How To Interpret And Leverage Results For Effective Advocacy: HCV Quest Global Patient Survey

Webinar 2
10.00 – 11:00 GMT
10 March 2016

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WELCOME AND INTRODUCTIONS

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Agenda

**Topic**

- The importance of surveys as a tool for lobbying and campaigning activity. Introduction to HCV Quest Global Patient Survey
- WHA member case study
- Leveraging HCV Quest on a local level. Introduction to HCV Quest Toolkit

**Speaker**

- Raquel Peck
- George Kalamitis
- Bridie Taylor

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Importance Of Surveys As A Tool For Lobbying And Campaigning Activity: Introduction to the HCV Quest Global Patient Survey

Raquel Peck
CEO, World Hepatitis Alliance

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DATA POWERS ADVOCACY

To consider:

- Can data help?
- How do you engage people/participants?
- Where will it come from?
- How do you interpret results?
- How do you ensure it’s reliable?
- How do you disseminate results?
Almost 4,000 responses from 73 countries
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
Poll

“Have you ever used a survey to support advocacy activities in your local area?”
WHA Member Case Study

George Kalamitis

Chairman, “Prometheus”, Hellenic Liver Patient Association, Greece

#ToolsForChange  @GKalamitis
Greek Case Study

Public awareness of hepatitis C – a priority to drive timely diagnosis and referral

53% of respondents from Greece knew about hepatitis C before diagnosis, but only 1% of those got this information from government awareness campaigns.

Survey findings

- In contrast to many other European countries, awareness about hepatitis C was relatively low in Greece, with 11% of respondents saying they had knowledge about the disease before their diagnosis.
- Few Greek patients involved in awareness campaigns had a history of hepatitis C through transfusion (25%), 1% through birth to a hepatitis C-infected mother, and 1% through sexual contact.
- Of those surveyed, 6% of patients were not aware they had hepatitis C.
- Despite 9% of patients being referred to a patient group, only 3% of respondents had heard of a patient group in Greece.
- The HCV Access Survey (HACS) survey of 370 patients in Greece identified a significant need for patient support services.
- All of these issues of patient group engagement in hepatitis C were highlighted in a report on patient experience and involvement in research.

What does this mean?

Governments must take a lead role in providing high-quality information about the risks and symptoms of hepatitis C and work together with effective patient groups.

Improve public awareness and education: We must ensure public awareness and education amongst patients and healthcare providers.
### Estimated number of persons per fibrosis stage in Greece (2012)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Assessment model of the total number of cases</th>
<th>% With diagnosis</th>
<th>Estimated number of diagnosed cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>F0</td>
<td>33784</td>
<td>7.9%</td>
<td>2655</td>
</tr>
<tr>
<td>F1</td>
<td>36265</td>
<td>7.9%</td>
<td>2850</td>
</tr>
<tr>
<td>F2</td>
<td>20606</td>
<td>20%</td>
<td>4121</td>
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<tr>
<td>F3</td>
<td>23822</td>
<td>30%</td>
<td>7147</td>
</tr>
<tr>
<td>F4-comp.</td>
<td>16867</td>
<td>40%</td>
<td>6747</td>
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<tr>
<td>F4-decom.</td>
<td>2101</td>
<td>100%</td>
<td>2101</td>
</tr>
<tr>
<td>total</td>
<td>133445</td>
<td>19.20%</td>
<td>25621</td>
</tr>
</tbody>
</table>

*Papatheodoridis et al, J Viral Hep 2014*
Estimated diagnosed patients with severe fibrosis / cirrhosis

<table>
<thead>
<tr>
<th></th>
<th>Estimated number of diagnosed cases</th>
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<tbody>
<tr>
<td>F0</td>
<td>2655</td>
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Approximately 16,000

Papatheodoridis et al, J Viral Hep 2014
Restriction-criteria

According to the latest data of EOPYY, patient access to the new therapeutic schemes for hepatitis C is based on 4 criteria.

1. Patients with liver fibrosis stage f3 or f4 that have failed previous therapeutic schemes
2. Patients with liver fibrosis stage f4
3. Patients with decompensated cirrhosis
4. Patients before or after liver transplantation

For a patient to obtain the new drugs from a foreign country, they have to be residents or the country and to have insurance coverage in the specific country
HCV Quest methodology

- Social media
- Members
- Clinics
- Treatment centers
- Personal contacts
HCV Quest: arguments to participate

- It is the first time patients have the opportunity share their experience as people living with HCV
- Our interest/need to improve the level of service we receive from the healthcare system
Leveraging HCV Quest On A Local Level

Bridie Taylor

Communications Officer, World Hepatitis Alliance

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@BridieErin
How country data can be used

Governments
- Improve healthcare response
- Raise awareness
- Implement anti-discrimination policies

Media
- Raise profile of the disease
- Pressure governments to act

Healthcare professionals
- Improve patient-doctor relationships
- Signpost patients to patient organisations
How to use the data: Example from Argentina

- **No one** had heard about hepatitis C from government awareness campaigns
- Governments committed to raising awareness in 2010 World Health Assembly resolution on hepatitis
WHA Member Case Study

George Kalamitis
Chairman, “Prometheus”, Hellenic Liver Patient Association, Greece

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HCV Quest Results

- The doctor-patient relationship
  - "Completely unsatisfactory" featured 1 in 5 patients the quality of communication with health professionals

- Patient participation in treatment decision
  - 55% participate in treatment planning configuration while 21% were not asked them for their opinion at all on treatment

- Clinicians and patient association
  - Only 2% of patients referred by health professionals to Patients Association at the time of diagnosis
HCV Quest Results

- HCV affects patients lives
  - Only 17% revealed their diagnosis to colleagues
  - 43% feel uncomfortable to disclose their diagnosis to employers
  - 1 in 3 felt HCV has a significant impact on physical (42%), emotional (34%) and psychological (37%) health
DISCUSSION / QUESTIONS AND ANSWERS

How to ask a question

You can submit a question by typing it in the Questions section in your meeting control panel

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Introduction To The HCV Quest Toolkit

Bridie Taylor
Communications Officer, World Hepatitis Alliance

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HCV Quest Toolkit

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HCV Quest Toolkit

- Press release
- Infographic
- Factsheet
- Standby Q&As
- Spokespeople biography
- Media outreach email
- Twitter and Facebook templates
- Social media graphics
- Policymaker letter
- External presentation
Join us to amplify the reach!

- Official media launch: EASL International Liver Congress
- Embargo for 13th April
- Edit the template press release
- Send to local media outlets
DISCUSSION / QUESTIONS AND ANSWERS

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SUMMARY AND CLOSE

Jeff Lazarus

Editor-in-Chief of Hepatology, Medicine and Policy & Professor, University of Copenhagen, Denmark
THANK YOU FOR ATTENDING

Access the HCV Quest Toolkit here

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  Awareness as a policy lever

  Understanding the Global Health Sector Strategy for Viral Hepatitis: Driving national policy change

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