

WEBINAR 2: How to Interpret and Leverage Results for Effective Advocacy: HCV Quest Global Patient Survey

The second webinar in the *'Tools for Change'* series titled, *'How to Interpret and Leverage Results for Effective Advocacy: HCV Quest Global Patient Survey'* was held on the 10 March 2016 and attracted participants from 15 different countries around the world. The webinar discussed how data from surveys can be a powerful advocacy tool with which to encourage governments to do more in the area of viral hepatitis. It also introduced the HCV Quest Survey and HCV Quest Toolkit, showcasing how the former is as an example and highlighting the knowledge gained from this survey is relevant for any advocacy groups wishing to carry out similar surveys in the future.

The following panellists shared insights on how to effect real, on-the-ground change:



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Key Learnings

Use Data as a Tool

Collecting information through surveys can be easy and inexpensive to do. The data collected can be used in advocacy efforts to urge governments to act more in the area of viral hepatitis. Statistics are vital in validating messages that patients are already articulating.

Engage Patients

Encouraging patients to respond to surveys will help improve the level of service they receive from their local healthcare systems in the future, and improve understanding of the disease among healthcare professionals and the general public.

Highlight the Patient Voice

Patient surveys offer the rare opportunity for the patient community to voice their opinions and experiences. HCV Quest was the first of its kind to provide this opportunity to hepatitis C (HCV) patients.

Highlight Unmet Needs

Surveys of this kind can sometimes highlight areas of importance that are currently not receiving the attention required, for example, it was widely accepted by hepatitis patients in Greece that hepatologists didn't spend enough time with them, especially around the time of diagnosis. The HCV Quest survey produced a real statistic on this issue that could be shown to hepatologists to encourage them to do more to help these patients.

Main Points

What is the HCV Quest Patient Survey?

HCV Quest is a global patient survey distributed by the World Hepatitis Alliance (WHA) in 2014 to investigate the impact HCV can have on patients' personal and social lives, education and work. It surveyed almost 4,000 people from 73 countries. Through HCV Quest, data has been generated and produced into a global report as well as 22 local country reports. The reports provide important new data on a number of different issues in HCV including lack of awareness, stigma and discrimination.



Importance of Surveys as a Tool

- Surveys can produce data that empowers arguments in advocacy.
- Data can be easy to generate and cheap to produce ([Survey Monkey](#) is a free online service).
- Data collected from surveys such as the HCV Quest Patient Survey can help reaffirm perceptions around a disease, and be used as evidence in a professional setting, e.g. people presenting symptoms of HCV but not being diagnosed by their doctors. The data collected can help give an idea of the scale of a problem.
- Survey data can be used to start a conversation with governments to encourage increased awareness campaigns and implement anti-discrimination policies.
- Statistics generated from the surveys can be useful when reaching out to media to highlight the impact of the disease and raise awareness.
- Data can be used to raise the profile of your patient organisation with HCPs, while encouraging them to direct patients towards your organisation should they require emotional support or further disease information.

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CASE STUDIES



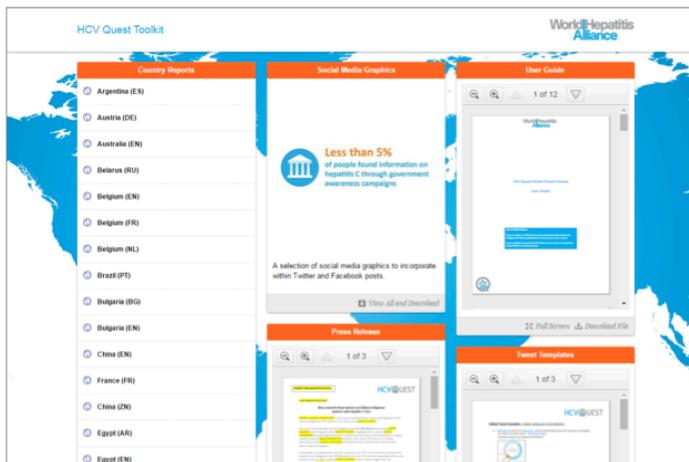
Greece: “Prometheus”, Hellenic Liver Patient Association

- Only 20% of people living with HCV in Greece have been diagnosed, which means that many are possibly living with significant liver damage without knowing it. If action is not taken now, the country will soon have to deal with the direct impact of the problem.
- The data collected from the survey is being used to urge the Greek government to implement a national HCV awareness campaign.
- Another interesting finding was that patients felt a disconnect with their doctors. The data was presented at the Hellenic Association for the Study of the Liver (HASL) at its annual conference, where almost every hepatologist in Greece was in attendance. Hepatologists accepted they were not spending enough time with patients and agreed in the future to refer new patients to Prometheus for further support.

HCV Quest Toolkit

To assist patient organisations in the dissemination and use of the HCV Quest survey data, the WHA produced the HCV Quest Toolkit. The Toolkit contains a User Guide and a range of adaptable templates to help with advocacy outreach to policy makers, media and healthcare professionals. All materials and content can be downloaded at <http://releasd.com/2c48>. Advice provided in the User Guide includes information on how to position key messages for various audiences, and when and where to use the materials to:

- Identify stakeholder engagement opportunities
- Plan media engagement activities and policy events
- Utilise traditional and social media to disseminate messages



Top Tips to Consider When Developing a Survey

While the HCV Quest Global Patient Survey has been unique in providing many countries with key statistics to advance advocacy activities, patient groups in other areas may wish to carry out their own surveys. The webinar provides tips to assist in developing surveys:

- Understand what information you hope to gain when developing your questions, ensuring they are strategic, for example:
 - Who are your target media, and what kind of information/statistics will encourage them to write a story?
 - What key messages are you already hearing from patients that would gain value from the support of survey data?
- Design your survey so that it covers your essential questions but is succinct and simple to use.
- Consider the best survey format to use among the options available.
- Consider the timing of your survey – do not for example issue during a holiday period when people may not be available to respond.
- Distribute your survey to a wide range of people, not just members of your organisation.
- Utilise relevant networks to maximise the reach of the survey.