The Euro Hepatitis Care Index

Tatjana Reic,
President of ELPA

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The Euro Hepatitis Care Index

• A systematic analysis of the current situation in Europe in the field of Hepatitis B and Hepatitis C.
• A survey of existing best practice in EU 27 + Norway, Switzerland and Croatia in the field of prevention, case finding, access to treatment, national strategy, patient involvements and outcomes.
• Operated by HCP with the support of ELPA and EASL.
The Euro Hepatitis Index is...

A tool to empower patients and physicians through comparing and reviewing health care provision and policies regarding hepatitis B and C in all EU member states, Switzerland, Norway and Croatia.

Increase transparency and comparability of healthcare systems

Increase public awareness, create discussion and indicate strong and weak aspects of each national healthcare system (pointing successful examples)

Helping European citizens to improve the services they receive.
Who made the Euro Hepatitis Index 2012?

ELPA

HCP

EASL
Background

Why the Index?
To exploit peer pressure among Member States with a view to create a race to the top

Why is the Index important?
To get Member States and the EU to make tackling Hepatitis a policy priority and translating this priority into concrete actions on prevention, diagnosis, treatment and management of Hepatitis in the context of EU actions and comprehensive national plans

What does ELPA aim to achieve with Index? To put pressure on Member States to elaborate national plans to fight viral hepatitis
Methodology

What did HCP do?

1st step: Set up different indicators based in the input of an independent expert panel

2nd step: send a questionnaire to all 27 + 3 health governments (hard data), send parallel the questionnaire to physicians and patient groups (soft data)

3rd step: analyze the data and ranking the individual indicators.

4th step: HCP publish a report with all results and subanalyses.
The Index concentrates on indicators reflecting properties and performance of healthcare systems

- Measures factors that can be changed by healthcare decision makers.
- Avoiding indicators which are closely correlated with GDP/capita.

Indicator Scoring

- Scientific soundness
- Measurability
Sub-disciplines/indicators

1. prevention 7
2. case finding/screening 6
3. access to treatment and process 8
4. national strategy /patient involvement and rights) 3
5. outcomes 3
Sources

“any source that can provide any reasonable data”

**Indata not symmetric – multiple data sources on the same indicator**

**Soft data**
- Ministry of Health
- Public Health Institutes
- Hospitals/Clinicians

**Hard data**
Data found from one single source based on a well-defined methodology such as WHO databases, ECDC, EMCDDA, scientific papers etc.
Validation

All countries are given the opportunity to review their own preliminary results before publication

- Ministries of Health / National Health Agencies/ and Patient Organizations given the opportunity to validate/update their country data (Country score sheet)

- Additionally used as feedback, Surveys to:
  - Patient Organisations.
  - Survey to physicians (EASL members, clinician’s societies)
Scoring system

Country scores assigned to one of three levels for each indicator:

3 (green): good (C)
2 (amber): intermediate (F); "n.ap." = 2
1 (red): not-so-good (D); "n.a." = 1

Total score:
- Maximum score: 1000
- Minimum score: 333

Calculated as % of maximum score under each sub-discipline – i.e. many indicators in one area does not provide added weight!
## Relative Weights

<table>
<thead>
<tr>
<th>Sub-discipline</th>
<th>Relative weight (&quot;All Green&quot; score contribution to total maximum score of 1000)</th>
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<tbody>
<tr>
<td>Prevention</td>
<td>275</td>
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<tr>
<td>Case finding/Screening</td>
<td>225</td>
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<tr>
<td>Access to treatment/ Process</td>
<td>225</td>
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<tr>
<td>National Strategy/ Patient involvement and rights</td>
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<td>Outcomes</td>
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<tr>
<td><strong>Total sum of weights</strong></td>
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# Euro Hepatitis Index 2012

## 1. Prevention

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<td>1.3 Vaccination in risk population</td>
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<td>1.4 HBV Vaccination payment</td>
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<td>1.5 Universal ante-natal HBV screening</td>
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<td>1.6 Harm reduction in prison</td>
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<td>1.7 Post exposure immunization for hepatitis B</td>
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Subdiscipline weighted score: 210 236 183 236 198 183 223 106 223 210 240 196 170 240 236

## 2. Case finding/screening

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<td>2.1 Free anonymous hepatitis testing and counselling</td>
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<td>2.2 Hepatitis C testing in the community</td>
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<td>2.3 Annual screening for infectious diseases to all IDU</td>
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<td>2.4 Annual HCV antibody testing for HIV-infected persons</td>
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<td>2.5 Is ALT determination routinely prescribed by GPs?</td>
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Subdiscipline weighted score: 150 163 113 175 163 138 163 100 150 200 175 150 175 163 150

