

European Liver Patients' Association

ELPA

The Euro Hepatitis Care Index

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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.

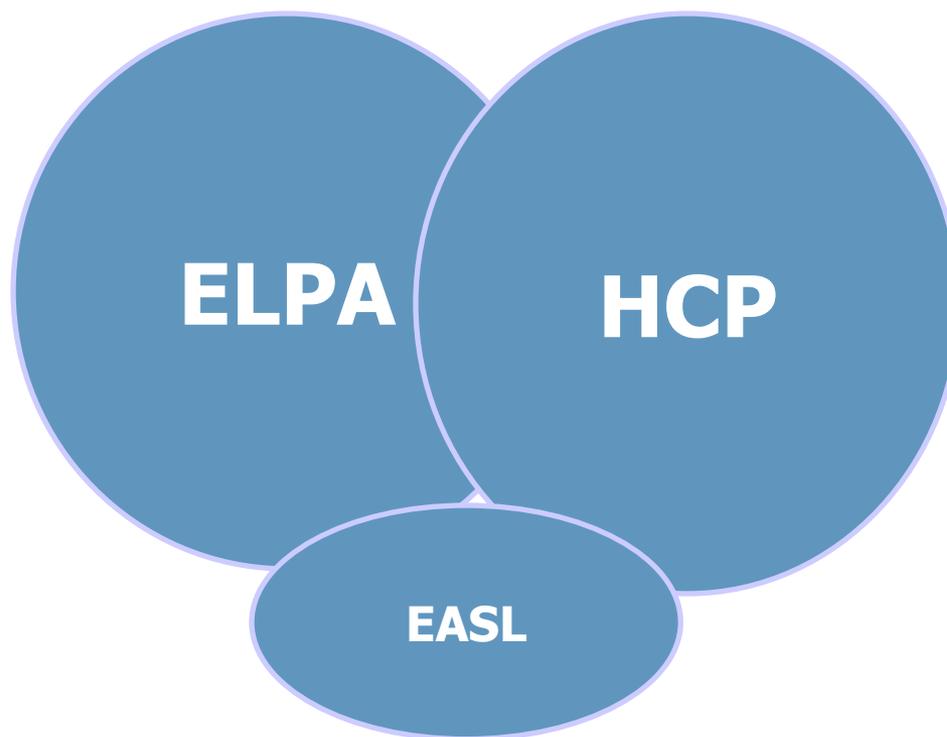
**Increase
transparency and
comparability of
healthcare
systems**

**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?

European Liver
Patients Association



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

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.

Indicators

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
- 
- A decorative wavy line at the bottom of the slide, transitioning from green on the left to orange on the right.

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

Sub-discipline	Relative weight ("All Green" score contribution to total maximum score of 1000)
Prevention	275
Case finding/Screening	225
Access to treatment/ Process	225
National Strategy/ Patient involvement and rights	125
Outcomes	150
Total sum of weights	1000

