



## Viral Hepatitis Empowerment Tools for Groups

Dear GP, Liver Unit and Support Group Leaders,

80% of both Hepatitis B and C patients still remain undiagnosed.

The British Association for the Study of the Liver recently noted London and Birmingham's inner cities have gone endemic (2% infected) and also that whole UK communities (Chinese and Ghanaian) are plus 7% HBV positive.

We are all losing the battle against viral hepatitis, diagnosing 30 to 50% less than similar health services.

The UK's 500,000 plus undiagnosed sufferers are providing as estimated by the All Party Commons Group in 2002, thousands of cases of end stage liver disease. To tackle this very treatable and preventable illness we have designed simple tools using messages that have worked around the world.

We target ethnic, social, occupational and patient groups so far overlooked by testing and vaccination messages. The plan is to air the posters as A3 laminates in participating Surgeries Waiting Areas, giving individual's time to ask their hepatitis risk question of GP's. When everybody is comfortable with that the GP's can then enquire on an individual basis, ie Ask the Question – Have they audited their Hepatitis B & C Risks?

50% diagnosis levels are the norm in the developed world, without them millions if not billions will need to be spent on expensive treatments and operations that are easy to prevent with a simple test and some good advice. As with any major carcinogen, the sooner it's discovered the less of a threat it presents

Your efforts as a lead Surgery or Help Group on this Project will save a great deal of lives and money.

Best Wishes

Paul Desmond Executive Director [www.hepb.org.uk](http://www.hepb.org.uk)

Targeting 280 GP's of Ealing, Harrow, Hackney, Edgware, Brent & Hillingdon Boroughs

Targeting 500 St John, Red Cross & the Met Local User Feedbacks

Targeting 18 Liver Units via Hepatology Nurses

Targeting Anne Milton, Sally Davies and HPA/SHA Immunisation Heads

Targeting London's, Boris's Health Boards and Borough PCT Disease Plans

Targeting 10 chemists and 27 WDP's

## How to include Hepatitis B patients into Liver Support Groups

If you run a liver support group for hepatitis C or a related liver disease these tools can help you feel confident about the needs of a hepatitis b patient in your group.

Firstly it is good to see the scale of good advice your groups already have for hep b patients. Ultimately the symptoms of and lifestyle recommended for all liver disease patients have similar golden rules. So many valuable supports can be shared in the following areas.

- Diet
- Avoiding Alcohol & Obesity
- Blood Hygiene
- Interpreting Liver Scans and Function Tests
- Emotional Reactions – Hep C groups often really understand these experientially already
- Liver Illness especially the tiredness, fogginess, 50 related ailments list
- Managing hepatitis treatment and avoiding dangerous medications
- Finding information – the motto of the foundation helpline is “We never guess.” Along those lines we offer the Website/Web Forum/Helpline with the tools

There are only a few key differences between hep b and c

- Hep b has a vaccine (vaccination schedule supplied)
- High Load Hep b is sexually infectious in semen and vaginal fluids
- Hep b has no cure, only daily pills to lower loads in advancing liver disease cases
- Hep b has complex laboratory results (see wheel tool)

### Key Support Needs

- The 4 month gap until consultant is filled by the internet scares
- any patients think they will die
- Many patients think they are infectious or unclean
- Many patients do not understand their liver or health status
- Many patients have no understanding of transmission or vaccination
- Many patients have never seen a consultant

In particular the Tools are designed to observe 4 cardinal points from the World Hepatitis Association, as mentioned by Charles Gore,

- To implement the eradication of hbv
- To count infections in and out of places eg prisons, borders, schools
- To look back and ask Am I Number 12? More often
- To keep asking for the 12 hepatitis Asks policy wise

- Themes for 6 sessions (15 minutes info blasts) Diet, Meds, Sex, Vaccines, Kids, Futures, Tests) Are being worked up for Support Groups as downloads

## HBV Group Tools – backed up by the website forum helpline

### Three Viral Hepatitis Posters

These Public Display Maps are to educate and inform citizens from here and around the world how viral hepatitis infects 1 in 4 humans and remains in 1 in 12, highlighting how knowing your status can save your life and remove the bulk of morbidity and mortality. Millions from endemic areas and many professions are often completely unaware of their up to 1 in 10 risk. The maps also inform travelers to endemic areas for vaccination. Plain English and St Mary's Liver Unit overviewed the text and WHO 2005 the Atlas's. The occupations poster has already emerged 34,000 Police and First Aid Workers for hbv vaccination

- |                          |                                 |
|--------------------------|---------------------------------|
| 1. HBV Pandemic Risk Map | attached for public A3 laminate |
| 2. HCV Pandemic Risk Map | attached for public A3 laminate |
| 3. Occupations Poster    | attached for public A3 laminate |

### Four simple Group Leaderdesk cards

To aid Groups with diagnosis, lab results, testing risk, counseling, blood hygiene and vaccination, cover at a glance all of the above topics. The goal is to note pandemic scale amid both communities and professions and national infection growth rates. Our Helpline has noted in 2011 more than 90% of patients detected during routine pregnancy screening had never heard of Hepatitis B prior to diagnosis. The Tools try to directly address this ignorance also.

