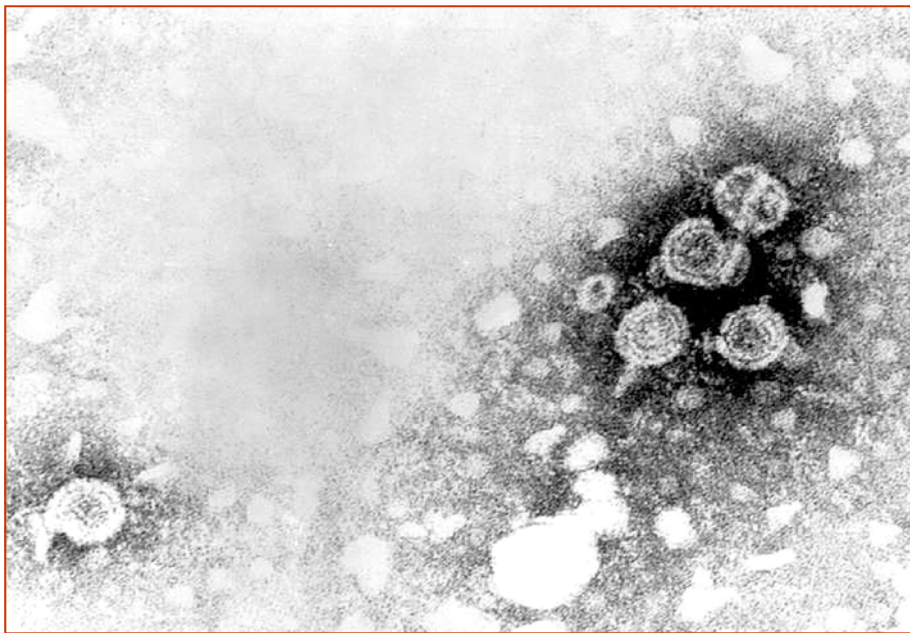


Improving the management of hepatitis B: A survey of health campaigners

Conducted and published by PatientView
With the support of Douglas Dieterich
New York University School of Medicine



"The report show clearly that we must not treat hepatitis B as a local problem ! We all have to work together, as we must understand that hepatitis B is a global problem. Thank you for a important report."

Erling Olsen, Hepatitis Foreningen (The Danish Hepatitis Association)

**March 2005
Sponsored by Sudler & Hennessey**

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The contents of this report is largely obtained through a survey of selected campaigners. PatientView is not responsible for the views expressed in this document.

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Results of survey: Highlights

- **The survey.** Over a two-week period between February-March 2005, PatientView (an independent research and publishing organisation) conducted a global email survey (in English, French, German, Italian and Spanish) of the 409 key health campaigners specialising in hepatitis B and/or liver disease [see Appendix 1] in its database. Included in the survey were groups specialising in hepatitis C, but which claimed an interest in hepatitis B as well. Some groups were affiliated to organisations representing people with HIV/AIDS. Others were self-help organisations run by parents with children with asymptomatic forms of hepatitis B. The aim of the survey was to gauge patient/consumer perceptions about the current management of hepatitis B, and to determine areas where improvements might be made.
- **Methodology.** The email sent to campaigners contained a personal invitation from Douglas Dieterich, Professor of Medicine, New York University School of Medicine, explaining the importance of the survey. The email also included the questionnaire, which was composed of ten short questions. The questions dealt with a range of topics, including access to patient information on the condition and its treatment; stigma; access to care and treatment; communication in the consulting room; the efficacy of medication; compliance with treatment; and possible national differences in the management of hepatitis B. Europeans were asked an additional question on information about diagnoses. [See Appendix 2.]
- **The respondents.** A total of 29 responses to the survey were received within the two weeks. This equates to a response rate of 7%, which is striking, given the short time-frame. Fourteen of the respondents came from North America (12 from the US, and two from Canada). Ten respondents were based in Europe, came from: Denmark (1), France (1); Germany (5); Italy (1); Norway (1); and Switzerland (1). The five respondents from the rest of the world (RoW) came from: Australia (2); Bangladesh (2); and Brazil (1). Of the 29 respondents, 62% worked for organisations with a local remit; 52% with a national remit; while 28% of the respondent groups had responsibilities of international proportions. (A number of the participants, too, were from organisations charged with more than one geographic area of responsibility). The majority of the respondents (69%) chose to provide their personal views in the survey. They were mostly senior executives of well-known patient organisations, carers or family members of patients with hepatitis B, or individuals responsible for communicating information about hepatitis to their constituency. A few were patients themselves. Just over half of the participants agreed to be attributed. [See Appendix 3 for participants that wanted to be named.]
- **Publicly-available information about hepatitis B and its treatment.** Only 28% of the participants said that it was easy to obtain such information in their respective countries. Nearly one third stated that it was difficult to get information about hepatitis B and its treatment. [See Appendix 5 for survey results].

