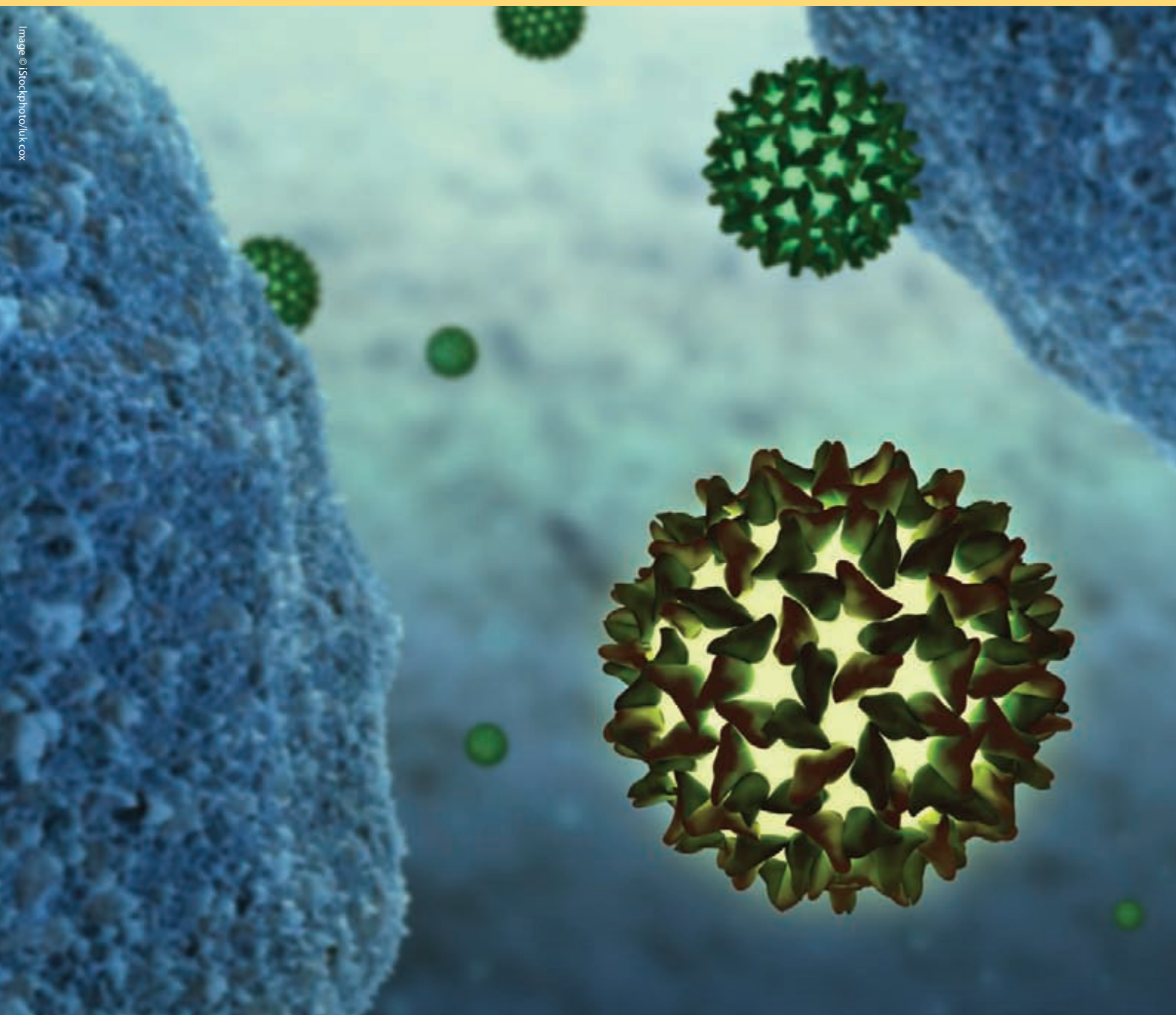




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Powerhouse

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# Euro Hepatitis Index

## 2012 report





**Health Consumer Powerhouse**

**Euro Hepatitis Index**

**2012**

**Report**

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## **Recipe for saving lives**

In European healthcare, with generally good tracking of epidemics, viral hepatitis is a neglected threat, although an estimated 23 million people live with chronic hepatitis. Even in countries with high disease awareness and active prevention policies, less than 40 % of the infections are detected. This means that even in well-organised countries such as UK and Germany, less than one out of five infected people know they carry the infection! In most other countries the detection rate is dramatically lower, which is why in parts of the EU still not even a single case out of one hundred people carrying the virus are diagnosed! This means that millions of Europeans are still unaware of their hepatitis.

A general, rather upsetting impression from this first ever comparison of hepatitis care performance around Europe is that effective action on hepatitis is not seen as a high priority by governments. Not only are the detection rates low or even almost non-existent; identified chronic hepatitis is often left untreated, with less than 20% of the patients receiving treatment. That explains why every year no less than 125 000 Europeans die from various hepatitis-related diseases such as liver cancer, liver cirrhosis, blood infection or HIV.

The lack of political focus may be explained by the “class stigma” of hepatitis diseases. High-risk groups for acquiring and spreading the disease are injection drug users, children of infected mothers, professional sex workers, prison inmates, migrant populations and men having sex with men. These people have little political clout. Policy makers should be aware that among the risk groups are healthcare staff as well as patients on blood dialysis. Lack of political awareness and focus eventually puts the general population at risk.

The Euro Hepatitis Index makes a comprehensive diagnosis of 30 European countries with regard to the capacity to handle the hepatitis threat. The Index not only provides a cross-Europe description of problems and opportunities but also offers an analysis of each country, with a recipe for forming a national hepatitis agenda. Thus the Index can be seen, and hopefully used, as a checklist for repairing and improving the conditions for millions of people in Europe. Implementation of a pan-European best practice would be essential. The EU has the authority to address this issue – but maybe practical life-saving cannot compete with the many rivaling attractions on the steadily expanding EU pallet?

The Health Consumer Powerhouse gratefully acknowledges the financial support from ELPA (European Liver Patient Association) making possible this piece of reality research and the co-operation with EASL (European Association for Study of the Liver).

Brussels, November 6, 2012

Johan Hjertqvist  
Founder & President  
Health Consumer Powerhouse

## **1. Summary**

### **1.1 What country provides good Hepatitis Care?**

Looking at the ranking results, the first thing that comes to mind is the good feeling that the positions of the countries in the Euro Hepatitis Index are independent of the hepatitis B and/or C prevalence, and hence probably more dependent on national variations in addressing the problem. Apart from a couple of indicators the ranking also seems unrelated with GDP per capita. The ranking, particularly positions 10 – 20 among the 30 countries, is noticeably influenced by the lack of data on the sub-discipline Outcomes (actual treatment results). Otherwise countries like Denmark, The Netherlands or Finland could climb into the top ten.

The scoring has intentionally been done in such a way that the likelihood that two states should end up sharing a position in the ranking is almost zero. It must therefore be noted that great efforts should not be spent on in-depth analysis of why one country is in 13<sup>th</sup> place, and another in 16<sup>th</sup>. Very subtle changes in single scores can modify the internal order of countries, particularly in the middle of the ranking list.

In general for those indicators finally included in the Index, access to data is quite good, apart from indicators on actual treatment results (“Outcomes”). This is unfortunately a very common condition for healthcare monitoring in Europe on almost all disease areas. The Index project has been trying to be very cautious and fair and not punish countries for their national epidemiological situation.

### **1.2 Top performances in the Index. What are they doing well?**

Good hepatitis care provision requires a number of well-implemented and coordinated programmes and actions, able to reach infected patients belonging to different parts of society. Patients are frequently unaware of their condition; at risk of being infected or on the way of infecting someone. Even in countries where national hepatitis plans are implemented, the rate of detected patients is less than 40%. That leads to a high risk for the health system, because natural progression of the viral infection may lead to cirrhosis and liver cancer, both very difficult to treat.

**In general, good hepatitis care starts with raising both professional and public awareness as an important component of reducing the burden of undiagnosed infection.**

It is also necessary to have implemented:

- Effective hepatitis B vaccination programmes for infants, children, adolescents and risk groups. The vaccines must be free of charge or reimbursed, at least for the main risk groups. It is well demonstrated that this improves coverage.
- Easily available and free-of-charge screening programmes for general population and for the main risk groups. Pre- and post-counselling need to be available to ensure that the patient understands and has a free choice to be tested, and in case the result is positive, the different options to be followed.
- Access to high quality treatment and care. Antiviral treatments, which will successfully clear the virus in the majority of patients, are available in most countries. However, for optimal treatment and care three components are necessary;

- effective strategies to increase the share of infected people admitted into medical care which requires good understanding of the infection and its treatment from the health care provider
- subsidized/reimbursed treatment
- appropriate patient education to optimize treatment results.
- qualified professionals, to optimize the processes and the management of the disease according to best practice. This includes professionals (such as specialist nurses) dedicated to providing patient education.
- good registries for proper data acquisition to analyse in detail the disease patterns and where to use available resources in the best way possible, to facilitate detection and reviewing areas for improvement.

The Euro Hepatitis Index 2012 shows France (872 points out of a maximum possible of 1000) as the country with the best hepatitis care delivery in Europe. It is well known that France, together with Scotland, has some of the best practice regarding hepatitis care<sup>1,2,3</sup>. These two countries are the only which have had an implemented national hepatitis strategy plan for several years.

Part of the French viral hepatitis strategy includes an annual mass-media campaign targeted at the general public as well as specific campaigns to raise awareness among healthcare workers and groups at high risk.

Prevention and control of viral hepatitis has been considered a public health priority in France since the early 1990s. During the last decade, further progress has been made in reducing morbidity and mortality due to viral hepatitis. However, vaccination of target groups for hepatitis B immunization (persons at risk, infants, children and adolescents) remains insufficient<sup>4,5</sup>, which is also reflected in the EHepI.

French national hepatitis programmes have resulted in effective screening campaigns, very good access to treatment and enhanced hepatitis surveillance systems. An extensive network of hepatology reference centers and excellent hepatitis research programmes across the country have also come out of these programmes. In conclusion: very good performance but still room for improvement!

Second in the ranking is Slovenia at 827 points. The situation in Slovenia is in the hands of very engaged clinicians. Being a small country has the advantage that it makes coordinated management of hepatitis care possible from the hospital level. In Slovenia there are a number of hospitals and drug units around the country coordinating their performance. Reporting and epidemiology data is very limited in Slovenia; Health officials are often not aware of the real clinical performance, and base their knowledge on a very limited “obligatory” surveillance system.

Slovenian performance is very good in sub-disciplines such as Prevention, Case Finding or Access to Treatment and Process. Slovenians should thank their very dedicated physicians for this.

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<sup>1</sup> Delarocque-Astagneau E, Meffre C, Dubois F et al., 2010

<sup>2</sup> NHS Scotland, 2011

<sup>3</sup> Hatzakis, A., Wait, S. *et al.*, 2011

<sup>4</sup> Gautier, A. & Jestin, C.; 2009,

<sup>5</sup> Partouche H. *et al.*; 2012

Third place in the Index is taken by Germany (797 points), a country performing very well in most sub-disciplines. Very good at prevention and case finding and exceptional at Access to treatment, a general strong point of the German healthcare system. Germany practices general vaccination of all newborns since 1995. In addition to that, they have several programmes for different vaccination groups and implemented Screening programmes for a number of groups of population at risk (See tables 8.1 and 8.2.1, 8.2.2).

Less encouraging about Germany was the discovery that national government does not have viral hepatitis among its priorities. Awareness campaigns and education are in the hands of physician societies and patients' organizations. These will soon be launching a German national hepatitis strategy, which has been privately funded.

After the three first countries, four countries follow within 16 points. The present internal order of these four could be modified by any small change in the data:

Sweden, (766 points) does not have general Infant vaccination but currently reviews plans for introducing universal Hepatitis B vaccination in the near future<sup>6</sup>. There are several vaccination programmes implemented in the country to approach population at risk, as can be seen from Tables 8.1. Sweden does not have a National Hepatitis Strategy but hepatitis prevention is included in the national HIV prevention strategy. Sweden has an exceptional reporting system, probably the best system and data collection in Europe<sup>7</sup> and very good performance on Access to Treatment and Process, and also on Case Finding and Screening.

Very close in the ranking is Portugal (765 points). Again, like Slovenia, in Portugal there is very minimal epidemiological research and surveillance is not optimal. Additionally, no National screening guidelines are in place. Most information collected in the Index comes from unpublished data presented by a large number of knowledgeable physicians.

In Italy (752) data and performance vary greatly between regions, which is an observation that the HCP has made also in previous European Indexes. It is difficult to find national data on anything, and this is not different for viral hepatitis. Screening, surveillance and Access to Treatment/Process are in general very asymmetric from north to south. Italy is 6<sup>th</sup> in the ranking mainly because of excellent performance on Outcomes.

The U.K (750 points) is a country with relatively low prevalence of Hep B and C infections. They have good Prevention programmes, in spite of not including universal Hep B vaccination at birth or during childhood because of a governmental concern that this may not be cost effective. Ongoing studies in Scotland with a new vaccine (MF59-adsorbed HBsAg<sup>\*,\*\*</sup>) may change this in coming years.

Their guidelines include recommendations for vaccination for a large number of groups at risk. However, it would seem that there is room to improve vaccination coverage. U.K performance in case finding and screening could improve. Neither screening policies nor guidelines include all groups who are of relevance to control the disease. Access to treatment is good and the development of clinical networks and multidisciplinary teams has been essential to improve care delivery. UK is also one of the few countries that have introduced hepatitis specialist nurses, which has led to a good, continuous service for patients.

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<sup>6</sup> JunQing Chu *et al*; 2012

<sup>7</sup> Cornberg *et al*; 2011

\* An **adjuvant** is a pharmacological or immunological agent that modifies the effect of other agents, such as a drug or vaccine. They are often included in vaccines to enhance the recipient's immune response to a supplied antigen, while keeping the injected foreign material to a minimum.

\*\* **HBsAg**; the surface antigen of the hepatitis B virus.