- |                                    |  |
|------------------------------------|--|
| 1. Serological HBV Test Wheels     | A5 Mailed                              |
| 2. Pre + Post Test Counseling      | attached double sided A5 or 4 laminate |
| 3. ELPA all risks + Blood Hygiene  | attached double sided A5 or 4 laminate |
| 4. HBV Vaccination Schedule + OA/K | attached double sided A5 or 4 laminate |

### Patient Just Diagnosed Booklet information tools (in 14 languages)

With the rise of the internet and patient access to information more than 70% of patients calling the helpline have exaggerated ideas about their infection, many become alone and isolated, depressed, even suicidal for years. The tools below try to give patients our helpline, key background information and links to correct information, bridging the bumpy ride of tests and fears until they meet a consultant and maximizing vaccination and education.

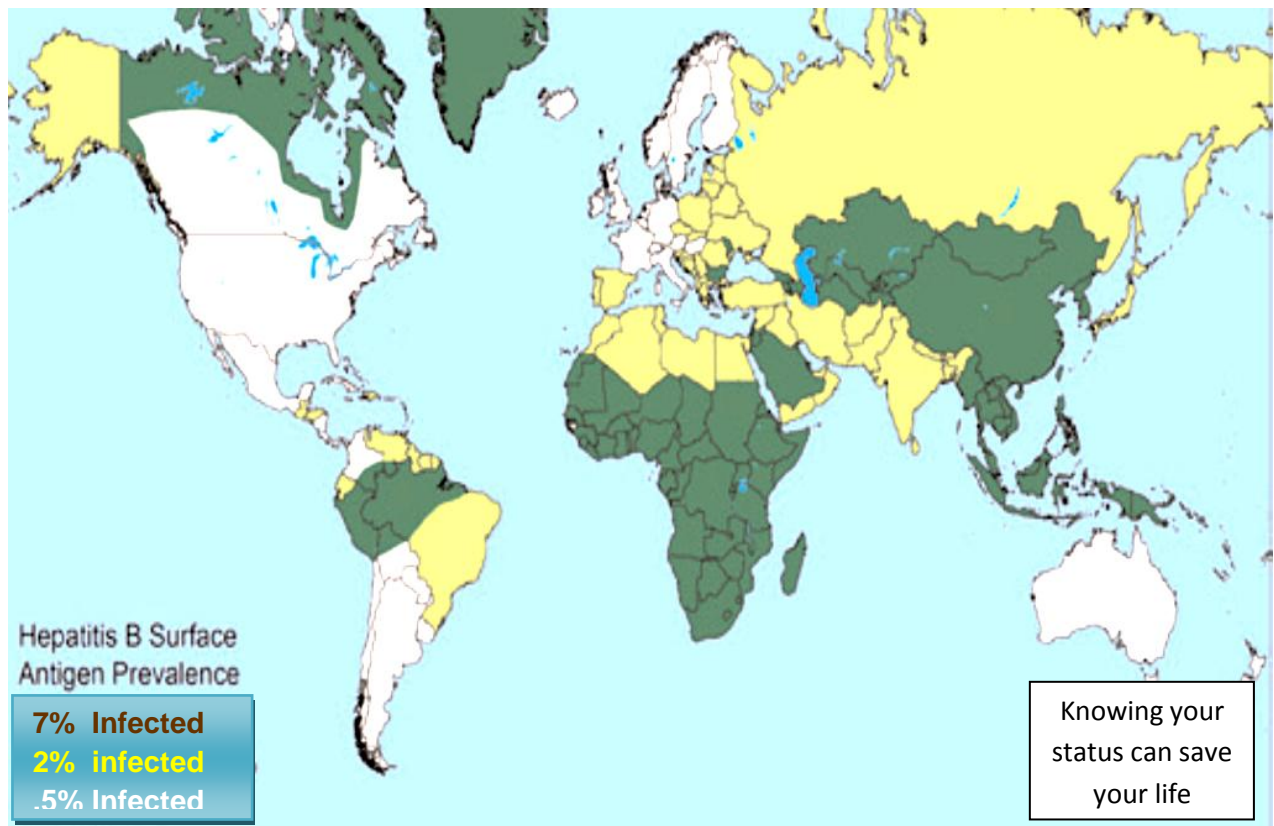
- |   |                  |
|---|------------------|
| • Just Diagnosed HBV Booklet                  | for each patient |
| • HBV Vaccination Schedule                    | for each patient |
| • Confidential anonymous data collection form | for each patient |