The results from Europe were somewhat polarised, with 40% of European respondents saying that information on hepatitis B and its treatments was easy to get, but 50% also insisting that the information was difficult to get. One German respondent ticked both opposing views. A possible explanation for these results is to be found in the comments from participants [see Appendix 4]. European participants stated that people can obtain information from doctors, leaflets, patient organisations, self-help groups and the Internet. Popular websites in Germany are:

- ⇒ www.hep-net.de
- ⇒ www.leberhilfe.org
- ⇒ www.bag-leber.de

But a participant from Norway also noted that obtaining information from webpages is dependent on having access to the Internet. In the case of Norway, the public also need to have a good grasp of epidemiology and statistics, to comprehend Internet data (even in the Norwegian tongue). Another criticism was that leaflets tend to focused only on individuals who might acquire hepatitis B through sexual intercourse or by intravenous drug abuse.

Public access to information is slightly better in North America compared with the global average. 90% of the American and Canadian participants reported that people in their countries “could easily get the information, or that sometimes the information was easy to get”; against a figure of 73% for all 29 participants. A number of North American participants, however, acknowledged that high-quality information was “challenging” to obtain. Two American participants felt that greater efforts should be made to reach out to Asian and homosexual populations, who are vulnerable to contracting hepatitis B, and who often do not get the reliable data they need.

- **Stigma.** According to 83% of the participants in the survey, patients with hepatitis B feel stigmatised virtually everywhere across the globe—at least some of the time. The problem, declared participants, is at its greatest within Asian communities. One American participant wrote: “Asians are afraid to see the doctor, and are afraid to tell friends and relatives that they have hepatitis B, due to the fear that people won’t socialise or eat with them”. The participant from Brazil also indicated that the situation is exacerbated because of public misunderstandings about the condition. The public, said this respondent, typically believe that the infection is highly contagious, and can be passed on with a handshake. A German participant noted that as a result of “medical stigmatisation” HBV-patients (hepatitis B virus-patients) develop more serious chronic conditions (e.g. cirrhosis).
- **Access to specialists.** The consensus view of the participants was that their countries either did not have sufficient numbers of hepatologists (35%), or that hepatologists were unavailable in some parts of their country (28%). A participant from Germany qualified this opinion by declaring that because the German healthcare system usually requires referrals from family doctors to specialists, many of the doctors seen by patients may be

inexpert at diagnoses and thus do not get referred. Another participant said that children with asymptomatic forms of the condition are primarily seen by GPs, who are not equipped to monitor infections in their patients. More effort, stated the participants, should be made to attract people to the field.