## 2. Results of the Euro Hepatitis Index 2012

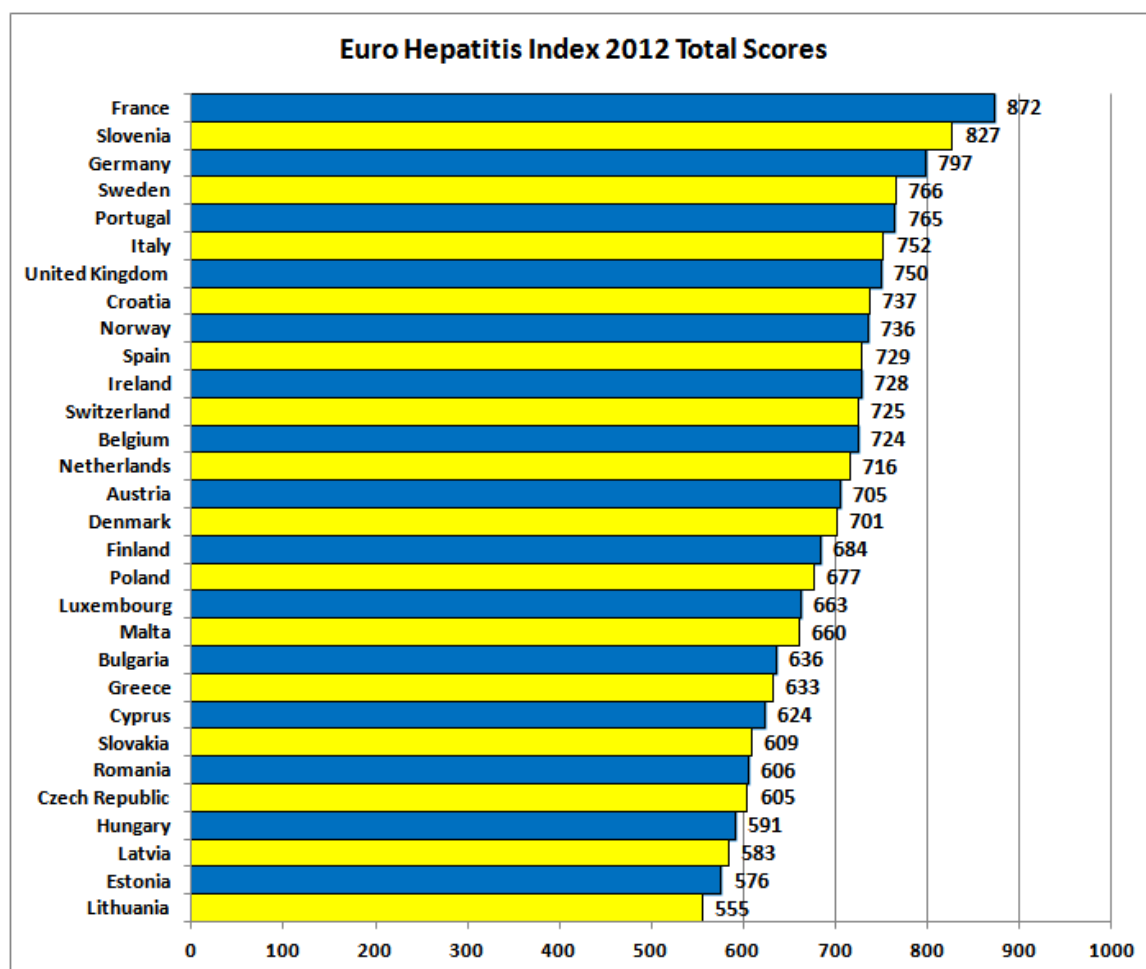
### Euro Hepatitis Index 2012

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																
	<b>Subdiscipline weighted score</b>		210	236	183	236	196	183	223	196	223	210	249	196	170	249	236
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																
	<b>Subdiscipline weighted score</b>		150	163	113	175	163	138	163	100	150	200	175	150	175	163	150
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?																
<b>Subdiscipline weighted score</b>		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?																
	<b>Subdiscipline weighted score</b>		69	83	97	83	56	56	69	56	83	97	69	69	56	83	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.			
	<b>Subdiscipline weighted score</b>		117	83	83	83	50	50	50	83	50	150	117	67	50	83	133
<b>Total score</b>			705	724	636	737	624	605	701	576	684	872	797	633	591	728	752
<b>Rank</b>			15	13	21	8	23	26	16	29	17	1	3	22	27	11	6

# Euro Hepatitis Care Index 2012

Sub-discipline	Indicator	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Prevention	1.1 Public awareness about hepatitis															
	1.2 % Universal infant HBV vaccination coverage														n.ap	
	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															
	<b>Subdiscipline weighted score</b>		157	157	223	236	236	210	183	223	170	183	249	236	183	249
2. Case finding/ screening	2.1 Free anonymous hepatitis testing and counselling															
	2.2 Hepatitis C testing in the community															
	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															
	<b>Subdiscipline weighted score</b>		100	100	138	188	150	200	175	188	138	138	200	163	200	150
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							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.											
	3.7 Hepatitis specialist nurses?															
	3.8 Is there an HCC registry?															
<b>Subdiscipline weighted score</b>		159	131	197	131	197	188	169	169	131	169	206	178	216	188	188
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					n.ap				
	4.3 Governmental funding of Hepatitis strategy?															
	<b>Subdiscipline weighted score</b>		83	83	56	56	83	56	83	69	83	69	56	69	83	56
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.	
	<b>Subdiscipline weighted score</b>		83	83	50	50	50	83	67	117	83	50	117	83	83	83
<b>Total score</b>		583	555	663	660	716	736	677	765	606	609	827	729	766	725	750
<b>Rank</b>		28	30	19	20	14	9	18	5	25	24	2	10	4	12	7

## 2.1 Results Summary



### 2.1.1 Country scores

There are no countries, which excel across the entire range of EHepI indicators. The national scores seem to reflect more of “national and organisational cultures and attitudes”, rather than mirroring how large resources a country is spending on healthcare. The cultural streaks have in all likelihood deep historical roots. Turning a large corporation around takes a couple of years – turning a country around can take decades!

## 2.1.2 Results in “Pentathlon”

The EHepI 2012 is made up of five sub-disciplines. As no country excels across all aspects of measuring a healthcare system, it can therefore be of interest to study how the 30 countries rank in each of the five parts of the “pentathlon”. The scores within each sub-discipline are summarized in the following table:

# Euro Hepatitis Index 2012

Sub-discipline	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom	
<b>1. Prevention</b>	210	236	183	236	196	183	223	196	223	210	249	196	170	249	236	157	157	223	236	236	210	183	223	170	183	249	236	183	249	236	
<b>2. Case finding/ screening</b>	150	163	113	175	163	138	163	100	150	200	175	150	175	163	150	100	100	138	188	150	200	175	188	138	138	200	163	200	150	163	
<b>3. Access to treatment and process quality</b>	159	159	159	159	159	178	197	141	178	216	188	150	141	150	150	159	131	197	131	197	188	169	169	131	169	206	178	216	188	188	
<b>4. National Strategy/ Patient involvement and rights</b>	69	83	97	83	56	56	69	56	83	97	69	69	56	83	83	83	83	56	56	83	56	83	69	83	69	56	69	83	83	56	97
<b>5. Outcomes</b>	117	83	83	83	50	50	50	83	50	150	117	67	50	83	133	83	83	50	50	50	83	67	117	83	50	117	83	83	83	67	
	705	724	636	737	624	605	701	576	684	872	797	633	591	728	752	583	555	663	660	716	736	677	765	606	609	827	729	766	725	750	
	15	13	21	8	23	26	16	29	17	1	3	22	27	11	6	28	30	19	20	14	9	18	5	25	24	2	10	4	12	7	

As the table indicates, the total top position of the French healthcare system is to a great extent a product of an even performance across the sub-disciplines, good Prevention and Case finding and screening approaches and excellent in Access to treatment and Process, National Strategy/ Patient involvement and rights and the only country scoring “all Green” on Outcomes.

Slovenia does well on Prevention strategies, very good results on Access and in general high scores in all sub-disciplines.

Sub-discipline	Top country/countries	Top Scores	Maximum score
<b>1. Prevention</b>	Germany, Ireland, Slovenia, Switzerland	249	275
<b>2. Case finding/Screening</b>	France, Norway, Slovenia, Sweden	200	225
<b>3. Access to treatment/Process</b>	France, Sweden	216	225
<b>4. National Strategy/ Patient involvement and rights</b>	France, Bulgaria, UK	97	125
<b>5. Outcomes</b>	France	150	150

### **3. Areas for improvement**

#### **3.1 Prevention efforts**

##### **3.1.1 Public awareness**

A high number of people potentially infected with HBV/HCV is unaware that they are chronically infected with hepatitis, they may not know that they are infectious to other people and they may benefit from the recent advances in new combination treatments for hepatitis. General community awareness could provide tangible health benefits to these people. Special awareness should be on (depending on each country) those populations at higher risk, which can and also be extremely marginalized, should be observed.

Additionally, campaigns and training for health care workers (nurses, physicians, public health experts, NGOs and other professionals working in the field) should be promoted to improve vaccination coverage, case finding and optimal treatment to address medical and social needs of individuals. Increased awareness should also help to reduce potential discrimination.

##### **3.1.2 Vaccination strategies**

Good vaccination programmes would be the cornerstone of prevention strategies against Hepatitis B. Public awareness of hepatitis and its risks and the relevancy of being vaccinated needs to be promoted. Physicians (particularly primary care doctors and pediatricians) should inform about and promote Hepatitis B vaccination. These doctors should also be involved in case finding programs.

It is disappointing to see the big contrast between the data on Universal vaccination programmes, where in general the outcomes are very positive, and the coverage for vaccination of risk groups. Throughout Europe, standards are very different and population coverage also varies a lot from country to country. In general, the Index study found two groups, Commercial sex workers and Men who have sex with men (MSM), both included among the high risk groups of “people with multiple sex partners” who are not well reached in almost any country. Good practice and good examples exist in Europe but there are typically only small projects on short-term budgets and no systematical long-term implementation<sup>8,9</sup>.

Vaccination should be free for all risk groups, depending on the situation in each country, including; Children (Universal vaccination programmes) and adolescents, newborns from HBsAg positive mothers, Health workers, IDU, Commercial sex workers, MSM, Prison inmates, Migrant populations, Ethnic minorities etc.

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<sup>8</sup> Sethi *et al*, 2006

<sup>9</sup> Baars *et al*, 2010

### **3.1.3 Situation in Prisons**

Across Europe, as well as globally, high average rates of hepatitis C, hepatitis B and HIV are seen in prison populations. This has been attributed to higher levels of injection drug use, tattooing and unsafe sexual activity occurring both in prisons and among individuals more likely to have to spend time in prison<sup>10,11,12</sup>.

Due to the high proportion of drug users in prisons, and the repetition of risk behaviours, prison settings provide both the opportunity and the need to promote awareness and to deliver prevention, treatment and care.

Vaccination and/or testing and access to treatment when necessary should be, together with pre- and post-test counselling, provided on a voluntary basis in all prisons.

## **3.2 Access to testing and treatment: Multidisciplinary teams approach**

### **3.2.1 Testing**

Rates of testing and diagnosis for hepatitis are low almost everywhere; the majority of people who have hepatitis globally are undiagnosed. Because Hepatitis B and C are largely asymptomatic, testing is necessary to determine whether someone has been exposed to the virus and to identify chronic HBV and HCV carriers in order to offer those positive patients all necessary support, as well as further assessment and, when appropriate, antiviral treatment. Early testing can prevent transmission and improve treatment effectiveness and quality of life. Since there is not Hep C vaccination, prevention efforts of HCV infection must be concentrated on the development of health education programmes targeting high-risk populations, and public campaigns to raise awareness in the general community that improve testing and case finding.

General practitioners are essential key players for improving case finding, vaccination and awareness of hepatitis among general population. Because of their close and regular relationship with their patients, well trained family doctors can make an impact in reducing the number of unaware people and increase the number of people being vaccinated against Hepatitis B. Hepatology and Gastroenterology Societies all around Europe, as well as patient organization and some governments, provide basic levels of information in the form of leaflets normally including an insight into the symptoms, the course of the disease and treatment. We know of more and more complex training course for family doctor and nurses being develop. Unfortunately, it is not so often as expected to find governments spending resources on this, probably because Hepatitis B and C do not represent (or they are not aware) one of the main burden diseases in their countries.

Testing should be available and easy to access for all members of the community, especially to all those at higher risk, as well as voluntary and confidential if desired. Any kind of barrier as cost, confidentiality, lack of health insurance etc can prevent individuals from approaching testing. **Free access for anonymous testing and counselling** are services normally at least partially offered outside of the normal health care setting with the idea to promote the participation of groups that will not be reached

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<sup>10</sup> Majó Roca, X. *et al*, 2011

<sup>11</sup> Jürgens, Q., 2009

<sup>12</sup> Stöver *et al*, 2008

otherwise. There are good examples of testing in Europe especially in NSP (Needle exchange programmes) setting, NGOs working with MSM and others (Ref. 8), but these are not available, or available in a very limited way, in many countries.

In general, testing in main risk groups is far from being optimal in Europe. An overview of the different countries shows that neither Screening policies, guidelines or systematic practice provide good coverage for the whole spectrum of individuals at risk.

### **3.2.2 Treatment:**

All countries should develop plans to improve access to treatment services.

Antiviral treatment is easily available in most countries. The cost of retroviral drugs or the timing to receive treatment can impede proper care.

High quality, accessible care (possibly in non traditional settings, *i.e.* outside clinics or hospitals) should be provided to improve results and adherence to treatment.

In parallel, trained professionals such as specialist nurses should provide health education to patients to improve adherence to and efficiency of treatments<sup>13</sup>.

In conclusion, professionals such as GP:s, nurses, pharmaceutical services, patient organizations and other health and social services workers are in positions to help raise awareness in the general population and in risk groups, encourage testing and treatment and to provide comprehensive support. They need to be trained to identify people at risk of infection and qualified to make early diagnosis and improve the uptake of treatment.

## **3.3 Registries, data and national strategies**

### **3.3.1 Hepatitis Data and registries**

In general, good availability of quality data is difficult to find in Europe. Data is often not collected nationally, only in some hospital or region. Additionally, there were limitations in the comparability of some of the data collected. It has been suggested that some kind of European registry must be created, where information on a large number of indicators would be collected using uniform definitions. One good example could be the EUBIROD project in the diabetes field (for more information <http://www.eubirod.eu/index.html>).

Some of the indicators included in the project initially were dropped because of lack of information. Some examples are: “number of hepatitis patients on treatment?”, “% of people at risk for HCC screened for liver cancer” and “% of dropout during treatment”. Also, in sub-discipline Outcomes, the data on “mother-to-child transmission rate”.

**Hepatocellular carcinoma (HCC) registries** need to be created and/or improved in most countries. Some HCC registries are available in Europe. However we found that they are not always or nor regularly updated, and the underlying cause is often not distinguished,

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<sup>13</sup> Larrey, D., 2012

thereby not providing good monitoring tools for improvement of service delivery and outcomes.

### **3.3.2 European lack of National action plans**

A framework or action plan provides an effective and coordinated response from all levels of government, the community, voluntary organizations, the health sector, scientific and research communities and people affected by hepatitis. Effective action plans are developed with all stakeholders working in the area of hepatitis and are linked with other relevant government policies such as those concerning drug use and public health.

The European Union should develop a European Strategy based on scientific evidence, and encourage member states to develop and implement national strategies accordingly. National and European drug strategies should include actions, guidelines and strategies for integrating and providing prevention, diagnosis and treatment services (ref. 3 and 11).

