

The Euro Hepatitis Care Index



Lilyana Chavdarova
Policy Manager, ELPA

European Liver
Patients Association

ELPA



TABLE OF CONTENTS

- I. Who are we?
- II. The Euro Hepatitis Care Index
 - 1. At a glance
 - 2. Key findings
- III. Conclusions

Elpa Members

33



- Austria
- Belgium
- Bosnia & Herzegovina
- Bulgaria
- Croatia
- Egypt
- Finland
- France
- Germany
- Greece
- Hungary
- Italy
- Israel
- Lithuania
- Macedonia
- The Netherlands
- Poland
- Portugal
- Romania
- Serbia
- Slovakia
- Spain
- Sweden
- Turkey
- Ukraine
- UK

OUR WORK

– **Policy-oriented**

Conducting policy meetings with ELPA members, governments and pharmaceutical representatives, advocating for patient rights on national and European level, engaging relevant institutional and professional stakeholders. Creating strategies and policy tools.

– **Science-oriented**

Conducting scientific meetings with pharmaceutical companies, distributing and collecting scientific data to and from ELPA members, reviewing protocols, working with EMA

European Liver
Patients Association

ELPA

OUR PARTNERS



✓ Organizations

- VHPB, EPF, ECL, IARC, ECPC, EATG, WHA, EASL, UEG, ILCA, HBCPPA, Correlation Network

✓ Institutions

- DG RESEARCH, DG SANCO, DG ENTERPRISE, ECDC, WHO, EMA, European Parliament, local governments

✓ Industry

European Liver
Patients Association

ELPA



THE EURO HEPATITIS CARE INDEX

European Liver
Patients Association

ELPA

<http://www.hep-index.eu>

How to start...

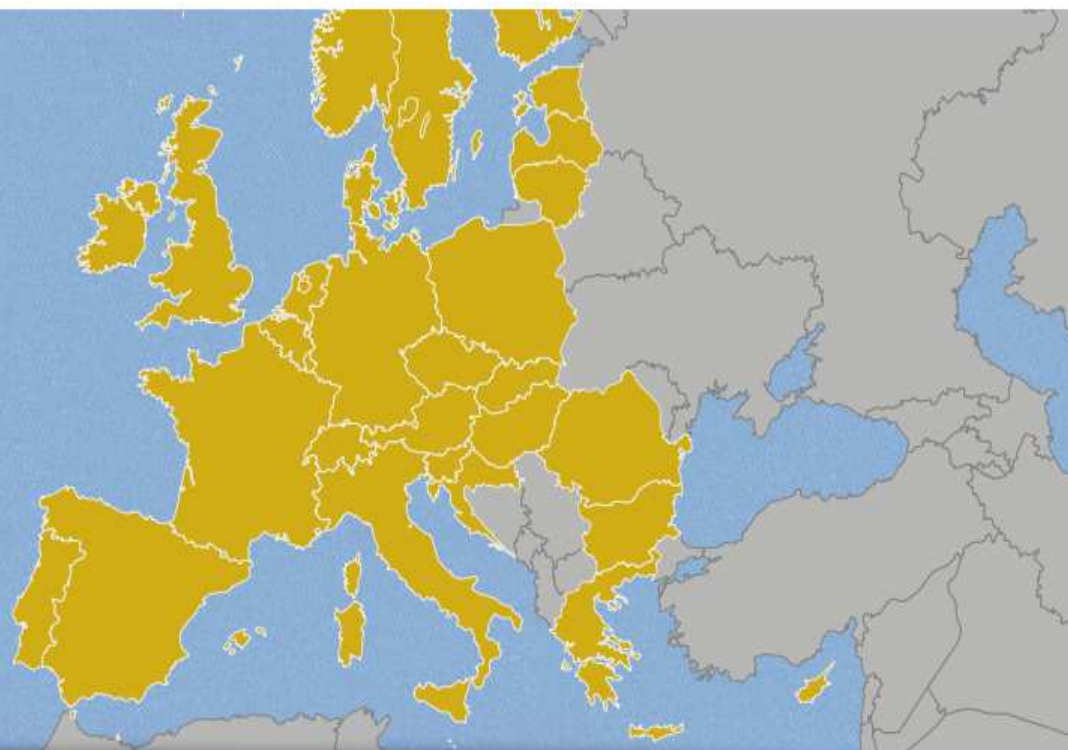
Select the countries from the map which you want to compare











OR

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

 pre-selected sets ▾

The overview can be found below on the page.