- **Access to treatment.** Over two thirds of the participants noted that patients with hepatitis B “do not” or “only sometimes get the treatment they need”. In Europe, the equivalent figure was 50% (although a further 30% said that they could not answer the question). And 64% of the participants from North America said that patients with hepatitis B “do not” or “only sometimes get the treatment they need”. In Brazil, not all treatments for hepatitis B have been approved for use. In the US, differences in community resources can determine availability of treatment. Although one German participant noted the existence of international consensus guidelines regarding appropriate interventions for people with hepatitis B, according to the levels of infection and inflammation detected within the individual. Another participant stated that the age of the infected individual might influence decisions to prescribe.
- **Communication in the consulting room.** Echoing the above findings, nearly three quarters of the survey participants believed that hepatologists “do not” or “only sometimes” inform patients with hepatitis B about their treatment options. In Europe, the equivalent figure for survey participants was a similar 70%. In North America, the figure was only marginally lower at 71%.
- **Effectiveness of treatments.** Few patients, it seems, are entirely happy with the medicine they receive for the treatment of hepatitis B. 55% of the participants said that “only sometimes” did patients (with whom they were familiar) report the therapy for their condition as effective. A further 14% of the participants said that patients suspected that their medication was ineffective. Findings were similar from across the globe. A German respondent stated that the success of treatment could be correlated with the skills of the treating physician. Another said that the nature of the treatment was such that therapies are usually unable to eliminate the virus entirely from the body. A third German respondent noted that the situation might improve with the introduction of new treatments, such as Pegasys.
- **Compliance with treatment.** Participants seemed to think that patients’ low expectations regarding the efficacy of treatment negatively influenced their ability to comply with treatment. Five out of the 29 participants said that patients complied with treatment. The figure was lowest in Europe, where only one of the ten respondents said that patients complied with treatment. Five of the European-based participants said that patients did not comply with treatment, or only sometimes. (The remaining three European respondents did not know).
- **Drug resistance.** Patients are concerned with problems of resistance, said 18 of the 29 participants of this survey—at least sometimes. The pattern of response to this question was almost the same worldwide. Two participants, however, felt that patients

would only be concerned with the question of drug resistance in hepatitis B treatment if they were properly informed. “Without such knowledge, the results can be fatal” emphasised a German participant.

- **Drug reimbursement.** For the most part, respondents felt that the treatment of patients with hepatitis B is shouldered by healthcare systems—with the exception of North America. Only three of the 14 US-based participants said that patient treatment was fully reimbursed. One US respondent commented that insurers may vary in their coverage of hepatitis B treatments. None of the 29 participants, though, specified that treatment was “never paid for by healthcare systems”.
- **National differences.** Few of the survey respondents believed in the existence of significant national differences regarding the management of hepatitis B. Although many respondents, in fact, felt unable to answer the question. However, comments from one of the German participants referred to the patients dislike of the physicians continued paternalistic attitudes that prevents the development of true partnerships between doctor and patients. Although doctors in Germany no longer have the godlike status they once enjoyed, German patients often complain that their doctors continue to act like Gods—or at show disdain toward patients’ own knowledge about their disease and treatments. One Canadian participant felt that countries with high ethnic populations had special medical needs in hepatitis B management and treatment. One American participant stated that the US should dedicate far more money to research into all iterations of hepatitis, as these communicable diseases are mostly “invisible” in the US. However, another participant from Germany, also noted the move in Europe toward an international consensus in the treatment of the condition.



Appendix 1: Profile of database used for this email survey

Country	Hepatitis	Liver	Total
Australia	3	-	3
Austria	1	-	1
Brazil	1	-	1
Canada	38	22	60
China	1	-	1
Denmark	11	-	11
France	13	-	13
Germany	42	-	42
Israel	1	-	1
Italy	6	1	7
International (Europe)	-	5	5
Netherlands	-	5	5
Poland	1	-	1
South Africa (children)	2	-	2
Spain	1	-	1
Switzerland	4	9	13
UK	13	-	13
USA	185	48	233
Totals	323	86	409

Appendix 2: The questionnaire used in this email survey

Dear health campaigner,

I am writing this short introduction to explain why we would like you to participate in this e-mail survey, which will greatly help the cause of **improving the management of hepatitis B**.

I am a clinician involved in the management of this devastating viral infection, and a long-time advocate for improvements in the quality of care of hepatitis B. I believe that this survey—which examines important issues in hepatitis B care, such as patient information, stigma, access, efficacy of treatment and ease of compliance to treatment—would contribute to a better understanding of the patients' perspective on hepatitis B care, worldwide.

As you are aware, hepatitis B is a global health problem. Yet many people do not know of the viral threat, and fail to seek diagnosis or appropriate treatment. This survey is an initial attempt to discover the scale of the problem at national and local levels, so that doctors (together with industry) can better communicate with hepatitis B patients.

