



First hepatitis B national consultations



hepatitis and kidney diseases

LivingWithHepatitisBSurvey

## 1<sup>st</sup> National Living with Hepatitis B Survey

**You are living with the hepatitis B virus.**

**Please respond to this inaugural national survey that marks the launch of the first *Etats Généraux de l'Hépatite B* (hepatitis B national consultations).**

**Enhancing the visibility of the real consequences of hepatitis B and optimising the care and follow-up of patients suffering from chronic hepatitis B are the two main stakes behind the launch of the national consultations through the SOS Hépatites association and many partners (associations of people living with hepatitis B, health professionals and health institutions).\***

**Today, the hepatitis B collective is enlisting your help to complete an initial survey designed to make an inventory of the main impacts of this illness, as well as your main needs and expectations in terms of improving your daily life.**

**The questionnaire enquires about:**

- > your perception of hepatitis B**
- > screening of your loved ones**
- > your medical and therapeutic care**
- > your everyday difficulties and expectations**

**You will need 15 minutes to complete this questionnaire.**

**Your responses are collected and processed under strictly anonymous and confidential conditions. The findings will be all the more impactful if many of you respond! They should help raise awareness among health authorities and the public in order to obtain “fair” recognition of the real difficulties we face when suffering from hepatitis B.**

**If you would like to be informed of the results of this survey, do not hesitate to send us your request:**

**- by email to [vero.ecoutemoi@soshepatites.org](mailto:vero.ecoutemoi@soshepatites.org)**

**or**

**- by phone: 0 800 004 372 (free of charge from a landline or mobile including from the overseas departments and regions).**

**Thank you for participating!**

\*SOS Hépatites, AIDES, ASUD (Self-Support for Drug Users), CHV (Viral Hepatitis Collective) – TRT5 (therapeutic treatment & research inter-association group), Transhépate, AFEF (French association for the study of the liver), ANGH (National Association of Hepatic-Gastroenterologists of General Hospitals), APSEP (Association for Health Professionals Serving in Prison), COMEDE (Health committee for individuals in exile), CREGG (Brainstorming club for hepatic-gastroenterology clinics and groups), FPRH (Federation of reference divisions and networks, and hepatitis networks), Médecins du monde, Family Planning, Agence nationale de la biomédecine (National biomedicine agency), ANRS (National Agency for Research on Aids and Viral Hepatitis), Cochin Hospital, Pitié Salpêtrière-Paris Hospital, Lille university hospital, Renne university hospital, Strasbourg university hospital, CIC (immunisation clinical investigation centre) of the Cochin-Paris Hospital, Croix Rousse-Lyon Hospital, Saint Joseph-Marseille Hospital, INSERM (National Institute of Health and Medical Research), BMSHV (Bordeaux Metropolis without Hepatitis).

\* 1. In which year was your hepatitis B detected?



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**Your perception of hepatitis B**

\* 2. Do you think hepatitis B is an illness?

- yes
- no
- I don't know

\* 3. Do you think hepatitis B is an illness that is

- mildly serious
- serious
- very serious
- is not really an illness
- I don't know

\* 4. Please indicate whether you think hepatitis B is more or less serious than the listed illnesses

	less serious	as serious	more serious	I don't know
heart attack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV/AIDS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
excess cholesterol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
lung cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 5. Had you heard of hepatitis B before being tested?

- yes
- no
- I don't know

\* 6. Did you feel concerned by hepatitis B before being tested?

- yes
- no
- I don't know



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**Your perception of hepatitis B (2)**