Only France, together with Scotland, have a public funded National Strategy in place so far. England is planning to have their national strategy ready by end of 2012 and Bulgaria just made the first movements in the same direction. In Croatia the health ministry has appointed a task force to design a national hepatitis action plan. In Germany the National strategy is also planned to be ready soon. However after the efforts from different organizations to get governmental support and funding, the strategy is being privately funded.

## **4. Background**

### **4.1 General information about hepatitis B and C**

“Hepatitis” means inflammation of the liver, most commonly caused by a viral infection.

Viral hepatitis refers to a set of at least five viruses that are known to cause hepatitis: hepatitis A (HAV), hepatitis B (HBV), hepatitis C (HCV), hepatitis D (HDV), and hepatitis E (HEV).

Infection with hepatitis B and C virus (HBV and HCV, respectively) affects the liver and results in a broad spectrum of disease outcomes. An infection with HBV can spontaneously resolve and lead to protective immunity, result in a chronic infection and, in rare cases, cause acute liver failure with a high risk of dying.

HBV: In patients infected in early life, the immune system initially tolerates the infection, which means liver damage and symptoms do not appear<sup>14</sup>. However, after a number of

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<sup>14</sup> Foundation for liver research, 2004



years or decades, the immune systems begin to fight the virus and signs of chronic hepatitis and liver damage appear.

In patients infected as adults or older children (more than five), the immune-response and symptoms of hepatitis develop much more quickly.

An infection with HCV becomes chronic in most cases. People with chronic hepatitis B and/or C virus infection remain infectious to others and are at risk of serious liver disease such as liver cirrhosis or hepatocellular cancer (HCC) later in life<sup>15</sup>.

The World Health Organization estimates that worldwide two billion people have been infected with the **hepatitis B** virus and more than 350 million have chronic (long-term) liver infections. Most are unaware of their infection.

About 600 000 people die every year due to the acute or chronic consequences of hepatitis B.

A vaccine against hepatitis B has been available since 1982. Hepatitis B vaccine is 95% effective in preventing HBV infection and its chronic consequences, and is the first vaccine against a major human cancer.

Every year, 3–4 million people are new infected with the **hepatitis C** virus. About 150 million people are chronically infected and at risk of developing liver cirrhosis and/or liver cancer. More than 350 000 people die from hepatitis C-related liver diseases every year and the number is increasing. As acute Hepatitis C rarely causes symptoms, it often goes undiagnosed and therefore untreated. There is currently no vaccine for hepatitis C, therefore prevention must be concentrated on awareness and testing, and treatment when appropriate.

## **4.2 Background of Health Consumer Powerhouse**

Since 2004 the HCP has been publishing a wide range of comparative publications on healthcare in various countries. First, the Swedish Health Consumer Index in 2004 ([www.vardkonsumentindex.se](http://www.vardkonsumentindex.se), also in an English translation). By ranking the 21 county councils by 12 basic indicators concerning the design of "systems policy", consumer choice, service level and access to information we introduced benchmarking as an element in consumer empowerment. In two years time this initiative had inspired – or provoked – the Swedish Association of Local Authorities and Regions together with the National Board of Health and Welfare to start a similar ranking, making public comparisons an essential Swedish instrument for change.

For the pan-European indexes in 2005 – 2008, HCP aimed to basically follow the same approach, *i.e.* selecting a number of indicators describing to what extent the national healthcare systems are "user-friendly", thus providing a basis for comparing different national systems.

Furthermore, since 2008 the HCP has enlarged the existing benchmarking program considerably:

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<sup>15</sup> Hepatitis C in the UK, 2011

- In January 2008, the Frontier Centre and HCP released the first Euro-Canada Health Consumer Index, which compared the health care systems in Canada and 29 European countries. The 2009 edition was released in May, 2009.
- The Euro Consumer Heart Index, launched in July 2008, compares 29 European cardiovascular healthcare systems in five categories, covering 28 performance indicators.
- The first edition of Canada Health Consumer Index was released in September 2008 in co-operation with Frontier Centre for Public Policy, examining healthcare from the perspective of the consumer at the provincial level.
- The Euro Consumer Diabetes Index, launched in September 2008, provides the first ranking of European diabetes healthcare services across five key areas: Information, Consumer Rights and Choice; Generosity, Prevention; Access to Procedures and Outcomes.
- The Euro HIV Index 2009 measured 29 European countries in this first survey of HIV policy and best practice.
- The 2012 edition of the Euro Health Consumer Index covers 42 healthcare performance indicators for 34 countries.

Though still a somewhat controversial standpoint, HCP advocates that quality comparisons within the field of healthcare is a true win-win situation. To the consumer, who will have a better platform for informed choice and action. To governments, authorities and providers, the sharpened focus on consumer satisfaction and quality outcomes will support change. To media, the ranking offers clear-cut facts for consumer journalism with some drama into it. This goes not only for evidence of shortcomings and method flaws but also illustrates the potential for improvement. With such a view the EHCI is designed to become an important benchmark system supporting interactive assessment and improvement.

As we heard one of the Ministers of health saying when seeing his country's preliminary results: "It's good to have someone still telling you: you could do better."

### **4.3 Index scope**

The aim has been to select a limited number of indicators, within a definite number of evaluation areas, which in combination can present a telling tale of how the healthcare consumer is being served by the respective systems.

### **4.4 About the authors**

Project Management for the EHepI 2012 was executed by **Beatriz Cebolla, Ph.D.**

Dr. Cebolla joined the Health Consumer Powerhouse the first time in 2007 as project manager for the Diabetes Health Care index, presented in 2008, and the Euro HIV Index 2009.

In 2011, she finished her Master in Public Health with a final thesis about quality assurance in Health care.

Previously she was working as a researcher (Molecular Biology) for more than 10 years in prestigious research Institutes, among them Institute for Molecular Pathology (IMP) in Vienna and the Biomedical Research Institute in Madrid (IIB/CSIC) where she finished her PhD in Biomedicine in 2004.

**Arne Björnberg, Ph.D.:** Chairman & Chief Operating Officer of the Health Consumer Powerhouse. Dr. Björnberg has previous experience from Research Director positions in Swedish industry. His experience includes having served as CEO of the Swedish National Pharmacy Corporation ("Apoteket AB"), Director of Healthcare & Network Solutions for IBM Europe Middle East & Africa, and CEO of the University Hospital of Northern Sweden ("Norrlands Universitetssjukhus", Umeå).

Dr. Björnberg was also the project manager for the EHCI 2005 – 2012 projects, the Euro Consumer Heart Index 2008 and numerous other Index projects.

## **5. How to interpret the Index results?**

The first and most important consideration on how to treat the results is: with caution!

The Euro Hepatitis Index 2012 is an attempt at measuring and ranking the performance of healthcare provision from a consumer viewpoint. The results definitely contain information quality problems. There is a shortage of pan-European, uniform set procedures for data gathering. Still, European Commission attempts to introduce common, measurable health indicators have made very little impact.

The HCP finds it far better to present the results to the public, and to promote constructive discussion rather than staying with the only too common opinion that as long as healthcare information is not a hundred percent complete it should be kept in the closet. Again, it is important to stress that the Index displays consumer information, not medically or individually sensitive data.

While by no means claiming that Hepatitis Index results are dissertation quality, the finding should not be dismissed as random findings. Behind this results there are along number of very high standard professionals and knowledgeable experts in the field of hepatitis and liver diseases as well as National representatives from all over Europe. This project is the result of months of research and discussion. The HCP hopes that the Index helps the improvement of the European hepatitis care.

## **6. European data shortage**

### **6.1 Medical outcomes indicators included in the EHepI**

There is one predominant feature, which characterises European/Canadian public healthcare systems as opposed to their more industrialised counterparts in countries such

as the U.S.A.: there is an abundance of statistics on input of resources, but a traditional scarcity of data on quantitative or qualitative *output*.

Organisations such as the WHO and OECD are publishing easily accessible and frequently updated statistics on topics like:

- the number of doctors/nurses per capita
- hospital beds per capita
- share of patients receiving certain treatments
- number of consultations per capita
- number of MR units per million of population
- health expenditure by sources of funds
- drug sales in doses and monetary value (endless tables)

Systems with a history of funding structures based on grant schemes and global budgeting often exhibit a management culture, where monitoring and follow-up is more or less entirely focused on input factors. Such factors can be staff numbers, costs of all kinds (though not usually put in relation to output factors) and other factors of the nature illustrated by the above bullet list.

Healthcare systems operating more on an industrial basis have a natural inclination to focus monitoring on *output*, and also much more naturally relate measurements of costs to output factors in order to measure productivity, cost-effectiveness and quality.

The EHepI project has endeavoured to obtain data on the quality of actual healthcare provided. As can be seen in the high number of **n.a.** scores on the Outcomes indicators, data on actual treatment results have been hard to find.

## **7. Euro Hepatitis Care Index 2012**

The hepatitis project is an effort from the main European Patient organization working in the liver disease field, ELPA (the European Liver Patients Association) and the Health Consumer Powerhouse to compile information about hepatitis healthcare in Europe. ELPA and HCP were supported in their endeavours by EASL (the European Association for the Study of the Liver). The hepatitis care index project started in Brussels in January 2012 with a kick-off meeting where ELPA board members as well as EASL representatives and HCP agreed on a close cooperation to bring up quality information.

It is the first time that so many clinicians participate in a project of this nature. Their views have been essential to distinguish between what is described through protocols, guidelines or policies, and what happens in reality in day-to-day practice.

It is relevant to highlight that this disease like few others seems to be improving in some countries mainly by the continuous efforts of clinicians who often are taking the initiative, going ahead of any kind of policy established in the country. Presumably without their effort and persistence the situation in Europe would be a lot more alarming.

30 countries, the 27 EU member states plus Switzerland, Norway and Croatia have been included in this project.

It has been deemed important to have a mix of indicators in different fields; areas of service attitude and customer orientation as well as indicators of a “hard facts”-nature showing healthcare quality in outcome terms.

## 7.1 Indicator areas (sub-disciplines)

In the final form the Index is built up by 27 indicators grouped in five sub-disciplines as shown in the next table:

Sub-discipline	Number of indicators
1. Prevention	7
2. Case finding/Screening	6
3. Access to treatment/process	8
4. National Strategy/ Patient involvement and rights	3
5. Outcomes	3

As a novelty in this Project “**indicator scoring**“ was introduced. The expert panel members made a systematic and organized scoring on a long list of very interesting indicators on relevance, scientific soundness and measurability. This exercise ended up with 33 indicators that were considered relevant for the Index. From those some had been discarded for data availability reasons.

## 7.2 Scoring in the EHepI 2012

The performance of the respective national healthcare systems were graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of Green = good (👍), Amber = so-so (👎) and red = not-so-good (👎). A green score earns 3 points, an amber score 2 points and a red score (or a “not available”, **n.a.**) earns 1 point.

The “**n.ap.**” score, which earns 2 points, was applied to countries such as Estonia or Slovenia on the indicator “Treatment of children in specialist units” because they only have few children infected (definitely single-figure numbers).

Since 2006, the same methodology has been used: For each of the sub-disciplines, the country score is calculated as a percentage of the maximum possible (*e.g.* for Waiting times, the score for a state has been calculated as % of the maximum  $3 \times 5 = 15$ ).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added up to make the final country score. These percentages were then rounded to a three digit integer, so that an “All Green” score on the 42 indicators would yield 1000 points.

### 7.3 Weight coefficients

The possibility of introducing weight coefficients was discussed already for the EHCI 2005, *i.e.* selecting certain indicator areas as being more important than others and multiplying their scores by numbers other than 1.

For the EHCI 2006 explicit weight coefficients for the five sub-disciplines were introduced after a careful consideration of which indicators and sub-disciplines should be considered for higher weight. For the EHepI 2012, Prevention and Case finding/screening as well as Access to treatment and process were decided as the main candidates for higher weight coefficients based mainly on discussions with the expert panels, who considered those sub-disciplines to be the most relevant for the proper management of the disease. The number of indicators in each sub-discipline and the quality of the data acquired for each indicator were also taken into account. In the EHepI 2012, the scores for the five sub-disciplines were given the following weights:

<b>Sub-discipline</b>	<b>Relative weight (“All Green” score contribution to total maximum score of 1000)</b>	<b>Points for a Green score in each sub-discipline</b>
Prevention	275	40
Case finding/Screening	225	45
Access to treatment/ Process	225	28
National Strategy/ Patient involvement and rights	125	42
Outcomes	150	50
<b>Total sum of weights</b>	<b>1000</b>	

Consequently, as the percentages of full scores were added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a national healthcare system in the Index is 1000, and the lowest possible score is 333.

It should be noted that, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, the final ranking of countries presented by the EHepI 2012 is remarkably stable if the weight coefficients are varied within rather wide limits.

The project has been experimenting with other sets of scores for green, amber and red, such as 2, 1 and 0 (which would really punish low performers), and also 4, 2 and 1, (which would reward real excellence). The final ranking is remarkably stable also during these experiments.

### 7.4 Regional differences within European states

The HCP is well aware that many European states have very decentralised healthcare systems. Not least for the U.K. it is often argued that “Scotland and Wales have separate

NHS services, and should be ranked separately”. In this project, for the first time it was considered to introduce Scotland as a separate service, considering its well known excellence regarding Hep C management. Finally, as there are several indicators related with Hepatitis B in the project, it was decided to proceed like in previous Indices. Anyway, the uniformity among different parts of the U.K. is probably higher than among regions of Spain and Italy, Bundesländer in Germany and possibly even than among counties in tiny 9½ million population Sweden.




Grading healthcare systems for European states does present a certain risk of encountering the syndrome of “if you stand with one foot in an ice-bucket and the other on the hot plate, on average you are pretty comfortable”. This problem would be quite pronounced if there were an ambition to include the U.S.A. as one country in a Health Consumer Index.

As equity in healthcare has traditionally been high on the agenda in European states, it has been judged that regional differences are small enough to make statements about the national levels of healthcare services relevant and meaningful.




## 7.5 Indicator definitions and data sources for the EHepI 2012




The aim has been to select a limited number of indicators, within a definite number of evaluation areas, which in combination can present a telling tale of how the healthcare consumer is being served by the respective systems.

It is important to notice, that in this project we almost did not use any hard data or European data base for any indicator. Most data is coming from interviews with National health care officials, public health experts and physicians. The data has been reviewed through different validation and feedbacks.