I strongly urge you to participate in this survey being conducted by PatientView and sponsored by Sudler & Hennessey. You will find the ten-question survey below. It should take no more than ten minutes of your time to complete.

Yours sincerely,
Douglas Dieterich
Professor of Medicine
New York University School of Medicine

Note to the respondent from the survey manager, PatientView

The survey is worldwide. It is being sent to patient groups with an interest in hepatitis B, or hepatitis generally, or liver disease generally. No pharmaceutical companies are involved in the sponsorship of the project.

You can answer the survey anonymously. Or you can request that your group be attributed in the survey report.

The survey's findings will appear in a short report, due to be issued late March 2005. **To thank you for participating in the survey, you will be sent a copy of the report** (which will be in PDF, in English).

To fill out the questionnaire, simply hit the reply button to this email, enter your answers in the boxes supplied, and press 'Send'. Your responses will be returned back to PatientView.

Any further correspondence should be addressed to PatientView (contact details are at the end of this email).

About Douglas Dieterich

Dr. Dieterich is Professor of Medicine at the New York University (NYU) School of Medicine. He holds positions at three New York hospitals: NYU Tisch Hospital, and Beth Israel North, both as an attending physician, and Bellevue Hospital Center, as a clinical assistant. He is a Fellow of the American College of Physicians and the American College of Gastroenterology, and a member of many professional societies. He has served on several committees of the AIDS Clinical Trials Group, National Institutes of Health (NIH)—including the steering committee of the Opportunistic Infections Core Committee. He has also served on the NIH Study Sections for cytomegalovirus (CMV) and cryptosporidiosis. Dr. Dieterich has many publications to his name on the subject of viral hepatitis and AIDS-associated infections of the gastrointestinal tract and liver and their treatment. He sits on the speaker bureaus for Roche Pharmaceuticals, Schering-Plough, Gilead Sciences, GSK, and Bristol-Myers Squibb. He receives research funding from Roche Pharmaceuticals, Schering-Plough, Merck & Co. Inc., and Gilead Sciences.

Worldwide survey of patient groups that deal with hepatitis B

SURVEY OBJECTIVE:

“To improve doctor-patient relations—so that the treatment of hepatitis B may get better ”

The Questionnaire

Question 1: Patient information

How easily can people in your country get information about hepatitis B and its treatment?

- Easy to get information on hepatitis B and its treatment.
- Sometimes easy to get—it depends.
- Difficult to get information on hepatitis B and its treatment.
- I do not know.

If you would like to add a short comment on the difficulty, or ease, with which information on hepatitis B can be gained by people in your country:

Question 2: Stigma

In your country, do people with hepatitis B experience stigma associated with the condition (and, if so, does it prevent them from coming forward for treatment)?

- A lot of stigma—which prevents people with hepatitis B coming forward for treatment.
- Sometimes people are stigmatised—it depends.

- People with hepatitis B do not experience stigma.
- I do not know.

If you would like to add a short comment on stigma and hepatitis B:
.....

Question 3: Access to specialists

Do you think that your country has enough specialist hepatologists to ensure that patients with hepatitis B receive treatment quickly?

- Yes—there are enough to ensure that patients with hepatitis B receive treatment quickly.
- Possibly enough.
- Hepatologists are available—but only in certain parts of my country.
- Not enough.
- I do not know.

If you would like to add a short comment on the numbers or distribution of hepatologists in your country:

Question 4: Access to treatment

Once a patient with hepatitis B has a consultation with a hepatologist, is treatment readily prescribed?

- Always.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on the readiness of hepatologists to prescribe:

Question 5: Communication with patients in the consulting room

Do hepatologists inform patients with hepatitis B about all possible treatment options?

- Always.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on the communicational ability of hepatologists in the consulting room:

Question 6: Effectiveness of medication

Do patients with hepatitis B (with whom you are familiar) report that their therapy for the condition is effective?

- Always.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on effectiveness of treatment:

.....

Question 7: Compliance with medication

Are hepatitis B treatment regimes easy for patients to comply with?

- Yes.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on why hepatitis B treatments are, or are not, easy to follow:

Question 8: Drug resistance

Are patients with hepatitis B (with whom you are familiar) concerned about resistance of the hepatitis B virus to treatment regimes?