✓ Austria 	✓ Belgium 	✓ Bulgaria 	✓ Croatia 	✓ Cyprus 
✓ Czech Republic 	✓ Denmark 	✓ Estonia 	✓ Finland 	✓ France 

METHODOLOGY

- Launched in 2012 by ELPA and the Health Consumer Powerhouse with the support of EASL
- **Scope:** 30 countries, the 27 EU member states plus Switzerland, Norway and Croatia
- **Sources of information:**
 - Literature review
 - Questionnaire to patient organisations
 - National and regional Health Authorities
 - Institutions (EHMA, ECDC, CDC, OECD and others)
 - Private enterprise (IMS Health, pharmaceutical industry, others)
 - Discussions with Expert Reference Panel*

*EXPERT REFERENCE PANEL

Name	Affiliation
Helena Cortez-Pinto, Dr	Associate Professor, Department of Gastroenterology, University Hospital of Santa Maria, Lisbon, Portugal
Anil Dhawan, Prof.	Consultant Pediatric Hepatologist. Clinical Director Child Health and Joint CAG Lead Kings Health P, UK
Ulrik Bak Dragsted, MD, PhD	Head of Infectious Disease Unit, Roskilde Hospital, Copenhagen, Denmark.
Stanimir Hasurdjiev, Dr	Executive director of ELPA
Deirdre Kelly. Prof.	Professor of Pediatric Hepatology at the University of Birmingham and Director of the Liver Unit, Birmingham Children's Hospital, UK
Achim Kautz	Executive Manager of the Deutsche Leberhilfe, Germany
Daniele Prati, Prof.	Director of the Department of Transfusion Medicine and Hematology at the Ospedale Alessandro Manzoni, Lecco, Italy; Board of Directors of the Italian Foundation for Hepatology Research (Fondazione Italiana per la Ricerca in Epatologia, FIRE) and EASL, Scientific Committee Member
George Papatheodoridis, Dr.	Associate Professor at 2nd Department of Internal Medicine Athens University School of Medicine, Greece; EASL Scientific Committee Member
Tatjana Reic, Dr., MSc.	President of ELPA
Siegbert Rossol, Prof. Dr. med., M.Sc.	Head of the Department of Internal Medicine Hospital Northwest, Frankfurt, Germany

METHODOLOGY

- **The result:** a mix of indicators in different fields
 - Attitude on service to determine healthcare quality
 - *Customer* orientated study

ASSESSMENT CRITERIA

1. Prevention
2. Case finding/screening
3. Access to treatment and process and rights
4. National Strategy/ Patient involvement and rights
5. Outcomes