Sub-discipline	Indicator	Explanatory comment	 Score 3	 Score 2	 Score 1	Main Information Sources
<b>1. Prevention</b>	<b>1.1 Public awareness about hepatitis</b>	a) Have there been public campaigns about viral hepatitis and its risks during the last 12 months? On TV? On radio? Newspapers? b) Are there leaflets in Healthcare centers about viral hepatitis?	Yes, recently and promoted by National funding/ Leaflets easy to find in most healthcare centers.	Not in the last 12 months, but during the last few years/ It has been paid by NGOs or other organizations / Leaflets not in some healthcare centers.	NO, no awareness campaigns, leaflets in health care centers not easy to find.	Interviews with health care officials, national physicians and public health experts.
	<b>1.2 % Universal infant HBV vaccination coverage</b>		≥ 90%	90-70 %	< 70% or No Universal Infant vaccination program.	Interviews with health care officials, national physicians and public health experts and ECDC report "Surveillance and prevention of hepatitis B and C in Europe" 2010.
	<b>1.3 Vaccination in risk population</b>	Health Care Workers, Commercial Sex Workers, Partners to and persons living with HBV-infected persons, IDU, MSM, Prison population.	Main risk groups (6-5 out of 6) vaccinated.	≥ 4 risk groups vaccinated	Only 1-3 of the 6 main risk groups vaccinated	<a href="http://www.emcdda.europa.eu/stats12/hsrtab6a">http://www.emcdda.europa.eu/stats12/hsrtab6a</a> . Completed with information from Interviews with health care officials, national physicians and public health experts.
	<b>1.4 HBV Vaccination payment</b>		100 % subsidised (= no co-payment) free of charge to the individual (priority or risk groups)	Partially subsidised, or only free for some priority or risk groups.	Only free for infants, all others including main risk groups pay 100% privately.	Interviews with health care officials, national physicians and public health experts.
	<b>1.5 Universal ante-natal HBV screening</b>		Yes, it is offer to every pregnant woman (Mandatory)	Yes, it is normally offered. Screening programme not in place	Not on regular basis	Interviews with health care officials, national physicians and public health experts and ECDC report "Surveillance and prevention of hepatitis B and C in Europe" 2010.



Sub-discipline	Indicator	Explanatory comment	 Score 3	 Score 2	 Score 1	Main Information Sources
	<b>1.6 Harm reduction in prison</b>	Needle exchange programme; Free available condom distribution; Substitution therapies (OST) Antagonist or agonist ; Bleach	All Prisons	Some prisons	None	WHO Prison Health data base and complete with Interviews with health care officials, responsible Prison services and public health experts.
	<b>1.7 Post exposure immunization for hepatitis B</b>		Yes, available for free to everyone (recommended) in need.	Available to everyone but not free for "non occupational exposure"	Not available or only available for health care staff	Interviews with health care officials, national physicians and public health experts.
<b>2. Case finding/ screening</b>	<b>2.1 Free anonymous hepatitis testing and counselling</b>		Yes, widely available to anyone	Not easy available, not for free, not anonymous, restricted to some risk groups.	Not offered	Interviews with health care officials, national physicians and public health experts.
	<b>2.2 Hepatitis C testing in the community</b>		Full: nearly all persons in need would obtain it	Extensive: a majority but not nearly all would obtain it	Limited: more than a few but not a majority would obtain it	<a href="http://www.emcdda.europa.eu/stats12/hsrtab6b">http://www.emcdda.europa.eu/stats12/hsrtab6b</a>
	<b>2.3 Annual screening for infectious diseases to all IDU</b>		Yes, offered systematically( more or less once a year)	Yes, but not systematically	Not normally offered or not for free	Interviews with health care officials, national physicians and public health experts.
	<b>2.4 Annual HCV antibody testing for HIV- infected persons</b>		Yes, offered systematically( more or less once a year)	Yes, but not systematically	People with HIV do not get screened for hepatitis	Interviews with health care officials, national physicians and public health experts.
	<b>2.5 Is ALT determination routinely prescribed by GPs?</b>		Yes, routinely prescribed	Only if liver disease is suspected	No, it is not often offered	Interviews with health care officials, national physicians and public health experts.
	<b>2.6 Screening funding</b>		100 % subsidized, i.e. free of charge to the individual (= no co-payment)	Partially subsidised, or only free from some priority or risk groups.	100% privately paid	Interviews with health care officials, national physicians and public health experts.

Sub-discipline	Indicator	Explanatory comment	 Score 3	 Score 2	 Score 1	Main Information Sources
<b>3. Access to treatment and process</b>	<b>3.1 Treatment Funding</b>	<b>Do Hepatitis patients get drugs on the same terms as other prescription drugs?</b>	They have special status (higher subsidy = lower co-payment than other patients, or for drugs not related to hepatitis)	They enjoy drug subsidies on the same terms as other patients or for other drugs.	Some drugs, essential for hep patients have a lower subsidy than common prescription drugs, or problem to access modern drugs.	Interviews with health care officials, national physicians and public health experts.
	<b>3.2 Waiting time for specialist appointment</b>		Less than 1 month	Between one month and 3 months	More than 3 months	Interviews with health care officials, national physicians and public health experts.
	<b>3.3 Treatment of children in a specialist unit</b>		All or a very high percent	Only some children or in some areas or hospitals	Only very few or no specialist unit for children	Interviews with health care officials, national physicians and public health experts.
	<b>3.4 Adherence to European (EASL) guidelines (Hep B, Hep C)</b>		Yes, to a high extent	Only partially or National guidelines based on EASL recommendation with modifications according to the country.	To a low extend or other set of guidelines followed.	Interviews with health care officials, national physicians and public health experts.
	<b>3.5 HCV Genotyping</b>		Yes, as a regular practice to all chronic patients before they start treatment	Yes to all chronic patients before they start their treatments but it is not for free	It is not regular practice.	Interviews with health care officials, national physicians and public health experts.
	<b>3.6 Availability of new drugs</b>	telaprevir and boceprevir available to patients	Yes, widely available	Limited availability	No	IMS MIDAS database, 12 months ending June 2012
	<b>3.7 Hepatitis specialist nurses?</b>	<b>With clinical accreditation</b>	Yes, widely available	Only available in some hospitals	None or very few.	Interviews with health care officials, national physicians and public health experts.
	<b>3.8 Is there an HCC registry?</b>		Yes, national	Yes, regional, not well updated, unable to see the underlying cause	Only in some hospitals	Interviews with health care officials, national physicians and public health experts.




Sub-discipline	Indicator	Explanatory comment	 Score 3	 Score 2	 Score 1	Main Information Sources
4. National Strategy/ Patient involvement and rights	4.1 National HCV/HBV(general hepatitis; liver) patient organization?		Yes, national	Only in some regions	None	Interviews with health care officials, national physicians and public health experts.
	4.2 Involvement of patient organisations in health decisions making?	Decisions related with health policies	Yes, statutory	Yes, by common practice in advisory capacity	No, not compulsory or generally done in practice	Interviews with health care officials, national physicians and public health experts.
	4.3 Governmental funding of Hepatitis strategy?		Yes	Strategy in preparation with Public funding	No National strategy/Strategy was or is being private funded	Interviews with health care officials, national physicians and public health experts.
5. Outcomes	5.1 % of patients treated who achieve sustained viral response (SVR} (For HCV)	HCV (all Genotypes)	More than 60 %	60-55%	Less than 60 %	Interviews with health care officials and national physicians, National registries
	5.2 Liver transplants per million population		> 15	15 - 10	< 10	Council of Europe Newsletter 16/2011: International Figures on Donation and Transplantation.
	5.3 Mortality on the waiting list for liver transplant		More than 19 %	18-15 %	Less than 15 %	Interviews with health care officials and national physicians, National registries

Table 7.5: Indicator definitions and data sources for the EHepI 2012

## 7.6 Additional data gathering – surveys

### 7.6.1 Patient surveys

In addition to public sources, a web-based survey to Patient organisations and patients was commissioned from PatientView (PV), Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales, Tel: 0044-(0)1547-520-965, E-mail: [info@patient-view.com](mailto:info@patient-view.com).

A number of Indicators from different sub-disciplines were selected for the survey. There were questions about funding (treatment, vaccination and screening), Waiting time for specialist appointment, involvement of patient organization in health decisions and some other indicators listed in [Appendix 1](#).

A total of 563 patient organisations/patients responded to the survey from 21 countries. 6 countries had only one or two responses and nine countries did not respond at all. Therefore, the responses from the PV survey have been used very cautiously. The PV survey results have only been used to double check the score based on national feedback data. When the PV survey responses indicated a radically different situation from that officially reported we went back to the National contact to clarify what is in reality the situation but the PV survey has not been used in any case as a main single source.

### 7.6.2 Clinician survey

As a novelty in this project, two surveys to be answered by clinicians were designed: one related with vaccination and case finding and one with questions about hepatitis care. (See Appendix 2.) The questionnaires were introduced to physicians through the EASL (European Association for the Study of the Liver) newsletters. Additionally, in some countries ELPA members mentioned and distributed the surveys to their contacts. In a few countries where the information was not sufficient, the national professional societies were approached to encourage them to take part in the survey.

As with the patient survey, the information gathered has been used only as feedback data and never as a source. In total, we received 53 answers from 9 different countries.

## 7.7 Additional data gathering – feedback from National Ministries/ Agencies, health professionals and patient organisations

On June 20<sup>th</sup>, 2012, preliminary score sheets (containing only scores for that respective country) were sent out to Ministries of Health or national agencies of all 30 states, and also to all ELPA branches giving the opportunity to review the data collected.

This procedure took around three months of extensive e-mail, telephone contacts and personal visits to ministries/agencies. Finally, feedback responses, in the form of returned “single country score sheets” and/or thorough discussions in personal visits to MoH:s/national agencies, have been had from official national sources as illustrated in the following table:

Country	Responded in 2012	P.Organizations responded in 2012
Austria	√	
Belgium	√	
Bulgaria	√	√

Country	Responded in 2012	P.Organizations responded in 2012
Croatia	√	
Cyprus	√	
Czech Republic		
Denmark	√	
Estonia	√	
Finland	√	
France	√	
Germany	√	√
Greece	√	
Hungary		
Ireland	√	
Italy	√	√
Latvia	√	
Lithuania	√	
Luxembourg	√	
Malta	√	
Netherlands	√	√
Norway	√	
Poland	√	
Portugal	√	
Romania	√	√
Slovakia	√	√
Slovenia	√	
Spain	√	
Sweden	√	
Switzerland	√	
United Kingdom	√	√

## 7.8 Threshold value settings

It has not been the ambition to establish a global, scientifically based principle for threshold values to score green, amber or red on the different indicators. Threshold levels have been set after studying the actual parameter value spreads, in order to avoid having indicators showing “all Green” or “totally Red”.

Setting threshold values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. The usually “S”-shaped curve yielded by that is studied for notches in the curve, which can distinguish clusters of states, and such notches are often taken as starting values for scores. A slight preference is also given to threshold values with even numbers.

The performance of national healthcare systems was graded on a three-grade scale for each indicator (see more information in [Scoring](#) section).

For each of the six sub-disciplines, the country score was calculated as a percentage of the maximum possible (e.g., for Outcomes, the score for a state has been calculated as percent of the maximum:  $7 \times 3 = 21$ ).

Thereafter, the sub-discipline score percentages were multiplied by the [weight coefficients](#) given in the following section and added to make the total country score. The scores thus obtained were rounded to a three digit integer, giving a score system where a state with “all Green” would receive 1000 points (and “all Red” 333 points).

One (minor) reason for this somewhat complex scoring methodology has been driven by the “competition” element of the Heart Index, reducing the likelihood of two or more

states ending up in a tied position. The Eurovision Song Contest, for example, changed the score in the same direction after four countries tied for first place in 1969.

## **7.9 CUTS data**

Whenever possible, research on data for individual indicators has endeavoured to find a “CUTS” (Comprehensive Uniform Trustworthy Source). If data on the underlying parameter behind an indicator is available for all or most of the 34 states from one single and reasonably reliable source, then there has been a definitive preference to base the scores on the CUTS. As CUTS would be considered EUCID data, WHO databases, OECD Health data, Special Eurobarometers, and scientific papers using well-defined and established methodology.

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS, when available, is that data collection primarily based on information obtained from 30 national sources, even if those sources are official Ministry of Health or National Health/Statistics agencies, generally yields a high noise level. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same, well-defined question. For example, in an earlier Index project, it was difficult to ask questions about a well-defined indicator such as “SDR of respiratory disease for males >45 years of age”. For one country protesting violently against their score, it took three repeats of asking the question in writing before the (very well-educated) national representative observed that the indicator was for “males 45+” only, not the SDR for the entire population. It has to be emphasized that also when a CUTS for an indicator has been identified, the data are still reviewed through cross-check procedures, as there have frequently been occasions where national sources or scientific papers have been able to supply more recent and/or higher precision data.

### **7.9.1 The “Rolls-Royce gearbox” factor**

Another reason for preferably using CUTS whenever possible is the same reason why Rolls-Royce (in their pre-BMW days) did not build their own gearboxes. The reason was stated as “We simply cannot build a better gearbox than those we can get from outside suppliers, and therefore we do not make them ourselves”. For the small size organisation HCP, this same circumstance would be true for an indicator where a Eurobarometer question, the WHO HfA database, or another CUTS happens to cover an indicator.

## **8. Content and construction of the EHepI 2012**

In this chapter is described the main findings in the different sub-disciplines. The description of the individual indicators is found in chapter 8.7.

### **8.1 Sub-discipline prevention**

**Public awareness:** Awareness about hepatitis is low amongst the general public, those who are at risk, public health authorities, and treating physicians.

Under this indicator has been measured the periodicity of public information campaigns about viral hepatitis and its risks, on TV, radio etc, as well as if there are leaflets with

information about viral hepatitis to inform the general public available in Health Care Centers.

The massive answer in both cases was **YES**. Public Campaigns and other awareness actions are taking place more or less once a year, normally close to the World Hepatitis day. And **YES** leaflets can be found in some centers, mainly in those where hepatitis or hepatitis related disease are taken care of.

There is a global concern about the lack of participation by national governments in these kinds of campaigns, not least regarding financing. Governments do not sponsor such activities in many countries – this seems to be done mainly by physician's societies and/or Patient organizations<sup>16</sup>. There seems to be a general lack of interest/or awareness from governments in many countries.

Most of the leaflets are in those surgeries or health care centers taking care of hepatitis which is very useful to inform patients about hep B and C, but does not improve awareness among undetected hepatitis carriers.

Finally, it is common to find clinical societies and some governments producing leaflets with relevant information and recommendations about HCV and HBV for general practitioners. There also is a limited number of examples of training courses offered to family doctors with the same purpose. More and more efforts are being done to train non-specialist physicians.

It would it be important, but was not possible to capture from these questions, how efficient those awareness campaigns are and how informed the general population is about hepatitis and its risks.

**Vaccination:** HBV vaccine has been available since the 1980's and can prevent acute and chronic infection of HBV (and HDV) with an estimated efficiency of 95%. In 1992, the WHO recommended to implement universal vaccination against hepatitis B for newborns in all countries with an HBV prevalence rate higher than 5% in 1995. All other countries were recommended to implement universal vaccination in 1997. Still in 2012, 5 countries have not introduced these programmes on the argument that health economic studies indicate that it would not be money well spent.

**In those countries where Universal Infant vaccination programs are in place** the coverage is generally more than 90%. Children receive hepatitis B vaccination as part of their routine infant vaccination program and it is free of charge.