### Further Resources

- |  |  |
|--|--|
| • GP & Public Risk Test Vaccinate Manual | Orderable for GP Resource for his desk |
| • Infomercials                           | Download for public broadcast          |

**50% Diagnosis levels an Olympic target 2012** [www.hepb.org.uk](http://www.hepb.org.uk)

**“1 in 4 humans innocently catch Hepatitis B,  
testing a Hep B risk is nothing to be ashamed of.”**



Hepatitis B is a virus that over 20-30 years can “silently” cause cirrhosis and cancer, a million people worldwide die each year due to late diagnosis. Millions of UK citizens are at some exposure risk, Hepatitis B infects without symptoms and most catch it innocently....

- From Maternity during birth in any of the coloured areas above
- From re used medical syringes / contaminated vials in any of the coloured areas above
- From Spilt Blood to an open wound when unvaccinated (common here)
- From Unprotected Sex (common here)
- From Injecting Drug Abuse (even once)

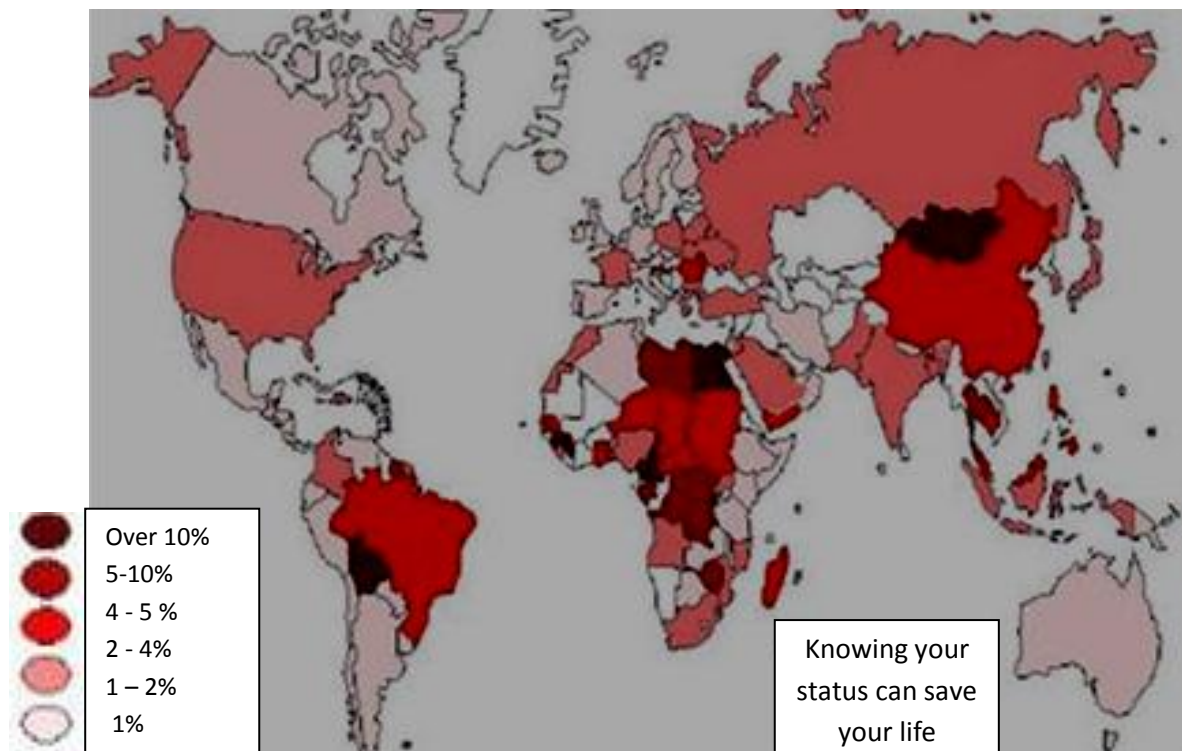
**Remember to ask your GP about a Hepatitis B Safety Test and Vaccination** if you have run any of the above risks or visit or were born in an Endemic area (yellow/brown on map). Most Hepatitis B patients often have no symptoms until real damage has been done. So especially, if your lifestyle is hard on your liver or you have poor liver function tests, knowing your Hepatitis B status can help safeguard your future.

08000 46 1911  
[www.hepb.org.uk](http://www.hepb.org.uk)

**Remember to ask your GP**

# 1 in 40 humans has healthcare hepatitis C

Hepatitis C is a virus that over 20-30 years undiagnosed can “silently” cause cirrhosis and cancer, up to 5 million UK citizens have run NHS or Overseas risks recommended for screening.