\* 7. Please indicate whether you agree or disagree with the following statements

	strongly agree	somewhat agree	somewhat disagree	strongly disagree	no opinion
Hepatitis B is linked to a virus that is present in blood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B can lead to chronic liver disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B cannot be cured today (in 2019)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B is transmitted through blood exchange between two people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B is transmitted during unprotected sexual intercourse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B can lead to liver cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B affects more people than HIV/AIDS in the world	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B can lead to significant fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	strongly agree	somewhat agree	somewhat disagree	strongly disagree	no opinion
Hepatitis B can lead to joint problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B is the focus of much medical research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is advisable to stop drinking alcohol when you have hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is advisable to stop smoking when you have hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B can manifest as muscle pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B is transmitted through saliva exchange between two people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a vaccine against hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hepatitis B can be transmitted from mother to child during childbirth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 8. Today, do you feel you are well aware of

	yes absolutely	somewhat yes	somewhat no	not at all	no opinion
how to avoid passing hepatitis B on to your loved ones in everyday life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
how to talk to your loved ones about hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
how to talk about hepatitis B with a new sexual partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
how hepatitis B treatment works	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
how to monitor your hepatitis B?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 9. On what occasion(s) did you obtain this information?

- during screening
- during medical consultations
- by searching for yourself
- when interacting with others affected by the virus
- Other (please specify)

\* 10. Today, among the impacts of hepatitis B, which one is the most challenging for you (several answers possible)

- fear of rejection
- uncertainty about disease progression
- lack of support from others
- disrupted sex life
- discouragement
- professional activities
- recreational opportunities
- the treatments
- fear of cancer
- fear of dying
- fear of infecting others
- how to have children with hepatitis B



## LivingWithHepatitisBSurvey

### Your hepatitis B screening

\* 11. Who offered or prescribed hepatitis B testing for you?

- your general practitioner
- another doctor
- a free anonymous screening centre [CEGIDD: Free Infection Screening and Diagnosis Information Centre: by the Human Immunodeficiency Virus (HIV), viral hepatitis and Sexually Transmitted Infections (STIs)]
- during a pregnancy or pregnancy plan
- I don't know

someone else (please specify)

\* 12. Did you have your liver examined (lab tests, ultrasound, or liver biopsy) after your hepatitis B screening?

- yes
- no
- I don't know

If yes, please specify which one.



13. After the screening, did you manage to talk to loved ones about your hepatitis B quickly?

	yes	no
less than one month	<input type="radio"/>	<input type="radio"/>
less than one year	<input type="radio"/>	<input type="radio"/>
more than one year	<input type="radio"/>	<input type="radio"/>

If yes, please specify which loved on(s) (sexual partner, rest of the family, friends, etc.)

14. If so, why? (several answers possible)

- to be honest with them
- to encourage them to be screened to
- encourage them to get vaccinated
- for their support
- other (please specify)

15. If not, why not (several answers possible)

- fear of being rejected because I am sick
- fear of being rejected because I can transmit the illness
- Other (please specify)

\* 16. Do you trust the hepatitis B vaccine?

- yes
- no
- I don't know

\* 17. Have you discussed hepatitis B prevention with loved ones?  
(Screening-Vaccination)?

- yes
- no



## LivingWithHepatitisBSurvey

### Your treatment

\* 18. Are you taking any hepatitis B medication?

- yes
- no (if this choice, go directly to question 25)

19. If yes, is it a treatment that is

- oral
- injected under the skin (Interferon)
- not concerned
- other (please specify)

20. What hepatitis B medication is it?

- Tenofovir (Viread or generic)
- Entecavir (Baraclude or generic)
- not concerned
- Other (please specify)

21. Do you ever forget to take your hepatitis B medication?

- never
- sometimes
- often
- not concerned

22. If you happen to forget or not take your medication, what are the reasons? (many options possible)

- weariness
- lack of motivation
- to feel better (fewer side effects)
- simply forgetting
- delay in refilling treatment at the pharmacy
- an unexpected event that resulted in you not having any medication with
- you
- not concerned

other (please specify)

23. Do you know why you need to take treatment?

- yes
- no
- not concerned

24. Do you have any side effects?

- yes
- no
- not concerned

If yes, which one(s) (please specify)

25. If you are not taking any treatment, please tick the situations that apply to you (several answers possible)

- I've never heard of it before
- Your doctor tells you that you don't need any
- You refuse to take the treatment
- You would have liked treatment
- not concerned
- Other (please specify)



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Your medical follow-up

\* 26. Have you been prescribed an ultrasound to monitor your liver?

	yes	no	I don't know
every 6 months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
once a year	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
other frequency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 27. Do you know if you have fibrosis?