In addition to infant vaccination programmes it is common to find adolescent's vaccination programmes in schools. The coverage is not so high but it tries to cover those children that missed Infant vaccination. Some examples are Latvia and Estonia.

Lack of knowledge of the benefits of hep B infant vaccination among parents, paediatricians and family doctors decreases the coverage of infant vaccination.

It is important to mention that this indicator (1.2) does not reflect if vaccination is mandatory or voluntary, only the coverage.

**Vaccination of HBV in risk groups (See table 8.1)** is especially well implemented in those countries where systematic hep B vaccination for infants or adolescents is not systematic.

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<sup>16</sup> ELPA, 2010

Neonates born to HBsAg positive mothers are vaccinated everywhere in Europe, normally through the universal vaccination programmes. In countries without such programmes there are special policies to ensure that these babies get vaccinated.

The information about vaccination for MSM (Men having Sex with Men) is vague. There are some programmes running, normally through NGOs, but the share of the MSM population approached is not known. In the Netherlands numbers around 60% are mentioned, and it is almost certainly lower in most other countries (Ref. 9).

Sex workers are probably the group for which least information is known. It is clear that there are no policies that mention obligatory sex workers vaccination. However, as one important risk group they are mentioned in recommendations and guidelines to be vaccinated. How many are reached through the running programmes is unknown.

Adults in prison are at risk for Hepatitis B virus (HBV) infection through sex with HBV-infected persons, injection drug use, and sharing close living quarters with other inmates infected with HBV. In addition, a high percentage of prison inmates have Hepatitis C virus (HCV) infection.

Prisons represent a good opportunity to vaccinate hard-to-reach groups, for example Injection Drug Users, who may have poor access to health care in the community. The transient nature of prison populations mean the benefits of hepatitis B vaccination extend beyond the prisoners themselves, and into the wider community.

This being said, it would sound logic to find that most of the countries do vaccinate prison inmates or offer Hep B vaccines to inmates. However (Please see table 8.1) not even half of the countries do have programmes for vaccination in prisons.

**Vaccination funding:** It is disappointing to find that countries like Estonia, Lithuania or Rumania do not offer hep B vaccination to the main risk groups for free, eventually preventing members from those groups to get vaccinated and the risk associated with that.



Vaccination for individuals at risk						
Countries	Health Care Workers	Commercial Sex Workers	Partners to and persons living with HBV-infected persons	IDU	MSM	Prison population
Austria	x		x	x		
Belgium	x		x	x	x	x
Bulgaria						
Croatia	x		x	x		
Cyprus	x		x			
Czech Republic	x					
Denmark	x	x	x	x	x	x
Estonia						x
Finland	x	x	x	x		x
France	x		x	x	x	
Germany	x	x	x	x	x	x
Greece	x		x	x		
Hungary	x		x			
Ireland	x		x	x		x
Italy	x		x	x		x
Latvia	x					
Lithuania	x					x
Luxembourg	x		x	x		
Malta	x		x	x		x
Netherlands	x	x	x		x	
Norway	x	x	x	x	x	x
Poland	x					x
Portugal	x		x	x		x
Romania	x		x			
Slovakia	x		x			
Slovenia	x		x	x		
Spain	x		x	x		x
Sweden	x		x	x	x	x
Switzerland	x		x	x	x	x
UK	x	x	x	x	x	x

**Table 8.1 Vaccination for individuals at risk**

Probably the programmes less developed, less coordinated and the area with biggest lack of information are related with **prisons**. Overall, there is an obvious lack of systematic monitoring and research on drugs and health issues in European prisons. There are some valuable starting points in gathering information, which could support health planning

and policy making, but these systems have to be improved and need strong support from national authorities.

In general, needle exchange programmes even though they are very much spread among Injection drug users have not been established in most of the countries inside of prisons. There is a debate after some pilot projects if these programmes are really effective (last example coming from Ireland). As an “alternative” some institutions provide their prisoners with bleach to disinfect the needles, but that number is limited to 12 countries out of 30. CEE countries need to make a big effort to introduce substitution therapies, which presently are not implemented.

	Needle exchange programme	Free available condom distribution	Substitution therapies (OST) Antagonist or agonist	Are disinfectants ("bleach") for cleaning of syringes available in prisons?
Austria	2	2	3	2
Belgium	1	3	2	3
Bulgaria	1	3	1	1
Croatia	1	2	3	1
Cyprus	1	1	1	1
Czech Republic	1	1	1	1
Denmark	1	1	3	3
Estonia	1	3	3	2
Finland	1	3	2	3
France	1	1	2	2
Germany	1	2	3	1
Greece	1	1	1	1
Hungary	1	1	1	1
Ireland	1	1	3	1
Italy	1	1	3	1
Latvia	1	1 (not free)	1	1
Lithuania	1	3	1	3
Luxembourg	3	3	3	No because they provide syringes
Malta	1	1	3	1
Netherlands	1	3	3	1
Norway	1	2	3	3
Poland	1	2	2	1
Portugal	1	2	3	3
Romania	1	2	1	1
Slovakia	1	1 (not free)	1	1
Slovenia	1	3	3	3
Spain	2	3	3	3
Sweden	1	3	3	1
Switzerland	2	3	3	2
UK	1	3	3	3

3= In all prisons

2= In some prisons

1= NO

Free condom distribution exists only in just over half of the countries included in the study. Even in those countries it is not done in all prisons.

On a different line, Free availability of PEP (Post-Exposure Prophylaxis) for health care personnel in case of accidents with infected material is available everywhere. In some countries the employer has to pay for it. It can occur, e.g. in Poland, that conditions vary between employers so that PEP is not free of charge for all staff. Free PEP provision in case of sexual, injection drug use or any other non-occupational exposure is less common: only around half of the countries offer this service.

## 8.2 Sub-discipline: Screening/Case finding

A very large number of infected people is still unaware of their infection, not only among population at risk but general population. Early diagnosis enables people with chronic hepatitis B and C to be evaluated on the severity of their disease and on the need to receive antiviral treatment. Successful response to antiviral therapy can prevent progression of liver disease. Furthermore, it allows people with chronic hepatitis B and C to receive counselling on lifestyle changes such as reducing alcohol consumption, which can reduce the risk of cirrhosis and liver cancer and can prevent further spread of infection.

One good way to improve case finding, awareness and early diagnosis of hepatitis in the general population is through primary care doctors. Hepatologists, gastroenterologists, infectious disease doctors and patient organizations agree about the need of primary health staff to get trained about viral hepatitis specially those serving communities with high prevalence. So far it has often been the task of mostly societies and patients organizations in Europe to produce leaflets with basic information and short recommendations for primary doctors. This seems to be insufficient.

The EHepI originally contained 3 indicators on GP's training in Hep C and B related issues. Due to lack of consistent data only 1 out of those 3 indicators stays in the index. The indicator asks about the ALT detection (for more information about ALT see indicator 2.5, section 8.7.2), As it is shown in the index, ALT is analysed in most of the cases only if liver disease is suspected, even though it is recommended and encouraged to prescribe ALT determination as a routine, to increase case finding among general population. At this point, it is important that General practitioners would know what to do with a patient receiving a positive test response.

All over Europe, screening programs in risk population normally only included pregnant women, blood and organ donors and sometimes depending on the country IDU and migrants from high endemic areas. Often, only data on screening in these two/three groups are systematically collected.

We are presenting two tables (See below table 8.2.1 and 8.2.2) with data on testing (HBV and HCV) in risk population; we collected information of which groups are in general recommended through policies, guidelines or just regular practice to be tested. Because of the complexity of the information **this indicator have not been scored**, the data it is only to be shown because we know it is of interest for the community.

As can be seen in tables 8.2.1 and 8.2.2, testing in risk group populations needs to be improved in all countries. There are groups that tend to be forgotten systematically such as sex workers, MSM, prison inmates or immigrants from high prevalence areas. The coverage of testing in most groups included in the tables is normally not available.

In order to increase testing in particular groups such as drug users or sex workers it is important to make these services as reachable and convenient as possible. Barriers to accessibility such as transportation, language, lack of anonymity or confidentiality, cost, lack of health insurance and/or stigma would mean less testing. In general, screening is free for risk groups in the majority of the countries but it is very disappointing to see that free anonymous hepatitis testing and counselling, walk-in facilities where appointments are not necessary, and testing given anonymously, meaning medical staff will not know the client's name, are services which are not easy to find in Europe.

Systematic testing in risk population (HBV)																	
Countries	Chronic HCV patients	HIV positive patients	Pregnant women	IDUs	Men that have sex with men (MSM)	Commercial sex workers	Prior to chemotherapy or treatment with biological drugs	Blood and organ donors	Partners to and persons living with patients with chronic viral hepatitis	Haemophiliacs	Patients in chronic haemodialysis	Patients with cirrosis	Persons with trisomi 21 (Down's syndrome)	Patients with unexplained elevated ALT/AST	Prison inmates	Immigrants from high-endemic areas	STI clinic patients
Austria	x		x	x		x	x	x	x		x	x		x		x	
Belgium	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x
Bulgaria			x	x				x				x		x			
Croatia	x	x	x					x	x	x	x	x					x
Cyprus	x	x	x					x	x	x	x		x	x			
Czech Republic	x	x	x				x	x		x	x	x		x			
Denmark	x		x	x				x	x	x	x		x	x			
Estonia		x	x					x		x	x				x		
Finland			x					x					x			x	
France	x	x	x				x	x	x		x	x		x			x
Germany	x	x	x		x			x	x	x	x	x	x	x			x
Greece			x					x			x						x
Hungary	x	x	x	x		x		x	x	x	x	x		x		x	
Ireland	x	x	x	x			x	x		x	x	x				x	x
Italy	x	x	x					x	x	x	x	x					
Latvia		x	x	x				x	x	x	x	x					
Lithuania	x	x		x				x		x	x	x		x	x		
Luxembourg	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x
Malta	x	x	x	x				x	x	x		x		x	x		
Netherlands	x	x	x		x	x	x	x	x	x	x	x					
Norway	x	x	x	x	x	x		x	x	x	x	x		x	x	x	
Poland		x	x	x	x			x	x	x	x	x		x			
Portugal		x	x	x	x			x	x	x	x	x		x	x		
Romania	x	x	x	x	x			x		x	x	x		x			x
Slovakia		x	x					x	x	x	x	x		x	x		
Slovenia	x	x	x	x	x		x	x	x	x	x	x	x	x	O		x
Spain		x	x	x			x	x	x	x	x	x		x	x		
Sweden		x	x	x				x	x		x				x		
Switzerland		x	x		x			x	x	x	x	x					
UK	x		x					x		x	x						

Table 8.2.1 Testing/case finding in population at risk (HBV)

Systematic testing in risk population (HCV)														
Countries	Chronic HBV patients	HIV positive patients	IDUs	Men that have sex with men (MSM)	Commercial sex workers	Blood and organ donors	Partners to and persons living with patients with chronic viral hepatitis	Haemophiliacs	Patients in chronic haemodialysis	Patients with cirrosis	Patients with unexplained elevated ALT/AST	Prison inmates	Immigrants from high-endemic areas	STI clinic patients
Austria		x	x			x			x	x	x			
Belgium		x	x	x		x	x	x	x	x	x	x	x	
Bulgaria			x			x		x				x		
Croatia	x	x				x	x	x	x	x				x
Cyprus	x		x			x	x	x	x	x	x	x		
Czech Republic	x	x				x		x	x	x	x			
Denmark			x			x					x			
Estonia		x				x		x	x			x		
Finland						x					x		x	
France	x	x	x			x	x	x	x	x	x			
Germany	x	x	x	x		x	x	x	x	x	x			x
Greece		x	x			x			x					x
Hungary		x	x			x	x	x	x	x	x		x	
Ireland	x	x	x			x	x	x	x	x				x
Italy	x	x				x	x	x	x	x				
Latvia		x	x			x	x	x	x	x				
Lithuania		x	x			x		x	x	x	x	x		
Luxembourg	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Malta	x	x	x			x	x	x		x	x	x		
Netherlands	x	x		x		x		x	x	x				
Norway		x	x	x	x	x	x	x	x	x	x	x		x
Poland		x	x	x		x	x	x	x	x	x			
Portugal		x	x	x		x	x	x	x	x	x	x		
Romania	x	x	x	x		x		x	x	x	x			x
Slovakia		x				x	x	x	x	x	x		x	
Slovenia	x	x	x	x		x	x	x	x	x	x	x		x
Spain		x	x			x	x	x	x	x	x	x		
Sweden		x	x			x	x		x			x		
Switzerland		x				x	x			x				
UK	x		x			x	x	x	x		x		0	

**Table 8.2.2** Testing/case finding in population at risk (HCV)

### 8.2.1 Hepatitis prevalence across Europe

Many patients who are infected with hepatitis can carry the infection for many years before developing symptoms. This is one major reason why it is inherently very difficult to obtain accurate prevalence data for hepatitis. This is not peculiar to hepatitis – the HCP Euro HIV Index 2009 did, rather unexpectedly, encounter the same problem with prevalence data for HIV, which turned out to be so inaccurate that it became impossible to measure any indicators, which needed the prevalence as a denominator.

There are prevalence data reported for European countries, but as can be seen from the graph below, several countries have no data in those reports, and the prevalence reported for some other countries seems rather underestimated. This is also confirmed by Reference 3: "Lack of reliable epidemiological data on HBV and HCV is one of the biggest hurdles to advancing policy. Risk groups such as migrants and injecting drug users (IDU) tend to be under-represented in existing prevalence studies".

With all the discrepancies found between medical practices in different countries, the medical profession might still be that, which has the most uniform practices of any profession on the planet – "based on science and proven experience" is a quite good platform for weeding out the worst idiosyncrasies.

One data set, which has a very high inherent accuracy, is the drug sales numbers provided by the IMS Health MIDAS database. With the assumption that the "proportion of hepatitis infected patients who are being treated" is fairly uniform across Europe, at least when looking at fairly inexpensive off-patent drugs, it might be that the drug deployment *per million population* could actually be a better indicator of hepatitis prevalence than the reported prevalence numbers themselves.