Patients can get hepatitis C from

- NHS Major Surgery or Dialysis before 1992
- NHS Caesarean Section before 1992
- NHS Organ or Tissue Transplant before 1992
- NHS Transfusions or NHS Plasma / Platelet Products before 1992
- These Surgery/transplant risks were **often** higher overseas and a substantial **current** risk from injection reuse remains in Africa, Asia and Eastern Europe

Remember to ask your GP about a Hepatitis B & C Safety Test if you have run any of the above medical risks or have had overseas operations or have **ever** injected street drugs.

Most hepatitis c patients have no symptoms until real damage has been done. So, especially, if your lifestyle is hard on your liver or you have poor liver function tests, knowing your hep c status can help safeguard your future.

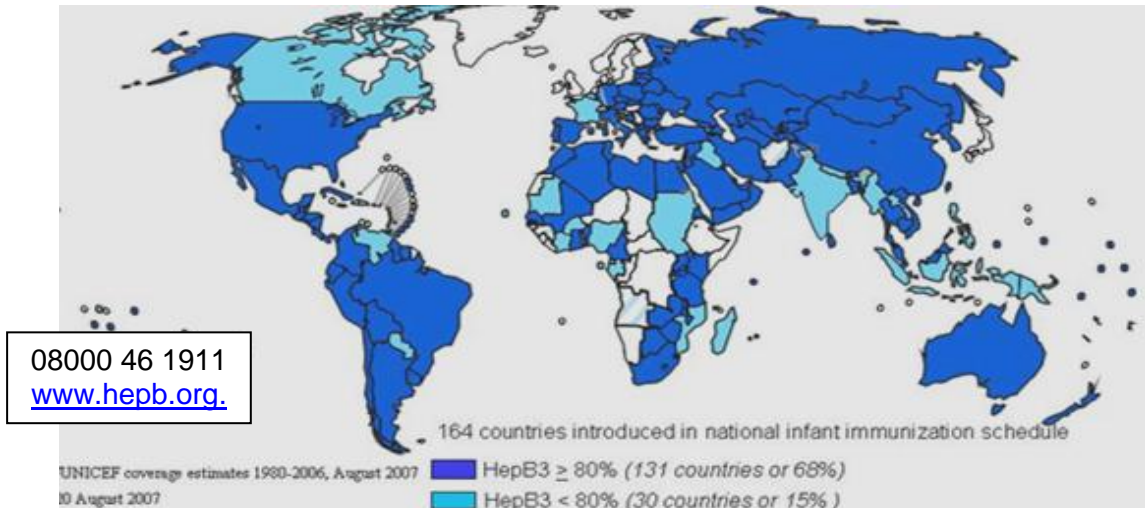
08000 46 1911  
[www.hepb.org.uk](http://www.hepb.org.uk)

## Remember to ask your GP

## Hepatitis B Vaccination (at a glance) Immunisation schedule

Source <http://www.patient.co.uk/doctor/Hepatitis-B-Vaccination-and-Hepatitis-B-Prevention.htm>

- The standard course of immunisation involves 3 injections over 6 months.
- An accelerated course over 2 months is possible - also for combined hep A & B vaccines.
- Many adults who need protection very **quickly** can have a schedule over 21 days. After an accelerated course, a booster at 1 year is recommended. It can be used in those who are immunocompromised, as with HIV infection, but a higher dose may be required or extra booster injections.



### **25% of UK babies are born into UK Endemic Communities, the World Health Organisation and the BMA recommends prompt vaccination for them.**

The vaccine should be given into the deltoid region or anterior thigh in babies. It is less effective if given into the buttock. It is quite possible that a course may give lifelong immunity,<sup>4</sup> but for health professionals one further booster at 5 years\* is recommended. Antibody titres should be tested 2 to 4 months after the primary course.

- A titre above 100 mIU/ml is regarded as adequate. Around 10-15% of adults fail to respond to three doses of vaccine or respond poorly.<sup>1</sup>
- Poor responders with titres of 10 to 100 mIU/ml should have a booster and those with a titre below 10 mIU/ml should repeat the course.
- Those over 40 years old, are obese or who smoke are more likely to fail to respond.
- Alcoholics are also reported as having lower seroconversion rates, particularly those with advanced liver disease.
- Patients who are immunosuppressed or on renal dialysis may also respond less well and require larger or more doses of vaccine.
- Failure to gain antibody after 2 complete courses should not be seen as necessarily meaning no immunity, as immunity to the disease is largely cell-mediated rather than by antibody.
- Post-exposure prophylaxis (PEP) involves giving hepatitis B vaccine and possibly immunoglobulin too if required within 48 hours.
- Of a thousand people vaccinated and having no boosters 3 became infected after 10-15 years. 5 years is chosen due to safety, health care workers are not suddenly "at risk" after 5 years.



