romania, with just 28% of individuals saying it is exemplary; 17% said it was poor or totally unsatisfactory
- More than three quarters of respondents (77%) have talked to their healthcare professional about new treatment options
- Shared decision making around treatment options is also inconsistent across the country, with only just over one third (34%) of respondents saying they had been consistently involved in decision-making
- Most patients said they felt comfortable asking questions about their condition and its treatment with their specialist physician (59%) or specialist nurse (20%) but 15% said they did not feel comfortable asking their questions to any members of their healthcare team
- 75% (of respondents) said they had access to a doctor or specialist they trusted as an authority on hepatitis C

What does this mean?

Individuals living with hepatitis C in Romania experience inconsistent degrees of communication with their healthcare professional, and there is clearly work to do in this area

It is vital that we encourage healthcare professionals to improve their communication skills, both written and oral, and to invite patients to be part of discussions about their treatment options. Allowing people with hepatitis C to be as involved as they want to be is likely to promote good co-operation around the management of hepatitis C.

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... being born again”

“For me, cure would mean... there are no barriers”

“For me, cure has meant... that I can live a normal life again. That I can be part of society without being discriminated against”



HCV Quest was supported by sponsorship from AbbVie

World Hepatitis
Alliance