- Yes.
- Sometimes—it depends.
- No.
- I do not know.

If you would like to add a short comment on resistance:

.....

Question 9: Access to reimbursement

Do patients with hepatitis B in your country usually have their prescribed treatment paid for by their healthcare system?

- Yes—fully paid for by the healthcare system.
- Partially paid for by the healthcare system.
- Sometimes paid for—it depends.
- No—they have to pay for their treatment out of their own pocket.
- I do not know.

If you would like to add a short comment on reimbursement of treatment costs:

Question 10: National differences

Are there any exceptional circumstances in your country that make the treatment of hepatitis B different compared to the rest of the world?

- Yes.
- Possibly—it depends.
- No.
- I do not know.

If you would like to add a short comment:

.....

Lastly, some profiling questions:

a.) Whose views are you expressing in this survey?

- Personal.
- My organisation.

b.) What are the geographic areas of interest for your organisation?

- Local.
- National.
- International.

c.) What area of expertise does your organisation specialise in?

- Hepatitis B only.
- Other types of hepatitis.
- Other liver disease/s.
- Other.

d.) What is your own position in the organisation?

.....

Do you wish your responses to:

- Remain anonymous.
- Be attributed to your organisation (please confirm the name of your organisation):

Thank you for your time. That concludes the survey.

The aggregated survey results will be sent to you in late March 2005

Yours sincerely,
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For more information: <http://www.patient-view.com/hscnetwork.htm>

Appendix 3: Groups that wanted to be named as respondents to this survey

Name Weblink	Country of origin
American Liver Foundation www.liverfoundation.org	US
Berliner Leberring e.V. www.berliner-leberring.de	Germany
Canadian Liver Foundation www.liver.ca	Canada
Hepatitis Foreningen www.hepatitisforeningen.dk	Denmark
Deutsche Leberhilfe e.V. www.leberhilfe.org	Germany
Gopalpur Welfare Club-Dristy Health Center Pabna	Bangladesh
Grupo Optimismo de Ayuda a Portadores de Hepatitis www.hepato.com	Brazil
Help C (Deutschschweiz) www.hepatitis-info.ch/helpcframe.html	Switzerland
Hepatitis-Ambulanz e.V. www.hepatitis-ambulanz.de	Germany
Hepatitis C Council of Victoria www.hepcvic.org.au	Australia
HepCure http://hepcure.junction.net/	Canada
Hepatitishilfe Mittelfranken e.V. www.hepatitisc-selbsthilfegruppe.de	German
L.I.F.E. Program at Shanti www.shanti.org	US
Selbsthilfe Lebertransplantierter Deutschland e.V. www.lebertransplantation.de	Germany
SOS hépatites Champagne Ardenne membre de SOS Hépatites Fédération	France
Source: PatientView, March 2005	

Appendix 4: Comments of respondents

[translated into English where necessary]

Comments are listed in the order of receipt.

Question 1: Patient information

- **Hepatitishilfe Mittelfranken e.V (Germany):** From self-help groups, specialists—as far as they are available.
- **Canadian Liver Foundation:** This disease is still a silent one, and although the information is available, it's always a challenge to get out there.
- **HepCure (Canada):** I am very interested in setting up hep-B community workshops for people to access information here in British Columbia. The problem here is that the hep-B community is largely composed of Asian immigrants. The Asians are afraid of seeking diagnosis or treatment, for fear of being deported.
- **Anonymous (US):** You can obtain information from the doctor or the Internet. However, there are too many different types of information on the Internet, and the quality of the information can vary and confuse patients. Hepatitis B is not a common illness in the US, and therefore is not widely known in this country (as is hepatitis C). However, it is common in certain ethnic groups (for instance, Asians, homosexuals). Information campaigns to these groups are needed to encourage screening and treatment.
- **Anonymous (Norway):** To obtain correct information in Norway one has to have access to the web-pages of the Norwegian National Institute of Health, which requires an Internet connection, and, preferably, a good grasp of epidemiology, or how statistics are generated. Information from local health workers is usually outdated, simplified and faulty. I recently read a Norwegian textbook on epidemiology (as well as official governmental web pages) that present hepatitis B as a problem for "marginalised groups" (drug abusers and immigrants)—using correct data in an improper setting to create the impression. There is a leaflet targeting groups which may spread hepatitis B sexually, or by intravenous drug abuse, but none for children with hepatitis B. The leaflet can be found in most physicians' waiting rooms.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** The only Portuguese site for hepatitis is www.hepato.com. But, for that, you need the Internet. We are preparing a project with la Sociedad Brasileña de Hepatología to set up a hotline with information on hepatitis B.
- **Berliner Leberring e.V. [Germany]:** www.Hep-net.de
www.Leberhilfe.org, www.bag-leber.de
- **American Liver Foundation:** In the United States, it is fairly easy to get information in English on hepatitis B from such organisations as the American Liver Foundation (ALF). However, it is very difficult and challenging for people of Asian descent to get good, reliable HBV information. That is why the American Liver Foundation created its THINK B programme.