## Is your job killing you?

**Nurses**

**First Aiders**

**Emergency Workers**

**Police/Security**

**Dental Assistants**

**Lab Technicians**

**Doctors**

**Morticians**

**Sportspeople**

**Hairdressers**

**Beauticians**

**Soldiers**

**Prison Officers**

**Tattooists**

**Cleaners**

**Sewage Workers**

**Custodial Staff**

**Sex Workers**

Every year thousands of people, including many from the professions above, make a simple mistake; they take medicines, put on weight or socially drink with undiagnosed viral hepatitis B or C. Many liver damage and some die as a result, it is estimated that every day a UK blood worker dies from hepatitis b. So if you have worked or work with blood, know the risks, and get tested and vaccinated,

- Remember each needle stick, blood spill, from a Hep B or Hep C infected source, to an open wound, is a 2-4% infection risk
- It is estimated at least one in a hundred of the people in the above professions are Hep B or Hep C infected and don't know.
- Early vaccination and diagnosis is the best way to avoid harm.
- It is your employer's responsibility to Hepatitis B Vaccinate you, if your occupation risks you coming into contact with blood.
- For the army of unpaid carers or volunteers at risk the responsibility is the GP's.

## Remember to ask your GP

# STOP

40 million people have HIV

350 million have inherited HBV

210 million have transfusion HCV

# CAUTION

HIV, HBV and HCV

Can live in spilt blood

And infect via contact

With an open wound

# USE

"Premiership Blood Hygiene"

Active plastering of all wound

Gateways using gloves, then

Bleach Kill the Spill & Virus

# BECAUSE

1 in 10 people on Earth and

1 in 75 people in the UK

Bleed a blood virus now.



To find out more about "Premiership Blood Hygiene" as an Olympic Legacy for all

[www.hepb.org.uk](http://www.hepb.org.uk)

## Ask the Risks Doctor (Risk Assessments by Easol and Elpa)

The definition of high risk groups is an essential tool in designing targeted screening programmes for viral hepatitis	
High risk groups for Hepatitis B	High risk groups for Hepatitis C
<ul style="list-style-type: none"> <li>• Persons with elevated liver enzymes and/or clinical sign of hepatitis</li> <li>• Patients with liver cirrhosis or fibrosis</li> <li>★ Patients with hepatocellular carcinoma</li> <li>• People who share or have ever shared needles (injecting drug users)</li> <li>• People with long-term imprisonment history</li> <li>• People who are undergoing or have undertaken hemodialysis</li> <li>• Men who have sex with men or heterosexual persons with multiple sex partners</li> <li>• People with HIV or HCV infection</li> <li>• Families and household members or sexual partners of persons infected with HBV</li> <li>★ Patients and staff in psychiatric institutions or residents of welfare institutions for mentally disabled persons</li> <li>★ Pregnant women and newborns of HBV-infected mothers</li> <li>• Recipients of organ transplants and blood products</li> <li>• Blood and organ donors</li> <li>• Patients before or during immunosuppressive treatment or chemotherapy</li> <li>• Migrants from countries with high prevalence of Hepatitis B</li> <li>• Unvaccinated healthcare workers and public safety workers who undertake exposure-prone procedures.</li> </ul>	<ul style="list-style-type: none"> <li>• Persons with elevated liver enzymes and/or symptoms of hepatitis</li> <li>★ Patients with liver cirrhosis or fibrosis</li> <li>• People who share or have ever shared needles (injecting drug users)</li> <li>• People with long-term imprisonment history</li> <li>• People who are undergoing or have undertaken hemodialysis</li> <li>• People who have received repeated percutaneous injections</li> <li>• People who have had invasive medical and paramedical or dental work in countries with high prevalence or poor sterilisation procedures, such as use of multidose vials</li> <li>★ People who received blood transfusions or other blood derived products outside the EU or before 1992 in the EU</li> <li>★ People who received organs and tissues transplants outside the EU or before 1992 in the EU</li> <li>• Haemophiliacs who received concentrated coagulation factors before 1987</li> <li>• People with HIV infection</li> <li>• People who have used intra-nasal cocaine</li> <li>• People with body piercings if being performed in non hygienic environments</li> <li>• Children of HCV-infected mothers</li> <li>• Healthcare workers and public safety workers who undertake exposure-prone procedures</li> </ul>

★ 75% of infections are accounted for by the white star risks alone

“Being born and/or Medical syringe reuse in endemic areas are the key risks.”

## Hepatitis Diagnostic & Vaccination Empowerment Tools Notes

These GP Notes can help support groups with hep b issues around, testing and vaccinating those at risk around the group member. One Chinese group member ultimately diagnosed 5 relatives and vaccinated many more, 41% of callers to the helpline needed help in this area.