Euro Hepatitis Care Index 2012		UK	Latvia	Lithuania	Luxembourg	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom	
Sub-discipline	Indicator																
1. Prevention	1.1 Public awareness about hepatitis	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	1.2 % Universal infant HBV vaccination coverage	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	1.3 Vaccination in risk population	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	1.4 HBV Vaccination payment	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	1.5 Universal ante-natal HBV screening	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	1.6 Harm reduction in prison	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q
	1.7 Post exposure immunization for hepatitis B	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	Subdiscipline weighted score		157	157	223	236	236	210	183	223	170	183	249	236	183	249	236
2. Case finding/screening	2.1 Free anonymous hepatitis testing and counselling	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	2.2 Hepatitis C testing in the community	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	2.3 Annual screening for infectious diseases to all ICU	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	2.4 Annual HCV antibody testing for HIV-infected persons	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	2.5 % ALT determination routinely prescribed by GPs?	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	2.6 Screening funding	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	Subdiscipline weighted score		100	100	138	188	150	200	175	188	138	138	200	163	200	150	163
3. Access to treatment and process	3.1 Treatment Funding	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.2 Waiting time for specialist appointments	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.3 Treatment of children in a specialist unit	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.4 Adherence to European (EASL) guidelines (Hep B, Hep C)	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.5 HCV Genotyping	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.6 Availability of new drugs	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.7 Hepatitis specialist nurses?	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	3.8 Is there an HCC registry?	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
Subdiscipline weighted score		159	131	197	131	197	188	169	188	131	169	206	178	216	188	188	
4. National Strategy/ Patient involvement and rights	4.1 National HCV(HBV/general hepatitis liver) patient organization?	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	4.2 Involvement of patient organisations in health decisions making?	Q	Q	n.a	n.a	Q	n.a	Q	Q	Q	Q	n.a	Q	Q	Q	Q	
	4.3 Governmental funding of Hepatitis strategy?	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	Subdiscipline weighted score		83	83	56	56	83	56	83	69	83	69	56	69	83	56	69
5. Outcomes	5.1 % of patients treated who achieve sustained viral response (SVR) (for HCV)	Q	Q	n.a	n.a	n.a	n.a	Q	Q	Q	n.a	n.a	n.a	n.a	n.a	n.a	
	5.2 Liver transplants per million population	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	Q	
	5.3 Mortality on the waiting list for liver transplant	n.a	Q	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	
	Subdiscipline weighted score		83	83	50	50	50	83	67	117	83	50	117	83	83	83	67
Total score		583	555	663	660	716	736	677	765	606	609	827	729	766	725	750	
Rank		28	30	10	20	13	9	18	5	26	24	9	10	6	11	10	

HOW DO WE MEASURE “GOOD” CARE?



Effective (free / reimbursed) hepatitis B vaccination programmes



Easily available and free-of-charge screening programmes



Pre- and post-counselling to ensure informed choice with respect to testing



Access to high quality treatment and care



Qualified professionals



Good registries with properly designed and collected data

LIMITATIONS

- Information quality problems exist due to shortage of pan-European, uniform set procedures for data gathering
- Displays consumer information, not medically or individually sensitive data
- HOWEVER, the data was provided by professionals and knowledgeable experts
- The results must be treated with caution!

THE OBJECTIVES

1. to identify current gaps
2. to trigger a constructive discussion

FRANCE IS NO. 1! WHY?

✓ Successes

- National hepatitis strategy
- Effective screening campaigns
- Very good access to treatment
- Enhanced hepatitis surveillance systems
- Extensive network of hepatology reference centers
- Excellent hepatitis research programmes

✗ Challenges

- Vaccination of target groups for hepatitis B immunization
- Public awareness and awareness in special risk groups
- Improvement in the prison setting
- Systematic testing in high risk groups
- Patient involvement