Euro Hepatitis Index 2012



Sub-discipline	Indicator	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy
1. Prevention	1.1 Public awareness about hepatitis	👍	👍	👍	👍	👎	👍	👎	👍	👍	👍	👍	👍	👎	👍	👍
	1.2 % Universal infant HBV vaccination coverage	👍	👍	👍	👍	👍	👍	👎	👍	👎	👍	👍	👍	👍	👍	👍
	1.3 Vaccination in risk population	👍	👍	👎	👍	👎	👎	👍	👎	👍	👍	👍	👍	👎	👍	👍
	1.4 HBV Vaccination payment	👍	👍	👎	👍	👍	👍	👍	👎	👍	👍	👍	👍	👎	👍	👍
	1.5 Universal ante-natal HBV screening	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👎	👍	👍
	1.6 Harm reduction in prison	👍	👍	👍	👍	👎	👎	👍	👍	👍	👍	👍	👎	👎	👍	👍
	1.7 Post exposure immunization for hepatitis B	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👎	👎	👍	👍
	Subdiscipline weighted score		210	236	183	236	196	183	223	196	223	210	249	196	170	249
2. Case finding/ screening	2.1 Free anonymous hepatitis testing and counselling	👍	👎	👎	👍	👍	👍	👍	👎	👍	👍	👍	👎	👍	👍	👎
	2.2 Hepatitis C testing in the community	👎	👍	👍	👍	👍	👍	n.a.	n.a.	👍	👍	n.a.	👍	👍	👍	👍
	2.3 Annual screening for infectious diseases to all IDU	👍	👍	👍	👍	👎	👎	👍	👎	👍	👍	👍	👍	👍	👍	👍
	2.4 Annual HCV antibody testing for HIV-infected persons	👍	👍	👍	👍	👍	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍
	2.5 Is ALT determination routinely prescribed by GPs?	👍	👍	👎	👍	👍	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍
	2.6 Screening funding	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	Subdiscipline weighted score		150	163	113	175	163	138	163	100	150	200	175	150	175	163
3. Access to treatment and process	3.1 Treatment Funding	👍	👍	👍	👍	👍	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍
	3.2 Waiting time for specialist appointment	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	3.3 Treatment of children in a specialist unit	👍	👍	👍	👍	👍	👍	👍	n.ap.	👍	👍	👍	👍	👍	👍	👍
	3.4 Adherence to European (EASL) guidelines (Hep B, Hep C)	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	3.5 HCV Genotyping	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	3.6 Availability of new drugs	👍	👍	👎	n.a.	n.a.	👍	👍	👎	👍	👍	👍	👍	👎	👎	👎
	3.7 Hepatitis specialist nurses?	👎	👍	👎	👎	👎	👎	👍	👎	👎	👍	👍	👍	👎	👍	👎
	3.8 Is there an HCC registry?	👎	👎	👎	👍	👍	👍	👍	👍	👍	👍	👍	👍	👎	👎	👎
Subdiscipline weighted score		159	159	159	159	159	178	197	141	178	216	188	150	141	150	150
4. National Strategy/ Patient involvement and rights	4.1 National HCV/HBV(general hepatitis; liver) patient organization?	👍	👍	👍	👍	👎	👎	👍	👍	👍	👍	👍	👍	👎	👍	👍
	4.2 Involvement of patient organisations in health decisions making?	👎	👍	👍	👍	👍	n.ap.	👎	n.ap.	👍	👎	👎	👎	n.ap.	👍	👍
	4.3 Governmental funding of Hepatitis strategy?	👎	👎	👍	👎	👎	👎	👎	👎	👎	👍	👎	👎	👎	👎	👎
	Subdiscipline weighted score		69	83	97	83	56	56	69	56	83	97	69	69	56	83
5. Outcomes	5.1 % of patients treated who achieve sustained viral response (SVR) (For HCV)	👍	n.a.	👍	n.a.	n.a.	n.a.	n.a.	👍	n.a.	👍	👍	👍	n.a.	n.a.	👍
	5.2 Liver transplants per million population	👍	👍	👎	👍	n.a.	👎	👎	👎	👎	👍	👍	👎	👎	👎	👎
	5.3 Mortality on the waiting list for liver transplant	👎	n.a.	n.a.	👎	n.a.	n.a.	n.a.	n.a.	n.a.	👍	n.a.	n.a.	n.a.	👍	👍
	Subdiscipline weighted score		117	83	83	83	50	50	50	83	50	150	117	67	50	83
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