Prevalence data and drug sales data p.m.p. are shown in the graph below. The HCP is not in a position to say which data set is the better prevalence indicator:

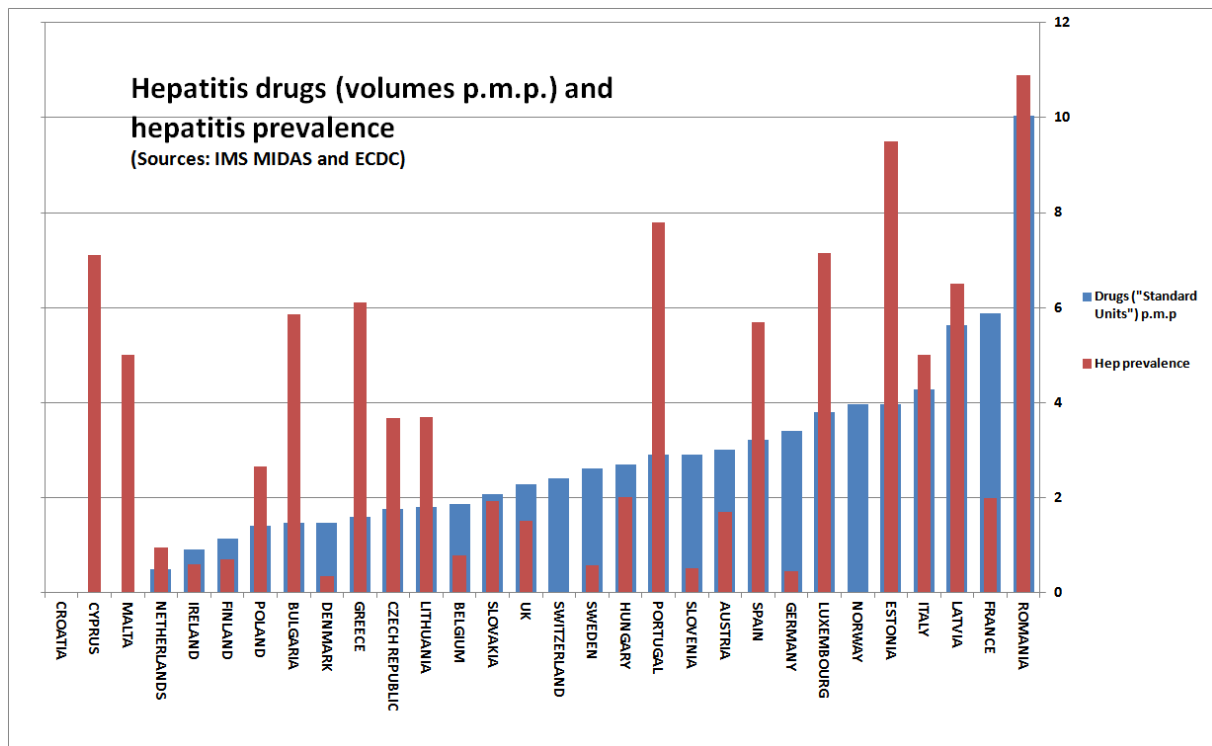


Figure 8.2.1. Hepatitis prevalence (% of population; right-hand Y-axis, narrow bars) and hepatitis drug deployment p.m.p (in volume, broad bars). For copyright reasons, the numbers on the drug use Y-axis have been removed, leaving only a relative measure.

### 8.3 Sub-discipline: Access to treatment/Process

To visit the hepatologist, gastroenterologist or infectious disease doctor for a follow up is not a matter of urgency. Experts suggest that a visit every month or six weeks is on average what is appropriate. For waiting time issues the patient surveys are core data.

There is a general agreement that patients in Europe do not suffer problems to access a liver disease specialist.

The population we studied, patients with health care insurance, have easy access to therapy with costs to patients that are fully reimbursed or with a small co-payment required. In countries like Romania the question is not if they have free access to treatment but how long can take for patients to get their treatments. Because of the way the Health Insurance allocates the money it can take (depending on the area of residence) 3 – 24 months for patients to get their medication.

Early in the project, there were three very important and interesting indicators which would have shown relevant information about treatment and care; “number of hepatitis patients on treatment?”, “% of people at risk for HCC screened for liver cancer” and “% of dropout during treatment”. Unfortunately all had to be dropped out because of lack of data.

There are 6 main HCV subtypes. It is strongly recommended to all chronic patients to be genotyped before starting their treatments. The hepatitis C genotype matters because it can affect how successful a person's hepatitis C treatment is likely to be, how long the hepatitis C medication will need to be taken, and which *type* of medication should be given. Our research shows that genotyping is widely and regularly performed almost in every country.

**Availability of new drugs;** patient organizations had grave concern about introduction of two new drugs for hepatitis C treatment (telaprevir and boceprevir) in their countries. As you can see in the results only five countries had general access to the new drugs in the sense that the drugs are included in pharmaceutical benefit systems and routinely prescribed in actual practice. Many countries have started very slowly and patients still face limitations. Sometimes, only some selected patients suggested by physicians and only in some regions are being treated with the new drugs. One third of the countries do not provide these new drugs yet. It has not been measured by any indicator but for HBV the situation is even worse: In a lot of countries only treatment is offered with old and ineffective drugs. With the new compounds established some years ago, HBV can be very well controlled. With the older drugs, this only the case for 25 % of patients.

**Hepatitis Specialist Nurses** The role of the nurses is often underestimated. Well-trained specialist nurses, just as for other chronic diseases are extremely beneficial. They are the professionals who guide the patient through their treatments, providing them with education about their disease. This is demonstrated to improve the results of treatment. It is disappointing to see that hepatitis specialist nurses are only available in one third of countries.

**Hepatocarcinoma (HCC) registry** Hepatocellular carcinoma (HCC) is a primary malignancy of the hepatocyte, generally leading to death within 6-20 months. Although it is currently one of the most common worldwide causes of cancer death, a major impact on the incidence of hepatocellular carcinoma should be achieved through current vaccination strategies for hepatitis B virus (HBV) infection, screening and treatment for hepatitis C virus (HCV) infections, and from the reduction of alcoholic liver disease. However, because the latency period from hepatic damage to hepatocellular carcinoma development is very long, it may be many years until the incidence of hepatocellular carcinoma decreases as a result of these interventions.

The collection and analysis of epidemiologic HCC data will play a critical role in guiding future disease prevention strategies and optimizing patient management. Good HCC registries are only available in very few countries around Europe; Denmark, CZ, Finland,

France (not national), Germany (not updated nationally), Luxembourg, Sweden, Switzerland and the UK.

## **8.4 Sub-discipline Governmental strategy and Patient involvement and rights**

HCP does not believe that a National strategy can rapidly improve the management of a disease. However, it is true that a well-formulated strategy helps to focus on the main problems, to coordinate all parts of society working in the field and to standardize data collecting processes, which it is essential for improvement and to know where to take action. It can also coordinate the effort of all bodies into one direction. There are only two well set up national hepatitis strategies in Europe: in France and in Scotland. There are 3 more on the way; that of the England supposed to be finished by end of the year, Bulgaria decided on a national strategy in September 2012, Croatia had a first conference to set up a task force and Germany, where it is not clear when it is going to be completed. In Germany this is a privately funded initiative.

## **8.5 Sub-discipline Outcomes**

Initially this sub-discipline had 5 indicators considered essential to show what results are achieved by hepatitis management in different countries. It was very disappointing to realize that only three indicators can be presented, and that with a large number of **n.a.** scores due to data quality problems.

We are aware that countries like Denmark, Germany, Spain and Sweden have data on these indicators. However the person/institution responsible for the registry did not make it available for the project or we did not reach the right people. In the rest of the countries the data is not nationally collected or not collected on a regular basis.

## **8.6 How the Euro Hepatitis Index 2012 was built – Production phases**

The Index does not take into account whether a national healthcare system is publicly or privately funded and/or operated. The purpose is health consumer empowerment, not the promotion of political ideology. Aiming for dialogue and co-operation, the ambition of HCP is to be looked upon as a partner in developing healthcare around Europe.

The EHepI 2012 was constructed under the following project plan.

### **8.6.1 Phase 1**

**1. Selection of a number of experts to be part of the expert panel and set up the first meeting.** The composition of the Expert panel can be found in section [9.3](#).

### **2. Start-up meeting with the Expert Reference Panel - Mapping of existing data**

The major area of activity was to evaluate to what extent relevant information is available and accessible for the selected countries. The basic methods were:



- Web search, journal search
- Telephone and e-mail interviews with key individuals, and
- Personal visits when required.

Web search:

- a) Relevant byelaws and policy documents
- b) Actual outcome data in relation to policies

Information providers:

- a) National and regional Health Authorities
- b) Institutions (EHMA, ECDC, CDC, OECD and others)
- c) Private enterprise (IMS Health, pharmaceutical industry, others)

Interviews (to evaluate findings from earlier sources, particularly to verify the real outcomes of policy decisions).

- a) Phone and e-mail
- b) Personal visits to key information providers

### **3. Pre-design a number of interesting indicators and possible sub-disciplines for the project which were discussed during the first expert panel meeting.**

#### **8.6.2 Phase 2**

- Indicator scoring. During the first expert panel meeting a large number of indicators were selected as being relevant to be included in the project. This “long-list” included more than 50 indicators. The experts then performed an indicator scoring in an organized and systematic manner to shorten the list and select the indicators most relevant for the project. The research team started working with 30 indicators.
- Data collection to assemble presently available information to be included in the EHepI 2012.
- Identification of vital areas where additional information needed to be assembled was performed.
- Collection of raw data for these areas.
- **Surveys to patients and Physicians.**

Consulting European **patient** advocates and **citizens** through HCP survey. The EhepI survey contained the questions found in Appendix 1 of this report and was commissioned from with Patient View. Sporadically in some countries ELPA branches helped with the distribution of the survey among their patients or branches. The survey was available in Internet from March 20<sup>th</sup> in English, German, French, Spanish, Polish and Swedish. The closing date was August 15<sup>th</sup>, 2012. 563 responses were received, mainly from Patient Organizations, with a high number of responses from Italy and Spain, which is unusual in HCP experience.

**Clinician survey** We developed two online questionnaires, one related mainly with vaccination and screening and one including general questions about hepatitis B and C care. The questionnaires were opened in April and the closing date was September 15<sup>th</sup>. They were mentioned and introduced to physicians through the EASL newsletter. Additionally, societies had been encouraged to answer them.

We received 53 responses from 9 different countries.

- A round of personal visits by the researchers to Health Ministries and/or State Agencies for supervision and/or Quality Assurance of Healthcare Services.
- Regular contact with the Expert Reference Panel mainly to discuss the indicators, the criteria to define them, and the data acquisition problems. Finally, we had a second meeting on September 10<sup>th</sup>, 2012, at which was discussed in detail each of the indicators, including those that could not be included in the Index due to lack of data. Also, the discrepancies between data from different sources were analyzed. Sub-discipline relative weights were discussed and set.

#### **8.6.2.1 “Score update sheet” send-out.**

On June 20<sup>th</sup>, 2012, all 30 states received their respective preliminary score sheets (with no reference to other states’ scores) as an e-mail send-out asking for updates/ corrections by August 31<sup>st</sup>. The send-out was made to contacts at ministries/state agencies as advised by states during the contact efforts prior to July 2012 and to all ELPA members.

Corrective feedback from states was accepted up until September 9<sup>th</sup>, by which time replies had been received from countries denoted in section [Additional data gathering – feedback from National Ministries/Agencies](#) for more information on national feedback.

#### **8.6.3 Phase 3**

Project presentation and reports

- A report describing the principles of how the EHepI 2012 was constructed.
- Presentation of EHepI 2012 at a seminar and web conference in Brussels.
- On-line launch on [www.healthpowerhouse.com](http://www.healthpowerhouse.com) .

### **8.7 Content of indicators in the EHepI 2012**

The research team of the Euro Hepatitis Index 2012 has been collecting data on 27 healthcare performance indicators, structured in a framework of five sub-disciplines. The indicators come numbered in the report, to provide more reader friendliness and clarity. This is the first index in which that the data collected comes basically from interviews, mails, telephone conferences and visits to National health officials, public health responsible and clinicians, as there is precious little data in the public domain. Data has been proven to be rather accurate. A number of feedback and validation processes were undertaken during the final months of the project. In addition, patient and clinician surveys were used (unfortunately not with respondents for every country) as supplementary feedback.

## 8.7.1 Prevention

### *1.1 Public awareness about hepatitis*

The information on the indicator Public awareness comes from two questions:

- a) Have there been public information campaigns about viral hepatitis and its risks during the last 12 months? On TV? On radio? Newspapers?
- b) Are leaflets about viral hepatitis generally available in Healthcare Centers?

When the indicator was designed, it was not the first intention to ask who has been sponsoring the awareness campaigns, but it is a topic that has been regularly mentioned. It seems there is a general disappointment about sponsors normally being physician societies or patient organizations and not governments. **Source:** Interviews with health care officials, national physicians and public health experts.

### *1.2 % Routine infant HBV vaccination coverage*

Universal Infant vaccination is recommended in most guidelines and is one of the main approaches to prevent HBV infection. In this indicator only coverage of infant vaccination is recorded, not data from adolescent vaccination. There is also no specification if vaccination is mandatory or voluntary – the indicator concentrates on what coverage is achieved. **Source:** Interviews with health care officials, national physicians and public health experts, completed and used as a feedback report from ECDC<sup>17</sup>.

### *1.3 Vaccination in risk groups*

This indicator was included to complete the information about the vaccination situation in countries. The proper approach for the main risk groups is very important, particularly in countries without universal infant vaccination. The number of risk groups can be long and diverse; we selected those thought to be the most relevant because of the relationship with the disease; Health Care staff, Commercial sex workers, Partners to and persons living with HBV-infected persons, IDU, MSM and Prison inmates. The score in this indicator has been calculated as the number of risk groups (from the maximum of all 6 included) systematically being vaccinated. **Source:** Interviews with health care officials, national physicians and public health experts.

### *1.4 HBV vaccination payment*

Who is paying for HBV vaccination can limit access to vaccination to some key groups inside of the society. Access to vaccination should be free of charge for at least the main risk groups plus newborns. **Source:** Interviews with health care officials, national physicians and public health experts. **Source:** Interviews with health care officials, national physicians and public health experts.

### *1.5 Universal ante-natal HBV screening*

To prevent HBV mother-to-child transmission it is recommended that all pregnant women receive prenatal testing for hepatitis B during each pregnancy by screening serum for the

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<sup>17</sup> ECDC, 2010.

presence of HBsAg, regardless of risk factors or immunization history. In addition to screening for prenatal HBsAg in the first trimester, testing should be repeated late in pregnancy for those women who tested negative if they have clinical and laboratory evidence of hepatitis or have ongoing risk for acquiring HBV infection. Source: Interviews with health care officials, national physicians and public health experts, completed and used as a feedback report from ECDC<sup>18,19</sup>.

### ***1.6 Harm reduction in prison***

This indicator is to show the strategies and policies set up in countries to reduce and prevent HBV and HCV in prison. We asked for information on

- a) Free condom distribution available in prison
- b) Needle exchange programmes
- c) Availability of substitution therapies (OST)
- d) Provision of disinfectant (Bleach) that can be used for cleaning of syringes available.

Data was acquired from the WHO prison health project and completed, reviewed and updated through National health officials, National representatives and prison services officials.