KEY FINDINGS

European Liver
Patients Association

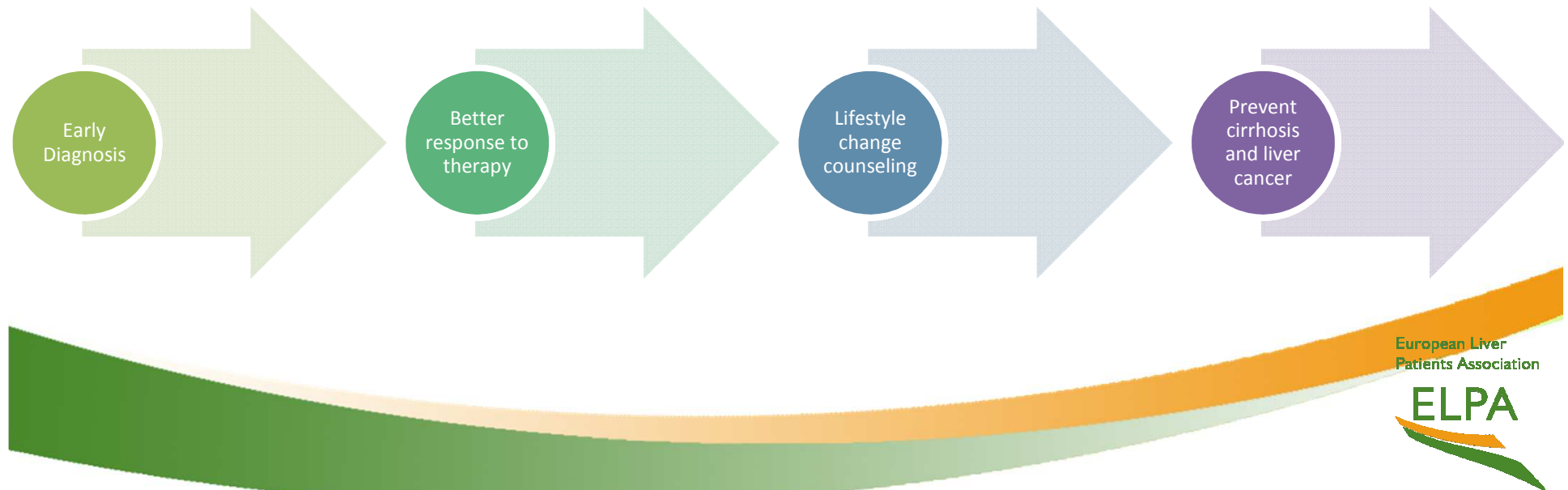
ELPA

Sub-discipline: PREVENTION

- **Public awareness** about hepatitis is low amongst the general public, those who are at risk, public health authorities, and treating physicians
- **Where universal Infant vaccination programs are in place** the coverage is generally more than 90%
- **Vaccination of HBV in risk groups** is especially well implemented in those countries where HBV vaccination for infants or adolescents is not systematic (mother-to-child, MSM, sex workers, prison inmates)
- Obvious lack of systematic monitoring and research on drugs and health issues in European **prisons**

Sub-discipline: SCREENING / CASE FINDING

- **Lack of reliable epidemiological data** on HBV and HCV
 - Risk groups such as migrants and injecting drug users (IDU) tend to be under-represented in existing prevalence studies
- The reported **prevalence is underestimated** (a silent disease)





European Liver Patients Association

ELPA

ADDRESSING RISK-GROUPS



- Insufficient basic information and short recommendations for GPs
 - ✓ **Action:** Training for health staff!
- ALT is performed mostly if liver disease is suspected
 - ✓ **Action:** Encourage GPs to prescribe ALT routinely!
- Risk groups are systematically ignored
 - ✓ **Action:** Increase testing in risk group population!
- Barriers to testing (transportation, language, lack of confidentiality, cost, lack of health insurance and/or stigma)
 - ✓ **Action:** make these services as reachable and convenient as possible!
- Free anonymous hepatitis testing and counselling are not widely available
 - ✓ **Action:** create community-based testing facilities!

Sub-discipline: ACCESS TO TREATMENT / PROCESS

- **Good access to a liver disease specialist**
- **Limited access to innovative treatment**
- Hepatitis **specialist nurses** are not widely available
- Good **HCC registries** are not widely available