## 3. Access to treatment and process

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<td>3.1 Treatment Funding</td>
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<td>3.2 Waiting time for specialist appointment</td>
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<td>3.3 Treatment of children in a specialist unit</td>
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<td>3.4 Adherence to European (EASL) guidelines (Hep B, Hep C)</td>
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<td>3.5 HCV Genotyping</td>
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<td>3.6 Availability of new drugs</td>
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<td>3.7 Hepatitis specialist nurses?</td>
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<td>3.8 Is there an HCC registry?</td>
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Subdiscipline weighted score: 150 159 159 159 159 178 197 141 178 216 188 150 141 150 156

## 4. National Strategy/ Patient involvement and rights

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<tr>
<td>4.1 National HCV/HBV (general hepatitis; liver) patient organization?</td>
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<td>4.2 Involvement of patient organisations in health decisions making?</td>
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<td>4.3 Governmental funding of Hepatitis strategy?</td>
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Subdiscipline weighted score: 69 83 97 83 56 56 69 56 83 97 69 69 56 83 83

## 5. Outcomes

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<tr>
<td>5.1 % of patients treated who achieve sustained viral response (SVR) (for HCV)</td>
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<td>5.2 Liver transplants per million population</td>
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<td>5.3 Mortality on the waiting list for liver transplant</td>
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Subdiscipline weighted score: 117 83 83 83 50 50 50 83 50 150 117 67 50 83 133

Total score: 705 724 636 737 624 605 701 576 684 872 797 633 591 728 752

Rank: 15 13 21 8 23 26 16 29 17 1 3 22 27 11 6
General situation in Europe

• Every year 125 000 Europeans die from various hepatitis-related diseases.

• Viral hepatitis is a largely neglected epidemic in the Europe, around 23 million people are estimated to live with chronic hepatitis B (HVB) or hepatitis C (HVC), **most carrying the disease without knowing it.**

  There is a very low detection rate of infected people. Even in countries with a national strategy, less than 40 % are detected. In countries like UK and Germany the detection rate is 14 – 18 %. In most other countries the rate ranges from 0.3 % (Greece) to 3 % (Poland).

• Chronic hepatitis is often left untreated, with less than 20% of the patients receiving treatment and therefore it is a major cause of liver cirrhosis and primary liver cancer.

• Data presented mostly representing only citizens with medical card.
Which countries provide good Hepatitis Care?

![Euro Hepatitis Index 2012 Total Scores Chart](chart.png)
Key findings

Post-Exposure immunization

• Broadly available in Europe. However often not subsidized for everyone in need but only for health care staff (Austria, Bulgaria).

Poor Knowledge and Training

• Lack of viral hepatitis training among GPs.

Routine infant vaccination

• Countries without infant vaccination have a better approach to high risk groups. However accurate data is not available for those countries and as a result it is difficult to measure the success of those programmes -Norway, UK, Sweden.

New hepatitis strategies

• Germany (2012-13), UK (2012) and Bulgaria (to be started) are working on a national strategy.
**Testing/case finding in risk groups**
- Data shows there is a big variety of practices to testing and screening in high risk groups.

**Specialist Nurses**
- Lack of specialized nurses.

**Waiting time**
- Average time to get an appointment with a specialist varies between one and three months (in some countries waiting time of 18 months).

**Funding of Screening, treatment and vaccination**
- Varies a lot from country to country. E.g. Lithuania and Romania do not subsidize vaccination for high risk groups.

**National HCC Registry**
- Most of the HCC registry is part of the cancer registry. Lack of accurate information because registry is not updated on a regular basis. The causes of HCC are not recorded and as a consequence it is impossible to distinguish patients whose disease is due to viral hepatitis.
The overall situation is bad in Europe

- Significant shortcomings in all categories across all countries
- High prevalence of viral hepatitis
- Low detection rate due to lack of consistent screening programmes especially among high risk groups
- Significant increase in late stage of viral hepatitis (cirrhosis & HCC)
- High inequality with regard to access to treatment options within and between countries and between EU regions
There are 3 main areas of improvement

• Lack of awareness of the risks of transmission especially among high risk groups
• Access to testing and treatment because once screened lots of possibilities for effective treatment exist.
• Lack of specific registries on viral hepatitis to keep track of infected patients and transmission threats
Solutions are obvious

- National strategies/plans focusing on the 3 areas of improvement are the main vehicle to address the shortcomings.
- Individual examples of best practices exist in Europe. They need to be consistently implemented across all countries.
- Patients’ empowerment is part of the solution. Patients need to be involved in the design and implementation of national strategies for these to succeed.
Thank you for your attention