### ***1.7 Availability of Post exposure immunization for hepatitis B***

PEP is what the name suggests; prophylaxis (preventive) medication given after an HBV or suspected HBV exposure to decrease the likelihood of HBV infection. This preventive procedure is beneficial to prevent not only the infection after occupational exposure but after Injection drug use or unanticipated sexual exposure. Experts believe access should be free in those cases recommended by the physician. **Data was acquired from interviews with National health officials.**

## **8.7.2 Case finding/screening**

### ***2.1 Free anonymous hepatitis testing and counseling.***

It is well known that the number of undiagnosed people carrying hepatitis in Europe is still very high. The general awareness about hepatitis and infection routes is rather low. Therefore the easier the access to testing or counseling, the higher the possibility that those persons improve their knowledge about the disease and prevent any further infection. **Source:** Interviews with health care officials, national physicians and public health experts.

### ***2.2 Hepatitis C testing in the community***

The availability of Hepatitis C testing in EU27, Croatia, Turkey and Norway was measured. The data is coming from a structured Questionnaire inside of the 'prevention and reduction of health-related harm associated with drug use' (SQ23/29), submitted by

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<sup>18</sup> EASL, 2011

<sup>19</sup> EASL, 2009

NFPs in 2011. **Data source:** European Monitoring Centre for drugs and drugs Addiction (EMCDDA).

### ***2.3 Annual screening for infectious diseases to all IDU***

Drug users are more likely than non-users to contract a variety of infectious diseases and, when infected, to progress to serious illness and death. Therefore routine screening is recommended. **Source:** Interviews with health care officials, national physicians and public health experts.

### ***2.4 Annual HCV antibody testing for HIV- infected persons***

In general there is a consensus about the benefits of performing hepatitis C test on HIV patients annually. It is normally performed during the first visit after HIV detection. The test may be repeated but not annually. In general, if risk behavior prevails or if there is any reason to fear infection, the person gets checked again. **Source:** Interviews with health care officials, national physicians and public health experts.

### ***2.5 Is ALT (Alanine AminoTransferase) determination routinely prescribed by GPs?***

A number of indicators to measure the grade of awareness and knowledge about hepatitis among general practitioners were designed. Indicator 2.5 is the only that survived the feasibility test.

In principle it is recommended to check levels of ALT regularly and not only if liver disease is suspected in order to improve case finding among general population.

ALT and AST (aspartate aminotransferase) are enzymes found in liver cells (hepatocytes) which have lots of contact with blood supply. AST and ALT can "leak" into the blood if the hepatocytes are damaged. Blood tests can determine the level of these enzymes in the blood and doctors can use this information to arrive at a diagnosis. Abnormally high levels of both liver enzymes show that liver cells have been damaged, but they cannot tell what caused the damage.

However, the ratio of AST to ALT, or the level of AST compared to the level of ALT, provides many clues to what is the problem. Based on these ratios, doctors can focus their attention on a particular kind of liver disease.

Because increased enzyme levels can be seen in other diseases (heart attack, obesity, diabetes mellitus, mononucleosis), they are just one piece of a larger puzzle. To give doctors a complete clinical picture, enzyme levels must be used with other blood tests, patient examination and medical history. **Source:** Interviews with health care officials, national physicians and public health experts.

### ***2.6 Screening funding.***

Data was acquired from interviews with Health officials and National bodies.

### 8.7.3 Access to treatment/Process

#### *3.1 Treatment Funding.*

It is important that drugs are subsidized/reimbursed to allow people to access the treatment they need. It was realized late in the project that in many of the countries treatment funding is not as big a problem as clinical examinations having to be privately paid by the patient, preventing in some cases the proper management of the disease.

**Source:** Interviews with health care officials, national physicians and public health experts.

#### *3.2 Waiting time for specialist appointment*

A visit to the hepatologist is usually not an urgent appointment. The expert panel considered visiting the doctor every 4 - 6 weeks appropriate. **Source:** Interviews with health care officials, national physicians and public health experts.

#### *3.3 Treatment of children in a specialist unit*

The indicator question is if all children infected are treated in special units with knowledgeable personnel that can manage their infection properly.

Countries scoring **n.ap.** on this indicator is because the number of infected children is so low per year (maybe one or two every 3 years) that they do have pediatricians to take care of the patients but not special, separate units inside of the pediatric hospital. **Source:** Interviews with health care officials, national physicians and public health experts.

#### *3.4 Adherence to European (EASL) guidelines (Hep B, Hep C)*

European Association for the Study of the Liver continuously presents guidelines to make the actions of European physicians more consistent and standardized with the aim to improve performance. Guidelines are eventually followed only partially, modified by some countries according to their public health situation. **Source:** Interviews with health care officials, national physicians and public health experts.

#### *3.5 HCV Genotyping.*

The genotype of Hepatitis C Virus (HCV) strains is an important determinant of the severity and aggressiveness of liver infection as well as patient response to antiviral therapy. Fast and accurate determination of viral genotype could provide direction in the clinical management of patients with chronic HCV infections. **Source:** Interviews with health care officials, national physicians and public health experts.

#### *3.6 Availability of new drugs*

Sales data on hepatitis drugs was available courtesy of IMS Health (MIDAS database). The scoring was calculated as the ratio between “drug sales numbers of New drugs /Drug sales numbers of old drugs”, New drugs being defined as telaprevir + boceprevir and old drugs Ribavirin + peginterferon alpha 2A + peginterferon alpha 2B. Sales data expressed in Standard Units (*i.e.* volume, not monetary value).

One advantage of this approach is that the rather inaccurate national hepatitis prevalence numbers are shortened out.

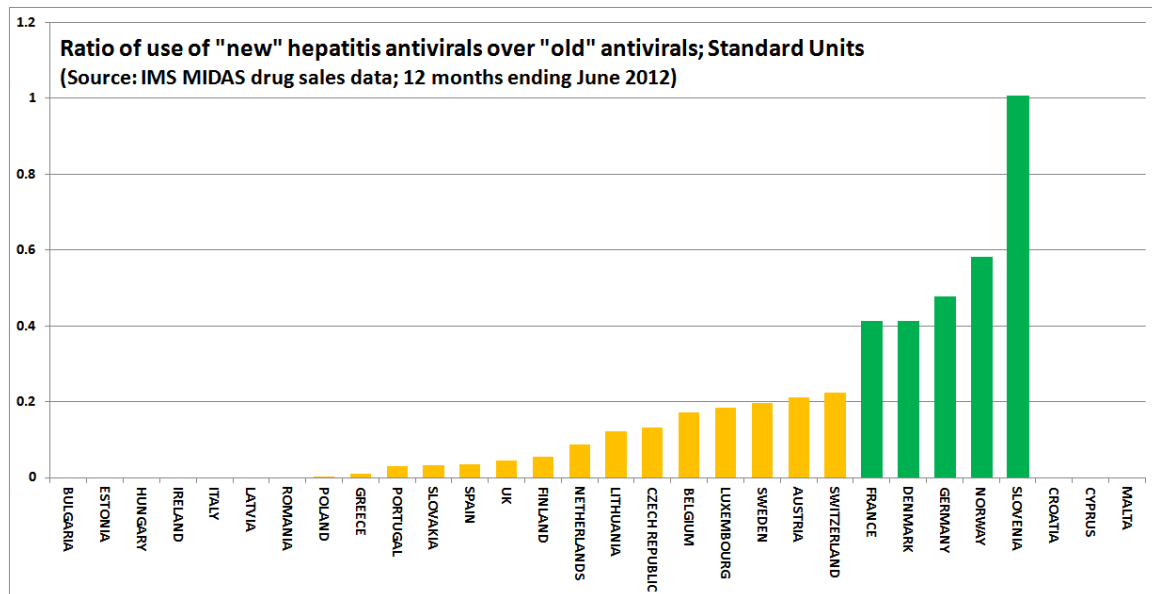


Figure 8.7.3.6. Ratio of “new” hepatitis drug use over “old” hepatitis drug use. NB! The indicator is not supposed to show that “the higher the ratio, the better”. What the indicator seems to show is that in 5 countries the “new” drugs are readily available, in 14 countries there is restricted availability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

### 3.7 Hepatitis specialist nurses

As in other diseases, multidisciplinary well trained teams of professionals improve outcomes. The indicator measures if and to what extent countries have hepatitis specialist nurses. They are accredited nurses who have completed additional education and clinical training. They are often focusing on health promotion and disease prevention activities, apart from other duties. **Source:** Interviews with health care officials, national physicians and public health experts.

### 3.8 Is there an HCC registry?

The purpose of this kind of registries is to have enough quality data to be able to study the factors which might cause hepatocellular carcinoma, the treatment for these patients and their follow up to understand the situation and monitor/improve service delivery and outcomes. **Source:** Interviews with health care officials, national physicians and public health experts.

### **8.7.4 National Strategy/ Patient involvement and rights**

This sub-discipline is testing the ability of a healthcare system to provide the patient with a status strong enough to minimize the information skew walling the professional and patient.

Why does HCP love this sub-discipline? Because it is a GDP non-dependent indicator family. Even the poorest countries can allow themselves to grant the patient a firm position within the healthcare system.

There are 3 indicators in this sub-discipline:

#### ***4.1 National HCV/HBV (general hepatitis; liver) patient organization***

Is there a national/regional or local patient organization in the country working with hepatitis B/C liver disease related problems? Information sources: National healthcare agencies.

#### ***4.2 Patient Organisations involved in decision making (Decisions related with health policies)***

Do patient organisations have right to participate in healthcare decision making?

Statutory/by law, by common practice or generally not? Sometimes we find that patient's organisations are welcomed to get involved, sometimes they do it by law, sometimes they do it only informally, sometimes not at all.

Sources of data: National healthcare agencies.

#### ***4.3 National funding of Hepatitis strategy?***

Two questions are asked for this indicator:

- a) is there a national strategy in place in the country or one going to be launched in the near future
- b) has the strategy been funded by governmental resources or privately.

National healthcare agencies; web and journal research.

### **8.7.5 Outcomes**

Due to the lack of data related with outcomes indicators only three out of the five initial indicators survive in this sub-discipline.

#### ***5.1 % of patients treated who achieve sustained viral response (SVR, for HCV).***

Conventional treatment (a combination of interferon and ribavirin) does not necessarily eliminate the hepatitis C virus from the liver. It can, however, *suppress* the virus to undetectable levels for an extended period of time. In clinical language, this is called a "sustained virologic response," or sustained response. It means that during the six months after completed treatment, there is no detectable hepatitis C virus in the blood.



The likelihood of a sustained virological response (SVR) is the most important factor for physicians and patients in the decision to initiate and continue therapy for chronic hepatitis C (CHC) infection. The data presented is for all genotypes and all treatments. It was reported from National Public Health services.

### 5.2 Liver transplants per million population

This indicator was inserted at a late stage, as it was observed that countries could report a low mortality on the waiting list for liver transplants coinciding with a low number of transplants p.m.p.. The indicator was included as it reflects the survival chances of citizens with severe liver dysfunction.

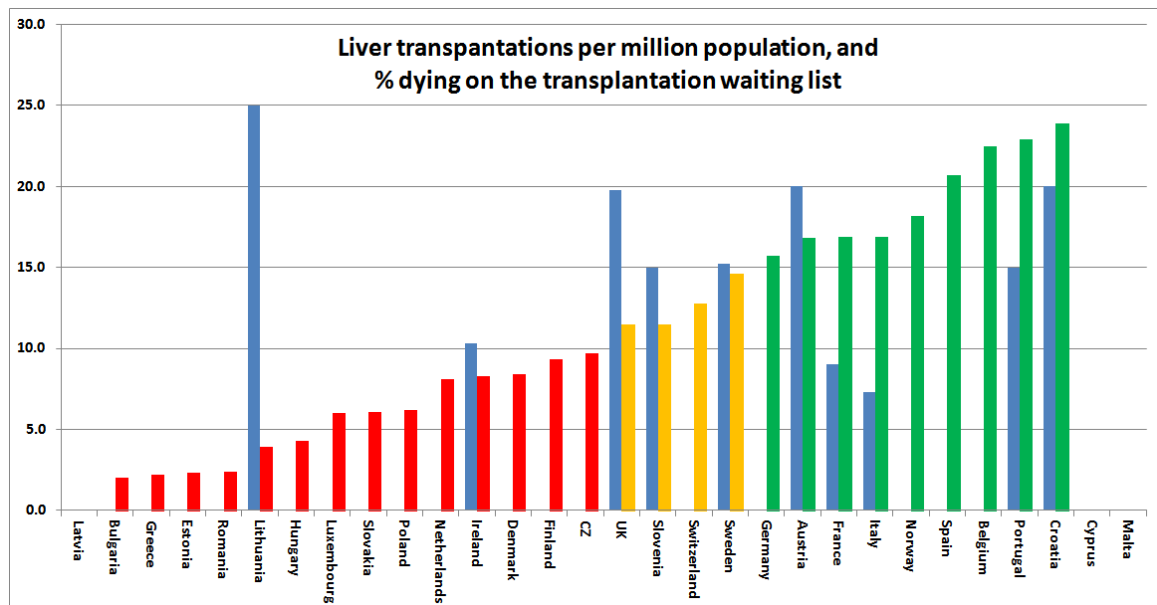


Figure 9.1.5.2 Blue bars: % of patients dying on the liver transplant waiting list. Red/Yellow/Green bars: Liver transplantations per million population.

Rather unexpectedly, the highest number in Europe is found in Croatia, not in any of the wealthier countries.

Source: The Council of Europe Newsletter Transplant 16/2011. CUTS data.

### 5.3 Mortality on the waiting list for liver transplant

Data on mortality on the waiting list for liver transplant was collected; for all disease codes for a period of 5 years. Source: reported from National Public Health services.

## 8.8 External Expert Reference Panel

As is the standard working mode for all HCP Indexes, an external Expert Reference Panel was recruited. The panel met for two 6-hour sittings during the course of the project. The following persons have taken part in the Expert Reference Panel work for EHePI 2012:

<b>Name</b>	<b>Affiliation</b>
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 Krautz	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 2 <sup>nd</sup> 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 Nordwest, Frankfurt, Germany

The Expert Reference Panel for a HCP Index has two core tasks:

- A. To assist in the design and selection of sub-disciplines and indicators. This is obviously of vital importance for an Index, if the ambition is to be able to say that a state scoring well can truly be considered to have good, consumer-friendly healthcare services.
- B. To review the final results of research undertaken by HCP researchers before the final scores are set. If the information obtained seems to clash too violently with the many decades of healthcare experience represented by the panel members, this has been taken as a strong signal to do an extra review of the results, and also to set the relative weights of each sub-discipline.

The HCP wishes to extend its sincere thanks to the members of the panel for their fundamentally important contribution to the Index work, and for very valuable discussions along all these months.

## **9. References**

### **9.1 Main sources**

The main sources of input for the various indicators are given in Table 7.5 above. For all indicators, this information has been supplemented by interviews and discussions with healthcare officials in both the public and private sectors.

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## Appendix 1. Questionnaire used in the survey commissioned from Patient View for the Euro Hepatitis Index 2012.