With the advent of swine and avian flu the NHS has developed a vaccination network that is often underused away from certain seasons, yet sudden demand can seriously tax Surgeries abilities. Further some Practices and Poly Clinics slipped easily into higher volumes.

There are many things that front line GPs can see and the questionnaire will have 20 questions covering key issues such as prevalences, growth of death/illness rates, costs and cost effects, streamlining/educating and Blurred Guideline/RCGP Presumptions, all in a focused UK City Area, served by excellent Liver Units.

If like our helpline you test a few people many valuable background lessons can be learned about

- Common behaviours that kill or injure people with hepatitis
- Common ways it is transmitted here and overseas
- Common communal, social, emotional reactions and misconceptions
- Complete disease ignorance and complex testing is a unique complication

**Phase 1** - Become comfortable with the Messages and set up systems of Care/Referral

- Deal with patients asking for tests for 1 to 3 months
- Master informed consent referral counseling
- **Engage St John, Police, Red Cross, Unions, Schools, Royal Colleges,**
- **Create supply chain delivery audit with SHA's and Dame Davies**

**Phase II** – GP's, Liver Units adding Local Support Groups, Chemists and Public Venues

- Start asking the at risk to safety screen/vaccinate targeting
- Endemic Area Migrants – All Asians, Africans and East European and 25% of newborns
- Old NHS Patients especially Pre 1992 Dialysis, Major Surgery, Transplant
- Occupations that work with blood – Police, St John
- Any with poor liver function
- **Develop Political, Retail, Council, Union, GP, GUM, DAT, Liver Unit and Patient Networks**

One aspect of group work is to be greatly encouraged, so far on the helpline some 20 professionals infected at work have expressed real concern about their colleagues unvaccinated or safety screened running the same risks. This has led to, in consultation with the professional, 20 industry vaccination packs, many stakeholders and 34,000 occupational vaccinations planned by St John and the Police alone. A London based hospital worker infected on the ward has a group for such staff and mums diagnosed when pregnant as she has the experience of having baby and avoiding onward infection too.

**The Hepatitis B Foundation is responsible for reportage and data auditing of questionnaire from patient and GP sources, both as service users and suppliers**