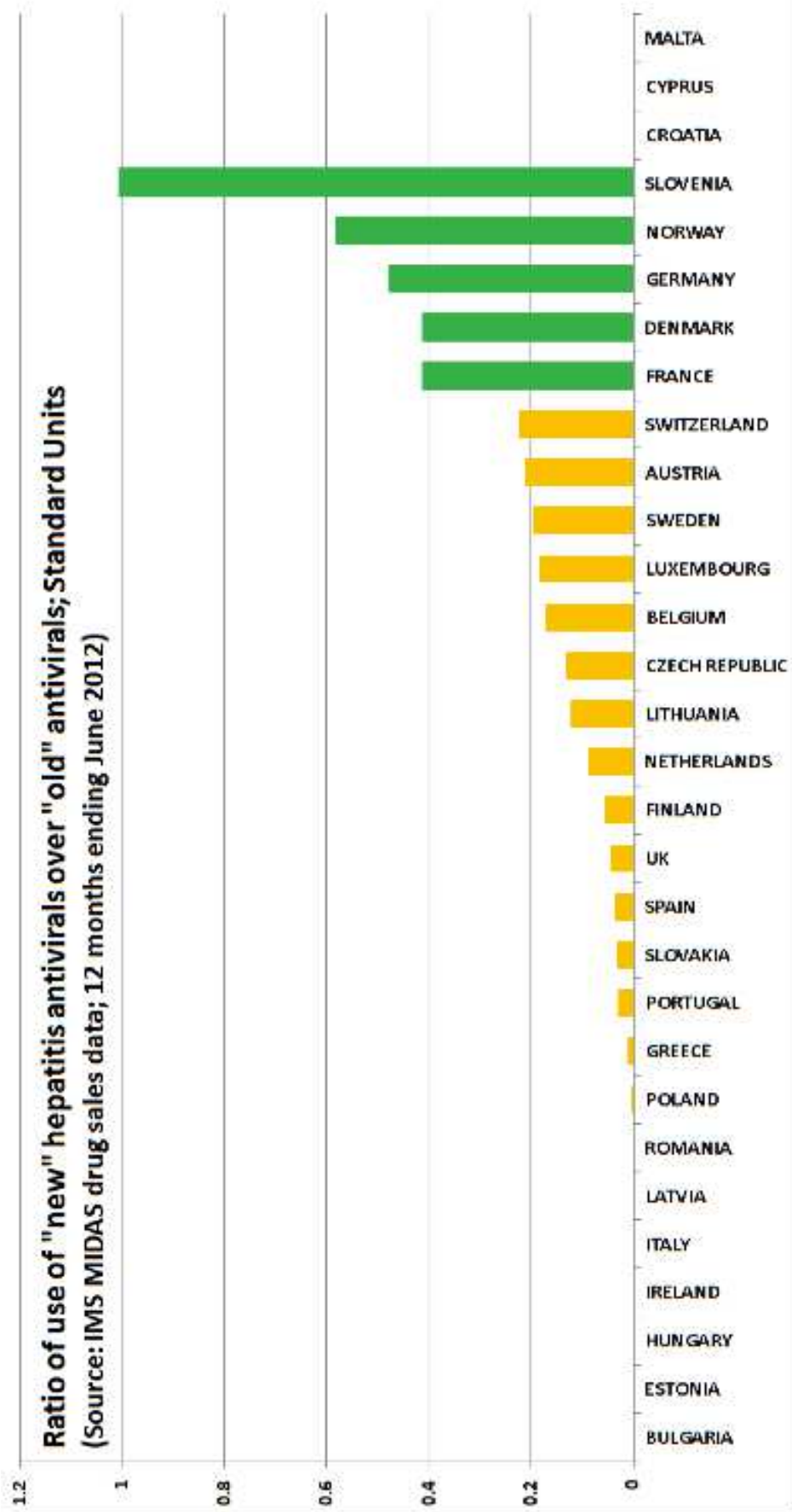


Figure 8.7.3.6. Ratio of "new" hepatitis drug use over "old" hepatitis drug use. NB! The indicator is not supposed to show that "the higher the ratio, the better". What the indicator seems to show is that in 5 countries the "new" drugs are readily available, in 14 countries there is restricted availability and in 11 countries there is no availability or no data.

Sub-discipline: GOVERNMENTAL STRATEGY/ PATIENT INVOLVEMENT AND RIGHTS

- Only two well-set up national hepatitis strategies in Europe: in France and Scotland
- In-progress:
 - England
 - Bulgaria
 - Croatia
 - Germany

Sub-discipline: OUTCOMES

- Data on hepatitis management is not nationally collected or not collected on a regular basis
- The ranking is noticeably influenced by the lack of data on the sub-discipline Outcomes (actual treatment results)
- There is abundance of statistics on **input of resources** BUT a traditional scarcity of data on **quantitative or qualitative output**

CONCLUSIONS

- National strategies/plans are the main vehicle to address the shortcomings!
- Create specific registries on viral hepatitis to keep track of infected patients and transmission threats!
- Increase awareness of the risks of transmission especially among high risk groups!
- Ensure equal access to testing and treatment!
- Implement best practice examples!
- Patients' empowerment is a **key** part of the solution!

THANK YOU!

European Liver
Patients Association

ELPA