- yes
- no
- I don't know
- other (please specify)

\* 28. Which doctor(s) or professional(s) have you consulted (or sought out) in the past 12 months regarding your hepatitis B (several answers possible)

- general practitioner
- hepatologist
- gynaecologist
- physiotherapist
- nurse
- chemist
- therapeutic educator
- surgeon
- psychiatrist
- volunteer or association manager
- social worker
- psychologist
- sports and/or physical activity professional
- none
- Other (please specify)



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**Your Health**

\* 29. The consequences and impacts of your hepatitis B on your daily life (today)

	yes, significantly	yes, moderately	not really	not at all	no opinion
Does your hepatitis B affect your morale?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your family life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your social activities (cultural outings, with friends, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your leisure time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your work life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your sex life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your relationship as a couple?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B affect your self-image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Does your hepatitis B interfere with your physical activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* 30. Were you offered or prescribed Hepatitis Delta (hepatitis D) testing?

- yes
- no
- I don't know

\* 31. You are living with the hepatitis Delta virus (Hepatitis D)

- yes
- no
- I don't know



\* 32. Are you concerned by one or more of these health issues:

- HIV/AIDS
- other chronic diseases: diabetes, asthma, allergies, etc.
- kidney failure
- awaiting liver transplant
- I have no health problems other than hepatitis B
- Other (please specify)



## LivingWithHepatitisBSurvey

### Your assistance and expectations against hepatitis B

\* 33. On a daily basis, who is/are the person(s) who helps/help and supports/support you against hepatitis B

- your spouse
- your children
- your parents
- your friends
- your doctor
- a patients' association
- no one

Other (please specify)

\* 34. For you, does hepatitis B generate specific financial expenses

- yes
- no

If yes, please specify the nature of the expense(s) and the amount?

\* 35. What are your needs in terms of better managing your hepatitis B and improving your daily life?

	yes	no	no opinion
be better informed about healthcare professionals who can help you with your care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about the treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about preventing transmission to loved ones	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about the disease in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about medical follow-up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about potential difficulties in working life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about difficulties when applying for a mortgage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better informed about what you can eat and drink	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
meet and discuss with other sick people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

\* 36. What do you expect from a patient association such as SOS Hépatites or the *Etats Généraux de l'hépatite B* (Hepatitis B national consultations)?

	yes, significantly	yes, moderately	not really	not at all	no opinion
to be able to contact someone easily to ask my questions (e.g. toll-free number)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to have access to information on hepatitis B and daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to have access to social information in order to better manage the consequences of hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
raise awareness of the challenges of people living with hepatitis B among health policy and decision makers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to promote vaccination in adults	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to extend the vaccination obligation until adolescence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to allow people living with hepatitis B to opt for the career of their choice, including those that they are currently barred from	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
develop a website dedicated to hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
set up a toll-free number dedicated to hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
draft hepatitis B information brochures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)



## LivingWithHepatitisBSurvey

### Your profile

\* 37. Your gender

- female  
 male  
 other (please specify)

\* 38. Your age group

- Age 16-30  
 Age 30-60  
 Over 60-years-old

\* 39. Your department (please specify)

\* 40. You live

- in a rural area  
 in an urban area

\* 41. You live

- alone  
 as a couple or family

\* 42. You have children

- yes
- no

any comments

\* 43. Do you have loved ones (family, friends, etc.) who are also affected by hepatitis B?

- yes
- no
- I don't know

any comments

\* 44. What is your education level?

- lower secondary studies
- high school
- professional certificate
- higher education
- no diploma
- I do not wish to answer

\* 45. Professional status

- active
- no occupation
- in search of work
- retired

\* 46. Were you born in France?

- yes
- no

If not, what is your country of origin?

47. If not, how long have you been in France?

- less than 3 months
- less than 1 year
- between 1-5 years
- more than 5 years



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**Thank you for participating**

48. Did you complete the survey

- alone
- with someone's help

if with someone's help specify the name of his/her organisation

49. Please provide us with your feedback and suggestions on improving the questionnaire