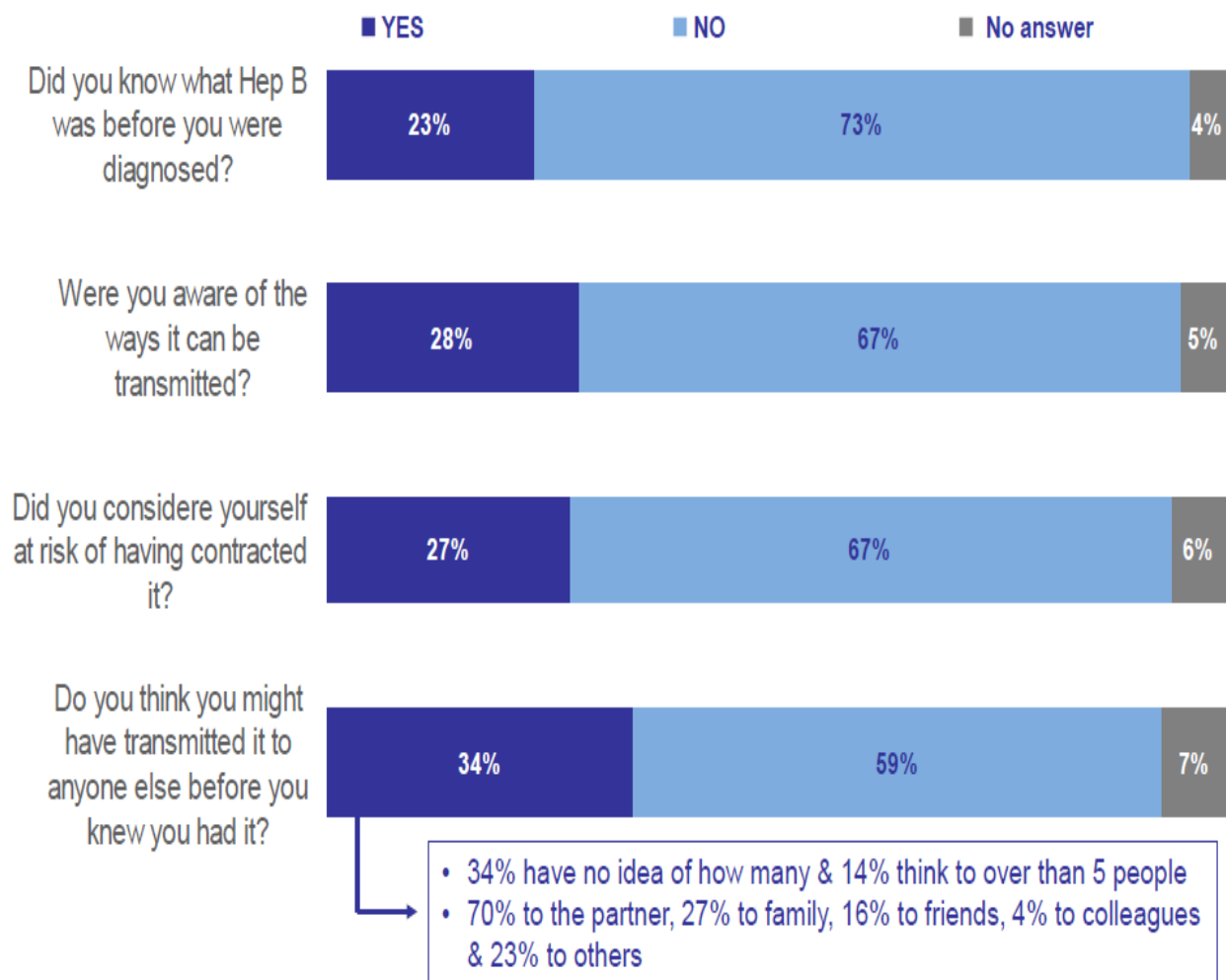
# Excellent ground work lessons

from ELPA for EU General Practitioners

- Across the EU 75% of the infected have never even heard of Hepatitis B
- We are well behind the EU average in advertising the Risks
- We are well behind the EU average in Doctors asking Risk Test Questions
- The root of the problem is ignorance
- Creating a lack of safety screening that is booming the death rate.