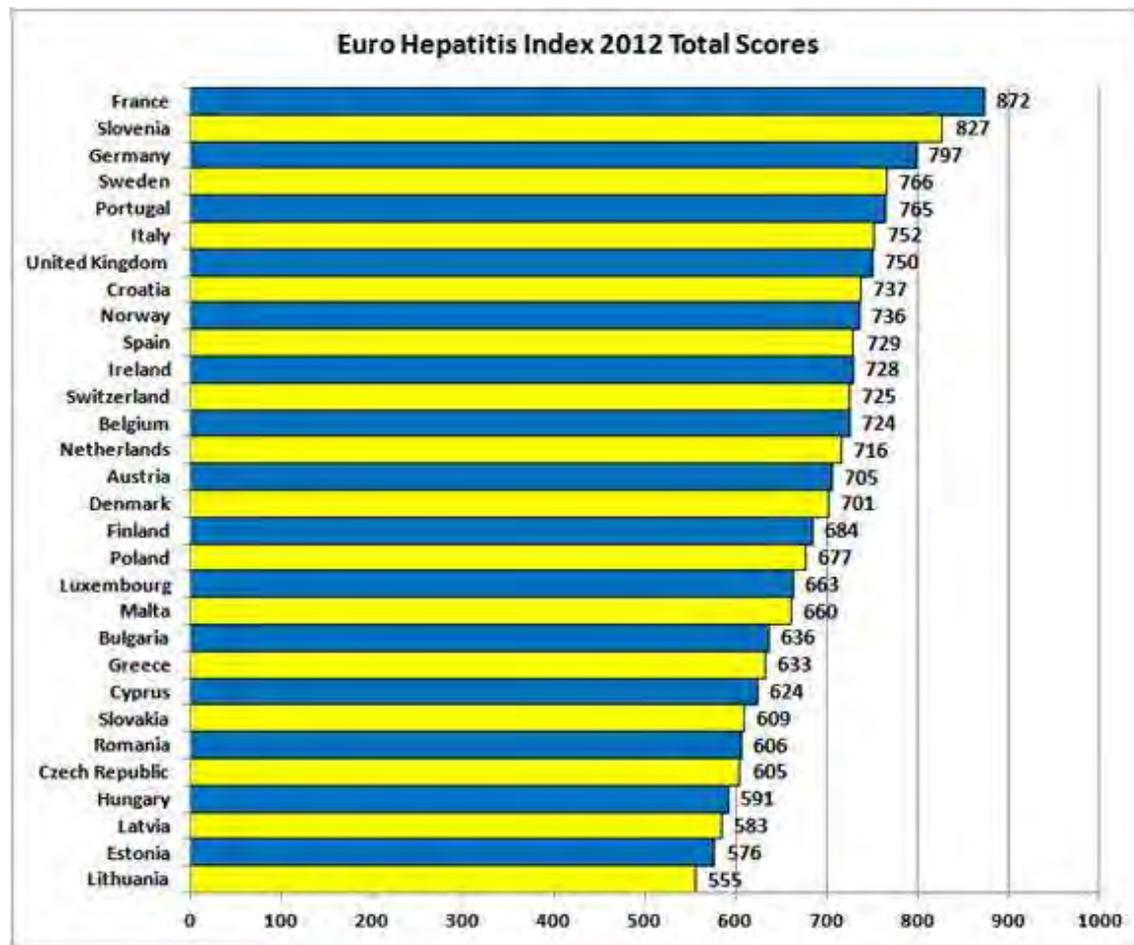
General situation in Europe

- 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?



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 focussing 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

www.hep-index.eu

Index map - Euro Hepatitis Care Index - Mozilla Firefox

Index map - Euro Hepatitis Care Index

www.hep-index.eu/index-map.html

hep index

Home Launch event Index map Sub-Disciplines & Indicators Methodology About Hepatitis Contacts

How to start...

Select one or more countries from the map below or search for a country.

Or

Select one of the "pre-selected sets" that show interesting relationships between individual indicators per country.

pre-selected sets

The overview can be found below on the page.

Country selection: [x] Austria [x] Belgium [x] Bulgaria [x] Croatia [x] Cyprus [x] Czech Republic [x] Denmark [x] Estonia [x] Finland [x] France [x] Germany [x] Greece [x] Hungary [x] Ireland [x] Italy [x] Latvia [x] Lithuania [x] Luxembourg [x] Malta [x] Netherlands [x] Norway [x] Poland [x] Portugal [x] Romania [x] Slovakia [x] Slovenia [x] Spain [x] Sweden [x] Switzerland [x] United Kingdom

Indicator selection: [v] Order countries by: [v] Download selected data as PDF

Indicator	France		Slovenia		Germany		Sweden	
	Rank	Total Score	Rank	Total Score	Rank	Total Score	Rank	Total Score
1 Prevention								
11 Public awareness about hepatitis								
12% Universal infant HBV vaccination coverage								

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Thank you for your attention