### Title: How user friendly is your country's healthcare system regarding hepatitis care?

#### SURVEY OBJECTIVE:

"To compare the provision of hepatitis care among the national healthcare systems of Europe".

Health Consumer Powerhouse is asking health campaigners across Europe who have an interest in the subject of hepatitis to help it compile the *EURO HEPATITIS CARE INDEX 2012* by completing this short questionnaire.

The INDEX is a brand-new, free HCP publication designed to measure both the user-friendliness, and the level of provision, of hepatitis care in 30 European countries. The INDEX hopes to highlight and contrast the policies actually being implemented in the different countries across Europe, with the intention of identifying important and immediate needs in hepatitis care.

This online questionnaire is short (11 simple questions) and should take no more than about 10 minutes of your time to complete. All responses will be ANONYMOUS (unless you wish otherwise).

This Health Consumer Powerhouse study will close on Wednesday, August 15th 2012.

To thank you for contributing your opinions to the study, and to allow you to read the results, PatientView, the survey manager, will send you (if you wish) the weblink to the EURO HEPATITIS CARE INDEX 2012 upon publication (scheduled for October 2012).

Yours faithfully,

Beatriz Cebolla, PhD,  
Project Manager  
Health Consumer Powerhouse,  
Danderyd, Sweden

Arne Björnberg, PhD,  
Chairman,

If you have any questions about this survey, please contact:

PatientView,

Registered office: Millennium Bridge House, 2 Lambeth Hill, London, EC4 4AJ, UK

Tel: 0044-(0)1547-520-965

e-mail: [info@patient-view.com](mailto:info@patient-view.com)

To continue the survey, just click 'NEXT>>'

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### The questionnaire

Firstly, could you please indicate in which European country you are based?

(If you are a patient group with a European or international remit, could you respond on behalf of the country in which you, as a respondent, reside.)

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Question 1/11:

**Have public campaigns been run in your country about VIRAL HEPATITIS and its risks during the last 12 months?**

**(Such campaigns could be on TV, on the radio, or in newspapers.)**

[Please specify only one option.]

- Yes.
  - Not in the last 12 months, but during the last few years.
  - Yes, but further back in time than a few years ago.
  - No, to my knowledge, we have never had such a campaign in my country.
  - I do not remember / I do not know.
- 

Question 2/11:

**Do healthcare centres in your country have leaflets about viral hepatitis?**

[Please specify only one option.]

- Yes, easy to find in every healthcare centre.
  - Not in every centre, but in some.
  - I have not seen such leaflets in any healthcare centres.
  - I do not know.
- 

Question 3/11:

**Do any hepatitis-specific patient organisations exist in your country?**

**(Such organisations may be dedicated solely to hepatitis, or to individual types of hepatitis, or they may be liver patient organisations. Your own organisation may be such a patient organisation.)**

[Please specify only one option on each line.]

**Rows**

- Operating across the whole country (national organisation).
- Operating in one or several regions of the country (regional organisation).
- Operating only at a local level (local organisation).

**Columns**

- One.
  - More than one.
  - None.
  - I do not know.
- 

Question 4/11:

**Are patient organisations in your country involved in healthcare policy decision-making at national or local government level?**

[Please specify only one option.]

- Yes, it is a legal requirement.
  - It is not a legal requirement—but patient organisations do tend to be involved in an advisory capacity, by common practice.
  - No, patient organisations do not tend to be involved.
  - I do not know.
- 

Question 5/11:

**Are vaccinations for hepatitis-B virus (HBV) subsidised in your country?**

[Please specify only one option.]

- They are 100 % subsidised (that is, free of charge to the individual—with no co-payment).
  - They have the same level of subsidy (co-payment) as other similar treatments in our public healthcare system.
  - They have a lower subsidy (higher co-payment) than other similar treatments.
  - Patients HAVE TO PAY 100% of the cost of the vaccination privately.
  - I do not know.
- 

Question 6/11:

**Is screening for hepatitis-B virus (HBV) and hepatitis C-virus (HCV) subsidised in your country?**

[Please specify only one option per column.]

**Rows**

- It is 100 % subsidised (that is, free of charge to the individual—with no co-payment).
- It has the same level of subsidy (co-payment) as other similar procedures in our public healthcare system.
- It has a lower subsidy (higher co-payment) than other similar procedures.
- Patients HAVE TO PAY 100% of the cost of the screening privately.
- I do not know.

**Columns**

- Screening for hepatitis-B virus (HBV).
  - For hepatitis C-virus (HCV).
- 

Question 7/11:

**A patient who has symptoms that might suggest hepatitis has an appointment to see a specialist (such as a hepatologist, or a gastroenterologist). How long does such a patient in your country typically have to wait to see that specialist?**

[Please specify only one option.]

- The patient can be seen by the specialist in the same week.
  - Between one and two weeks.
  - More than two weeks, but less than a month.
  - More than a month.
  - I do not know.
- 

Question 8/11:

**a.) Do people with HBV or HCV in your country get THEIR HEPATITIS-RELATED DRUGS (including prescription drugs) on the same terms as the drugs taken by people who have other medical conditions?**

[Please specify only one option.]

- In my country, drugs for people with HBV or HCV have a higher subsidy (lower co-payment) than the drugs for patients with other conditions.
- People with HBV or HCV in my country have their drugs subsidised on the same terms as patients with other conditions.
- Some drugs which are vital for people with HBV or HCV have a lower subsidy in my country than other prescription drugs.
- I do not know.

**b.) Is the same true for children with HBV or HCV in your country?**

[Please specify only one option.]

- Drugs for children with HBV or HCV in my country have a higher subsidy (lower co-payment) than the drugs for children with other conditions.
  - Children with HBV or HCV in my country have their drugs subsidised on the same terms as children with other conditions.
  - Some drugs which are vital for children with HBV or HCV have a lower subsidy in my country than other prescription drugs.
  - I do not know.
- 

Question 9/11:

**How readily available in your country is post-exposure immunisation for hepatitis B?**

[Please specify only one option.]

- It is available free to everyone in need, when recommended by a healthcare professional.
  - The general public have to pay to obtain such immunisation (unless they had contact with hepatitis because of their profession—occupational exposure).
  - The general public cannot obtain such immunisation at all, even if they wish to pay for it.
  - I do not know.
- 

Question 10/11:

**How often in your country is testing for hepatitis-C virus offered to people with HIV/AIDS who have high-risk behaviours (such as injecting drug use; multiple sexual partners; men who have sex with men [MSM])?**

[Please specify only one option.]

- It is offered to them at least once a year.
  - It is offered to them less frequently than once a year, but is still offered regularly.
  - It is offered to them—but not regularly at all.
  - It is never offered to them.
  - I do not know.
- 

Question 11/11:

**In your country, is systematic genotyping offered for free to all patients with HCV?**

**(Genotyping is the process of determining differences in genetic make-up.)**

[Please specify only one option per column.]

**Rows**

- Yes, it is offered free to all such patients BEFORE they start their treatments.
  - Yes, it is offered to all such patients BEFORE they start their treatments—but it is NOT FREE to them.
  - It is not normally offered.
  - I do not know.
-

## Appendix 2 Survey to clinicians: Hepatitis Care

**1. Firstly, could you please indicate in which European country you are based?**

**2. Which is your area of expertise?**

- Clinician
- Nurse
- Public Health Expert
- Academic/researcher
- Patient Organization representative
- Accompanying person
- Press
- Other
- Other (please specify)

**3. Immunization programs for Hepatitis B.**

**Has your country included Hepatitis B in their Universal Vaccination program?**

**Has your country implemented additional programmes for risk groups? (Please select all that apply)**

Universal Vaccination (routine Infant vaccination)

Neonate born to HBsAg + mothers

Health Care Workers

Commercial Sex Workers

Partners to and persons living with HBV-infected persons

IDU

Men that have sex with men

Prison Population

**4. Have public campaigns been run in your country about VIRAL HEPATITIS and its risks during the last 12 months? (Such campaigns could be on TV, on the radio, or in newspapers.)**

- a) Yes.
- b) Not in the last 12 months, but during the last few years.
- c) Yes, but further back in time than a few years ago.
- d) No, to my knowledge, we have never had such a campaign in my country.
- e) I do not remember / I do not know.

**5. Are there leaflets about viral hepatitis in health care centers?**

**[Please specify only one option.]**

- a) Yes, easy to find in every health care center.
- b) Not in every center but in some.
- c) I have not seen such leaflets in any healthcare centers.
- d) I do not know.

**6. Post exposure immunization for hepatitis B**

**[Please specify only one option.]**

- a) Yes, available for free to everyone (recommended) in need.
- b) Available to everyone but paid privately for "non occupational exposure"
- c) Not available or only available for health care staff



d) I do not know

**7. Annual HCV antibody testing for HIV- infected persons with continued high-risk behaviors,(such as Injection Drugs Users and Men who have Sex with Men)  
[Please specify only one option.]**

- a) Yes, offered at least once a year
- b) Less than once a year but regularly
- c) Yes, but not regular at all.
- d) Never
- e) I do not know

**8. Screening HBV/HCV funding  
[Please specify only one option.]**

- a) 100 % subsidized, i.e. free of charge to the individual (= no co-payment)
  - b) Same subsidy (co-payment) as other similar treatments in our public healthcare system
  - c) A lower subsidy (higher co-payment) than other similar treatments
  - d) We have to pay 100% privately.
  - e) I do not know
- Other (please specify)

**9. Are HBV vaccinations:  
[Please specify only one option.]**

- a) 100 % subsidized, i.e. free of charge to the individual (= no co-payment)
  - b) Same subsidy (co-payment) as other similar treatments in our public healthcare system
  - c) A lower subsidy (higher co-payment) than other similar treatments
  - d) Patients have to pay 100% privately
  - e) I do not know
- Other (please specify)

**10. Are HEPATITIS-RELATED DRUGS (including prescription drugs) on the same terms as the drugs taken by people who have other medical conditions?  
[Please specify only one option.]**

- a)They have special status (higher subsidy = lower co-payment than other patients, or for drugs not related to hepatitis)
  - b) They enjoy drug subsidies on the same terms as other patients or for other drugs.
  - c) Some drugs, essential for hepatitis patients have a lower subsidy than common prescription drugs.
  - e) I do not know
- Other (please specify)

**11. How long is the waiting time for specialist appointment?  
[Please specify only one option.]**

- a) In the same week.
  - b) Between one and two weeks.
  - c) More than two weeks but less than a month
  - d) More than a month
  - e) I do not know
- Other (please specify)

**12. Is Genotyping a (free) regular practice in your country? (HCV)  
[Please specify only one option.]**

- a) Yes, to all chronic patients before they start their treatments
- b) Yes to all chronic patients before they start their

treatments but it is not for free

e) It is not a regular practice.

f) I do not know

Additional comment

**13. % of children treated in a specialist unit?  
[Please specify only one option.]**

a) All

b) Only some of them or in some areas or regions

c) Only very few or we do not have specialist unit for children

**14. Adherence to European (EASL) guidelines (Hep B, Hep C)**

a) 100%

b) About 50%

c) We follow national society guidelines or others

d) I do not know

Additional comment

**15. Do you have Hepatitis specialist nurses in your country? (Means with clinical accreditation)  
[Please specify only one option.]**

a) Yes, widely available in the country

b) Only available in some hospitals

c) None or very few.

d) I do not know

additional comment

**17. Is there an HCC registry?  
[Please specify only one option.]**

a) Yes, national

b) Yes, regional

c) Only in some regions

d) Only some hospitals

e) None

f) I do not know

Other (please specify)

**18. Is there a HCV/HBV (general hepatitis; liver) patient organization in your country?  
[Please specify only one option.]**

a) National

b) Regional

c) I do not know

**19. Is there National funding for Hepatitis strategy in your country?  
[Please specify only one option.]**

a) Yes

b) No, the strategy was privately funded

c) We do not have a National strategy

d) I do not know

## Appendix 2 Survey to clinicians: Vaccination/testing

**1. Firstly, could you please indicate in which European country you are based?**

**2. Which is your area of expertise?**

- Clinician
- Nurse
- Public Health Expert
- Academic/researcher
- Patient Organization representative
- Accompanying person
- Press
- Other
- Other (please specify)

**3. Immunization programs for Hepatitis B.**

**Has your country included Hepatitis B in their Universal Vaccination program?  
Has your country implemented additional programmes for risk groups? (Please select all that apply)**

Universal Vaccination (routine Infant vaccination)

Neonates born to HBsAg + mothers

Health Care Workers

Commercial Sex Workers

Partners to and persons living with HBV-infected persons

IDU

Men that have sex with men

Prison Population

**4. Post exposure immunization for hepatitis B**

**[Please specify only one option.]**

- a) Yes, available for free to everyone (recommended) in need.
- b) Available to everyone but paid privately for “non occupational exposure”
- c) Not available or only available for health care staff
- d) I do not know

**5. Please indicate in the table below if HBV and/or HCV screening is performed systematically in your country for the subgroups listed? (Please tick all that apply)**

	HBV	HCV
Chronic HBV patients		
Chronic HCV patients		
HIV positive patients		
Pregnant women		
Blood and organ donors		
IDUs		
Men that have sex with men (MSM)		
Commercial sex workers		
Partners to and persons living with patients		

HBV	HCV
with chronic viral hepatitis	
Hemophiliacs	
Patients in chronic hemodialysis	
Patients with cirrhosis	
Persons with trisomi 21 (Down's syndrome)	
Patients with unexplained elevated ALT/AST	
Prison Inmates	
Immigrants from high-endemic areas	
Prior to chemotherapy or treatment with biological drugs	
STI clinic patients	

**6. Annual HCV antibody testing for HIV- infected persons with continued high-risk behaviors,**

**(such as Injection Drug Users and Men who have Sex with Men)**

- a) Yes, offered at least once a year
- b) Less than once a year but regularly
- c) Yes, but not regular at all.
- d) Never
- e) I do not know

**7. Screening HBV/HCV funding**

- a) 100 % subsidized, i.e. free of charge to the individual (= no co-payment)
  - b) Same subsidy (co-payment) as other similar treatments in our public healthcare system
  - c) A lower subsidy (higher co-payment) than other similar treatments
  - d) We have to pay 100% privately.
  - e) I do not know
- Other (please specify)

**8. Are HBV vaccinations:**

- a) 100 % subsidized, i.e. free of charge to the individual (= no co-payment)
  - b) Same subsidy (co-payment) as other similar treatments in our public healthcare system
  - c) A lower subsidy (higher co-payment) than other similar treatments
  - d) Patients have to pay 100% privately
  - e) I do not know
- Other (please specify)

**9. Adherence to European (EASL} guidelines (Hep B, Hep C}**

- a) 100%
  - b) About 50%
  - c) We follow national society guidelines or others
  - d) I do not know
- Additional comment

**10. Is there an HCC registry?**

- a) Yes, national
  - b) Yes, regional
  - c) Only in some regions
  - d) Only some hospitals
  - e) None
  - f) I do not know
- Other (please specify)



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