## 1. Disease awareness before the diagnosis



ELPA survey 2007-2008  
Elpa / October 2008

**75% of your HBV infected patients are at serious risk of Liver Cancer unless we Ask them the Risk Test Question**

# Excellent ground work lessons

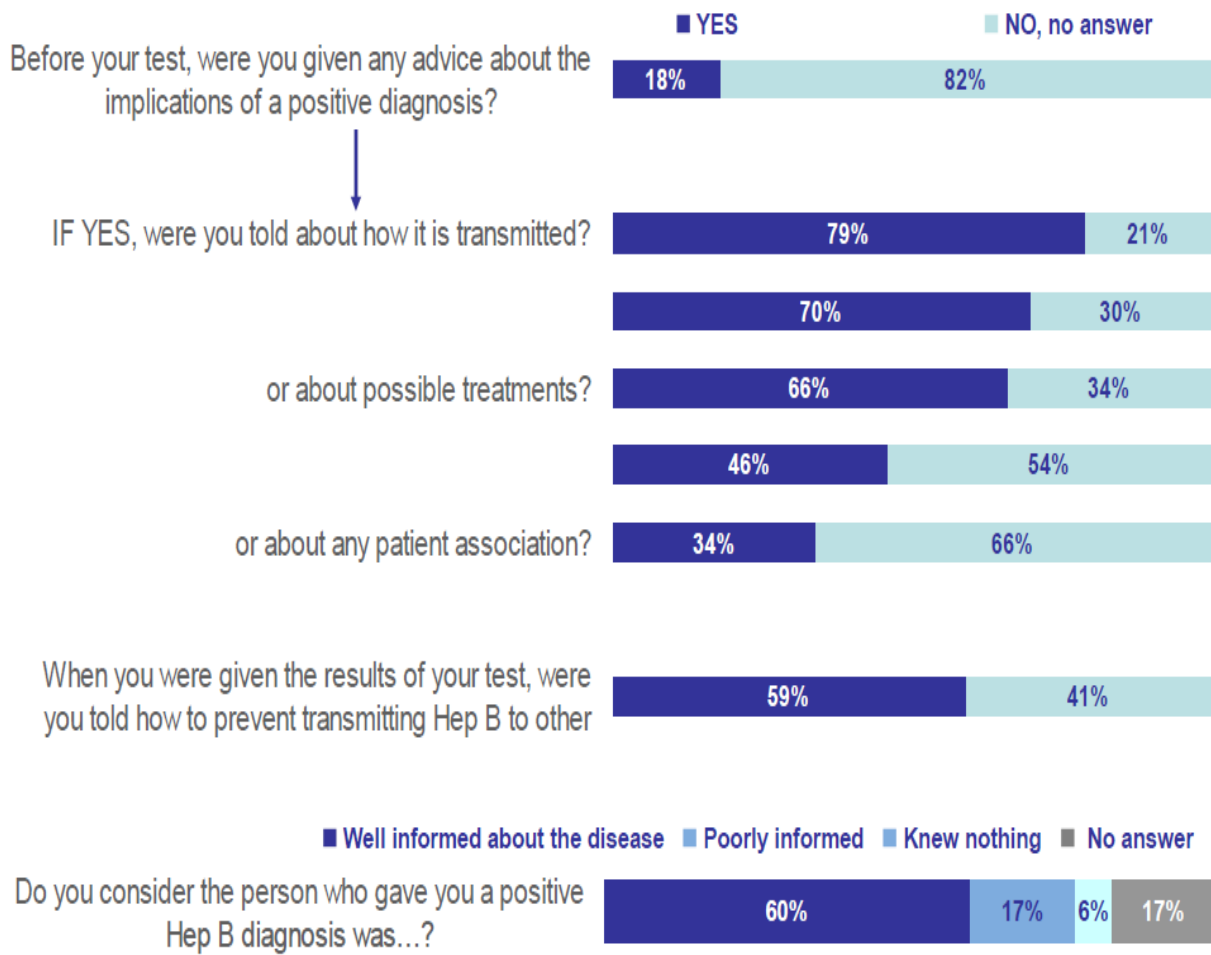
from ELPA for EU General Practitioners

- Across the EU 41% of HBV patients are not given correct counseling
- A third to 50% of HBV patients are missing key life saving care pathway information
- 77% of HBV patients felt their doctor was poorly informed



Hep B

## 5. Advices & information received during the diagnosis



ELPA survey 2007-2008  
Elpa / October 2008

**With Viral Hepatitis most Fatality, onward infections and Morbidity is avoided by the quality of the Counseling alone. GP's need to maximise patient opportunities to get this.**



## Communities need “Disease Sensitive Counseling”

### The Hepatitis Pre-Test Discussion

Should ask for informed consent for testing by the patient after explaining

- 1. Printed HVC/ HBV information** about the annual global deaths due to poor diagnosis. The value of knowing liver status.
- 2. Assessment of Infection Risks** and or Symptoms that need testing, Explanation of risks for HBV/HCV being 1 in 3 humans common.
- 3. Information** about confidentiality and the notification process. Very rarely insurers and employers may access this information, so arranging insurances or work issues if you are e.g. a surgeon or a boxer can be important.  
**On Occasion** it is necessary, to assess support for a result, e.g. children, mentally ill and the elderly, and to reduce infection risks, e.g. vaccination/safer injecting.

### The Hepatitis Post-Test Discussion

Should give the test result in a manner that is confidential, sensitive and appropriate to mental state, personally, covering

- 1. An Understanding of HCV / HBV's Disease Journey.** With HCV explain it is not a sex disease but a Super Bug Pandemic affecting 200 million
- 2. A Liver Friendly** lifestyle, explain how HCV/HBV kills with pills or alcohol
- 3. The Basics** of both HBV Vaccination and Blood hygiene precautions, people need to use plasters and bleach spills. HBV also requires safe sex as that virus is in sexual fluids
- 4. Medical Referral** to a liver specialist and a source of disease information, such as the Hep C Trust or Hep B Foundation, for the person's discretion.
- 5. Assessment** of mental state, I've seen people diagnosed with liver cancer and months to live and be very sensible and people diagnosed with a normal life expectancy and no damage have a breakdown and need a psychiatrist.  
**On Occasion** it is necessary to arrange Rehabilitation or Psychological counseling or therapy.



## Counseling Life Treatment Plans

### GP & Support Group Do's and Try Not To's

Do encourage liver good life, diet, attitude, vaccination, abstinence, education

Do print HBV Booklet with every diagnosis.

Do vaccinate all partners and relatives (work sport colleagues often)

Do support the unhealthy livers with Peg Inter and any constant side effects

Do make clear HBV is only caught by those forgetting their vaccine

Do assume 80% of presenting infections are unavoidable

Do not prescribe long term unless audited monitored risk

Do mention 21 units creates cirrhosis too

Do mention obesity doubles the danger

Do explain the healthy livers may not need treatment highlight they are healthy

Do not assume IDU or sex risks initially

Do assume totally innocent work, birth or childhood risks as often as you can

Do not call HCV sexual only transfusable

Do try, not mother to child, but Maternity Unit infections

Do encourage Premiership Blood Hygiene

### Do try to use simple terms for Hepatitis B results

<b>HBeAg</b>	<b>Got it replicating</b>	<b>(often high risk and quickly curable)</b>
<b>HBsAg</b>	<b>Got it</b>	<b>(often low risk manageable but incurable)</b>
<b>Anti-HBc Igm</b>	<b>Fighting it</b>	<b>(6 month window)</b>
<b>Anti HBs/HBe</b>	<b>Cleared it</b>	
<b>100 anti per ml</b>	<b>Immunised for it</b>	

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