- **Deutsche Leberhilfe e.V. (Germany)** Brochures of Deutsche Leberhilfe e.V. (written by Professor Zeuzem), as well as the patient magazine "Sign of Life" and Internet information via www.leberhilfe.org.
- **Anonymous (US):** If they want to get information it is easy on-line but the information obtained may be so varies that they get confused.
- **Selbsthilfe Lebertransplantiertes Deutschland e.V. (Germany):** Weblinks, publications and self-help groups.



Question 2: Stigma

- **Hepatitishilfe Mittelfranken e.V (Germany):** It depends on occupation. If you work in the city, country, or local district, within hospitals, or with older people, or generally in any caring profession, then, in Germany, people are stigmatised.
- **Canadian Liver Foundation:** The stigma is so great that very famous people who have passed away recently refuse to let it be known what killed them.
- **HepCure (Canada):** Particularly the Asian community.
- **Anonymous (US):** Certain ethnic groups are concerned with the stigma. For example, Asians are afraid to see the doctor and are afraid to tell friends and relatives that they have hepatitis B due to fear that people won't socialise or eat with them.
- **Anonymous (Norway):** There is definitely a stigma, but I do not think it prevents people from seeking treatment. Health workers may have low opinions, or be fearful, of the patients, but are generally law-abiding when it comes to not disclosing sensitive health issues. But the stigma is strong enough for some carriers to be shunned by other people in their community, if their condition is disclosed.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** Because of the lack of information provided by the Brazilian government, there is a misunderstanding about the causes of contamination. Stigma occurs because people believe that the infection can be passed by saliva, kissing, a handshake, or can be airborne.
- **Anonymous (Italy):** Personally, I know about hepatitis C, and cannot comment on hepatitis B. But I have felt no stigma.
- **Berliner Leberrig e.V. (Germany):** Patients with hepatitis C are more stigmatised.
- **American Liver Foundation:** HBV patients can sometimes be stigmatised, because people erroneously connect it with lifestyle choices. Increased education on HBV reduces stigma. However, stigmatisation is still very much a problem in both Asian and Anglo communities.

- **Deutsche Leberhilfe e.V. (Germany)**. We differentiate between social and medical stigmatisation. The social type often accompanies unemployment and racism. Medical stigmatisation concerns the interactions with the established general medical profession. As a result of ignorance, medical treatments can be regarded as unnecessary. As a result HBV-patients develop more serious chronic conditions (e.g. cirrhosis).



Question 3: Access to specialists

- **Hepatitishilfe Mittelfranken e.V (Germany)**: There are possibly enough. But, unfortunately, many physicians cannot diagnose correctly. We experience it in the consultation—physicians make an incorrect diagnosis of hep B again and again.
- **HepCure (Canada)**: We hope that a hepatitis strategy focusing on a liver-disease center of excellence will provide enough coordinating services for the province [of British Columbia], that specially-trained GPs and nurses can fill in the gaps.
- **Anonymous (Norway)**: Carriers are not supposed to see specialists until their ALT or AST have been seriously out of line for some time. The local GPs frequently are not up to what sort of test should be used, or how often they should be run. And so, liver problems may go undetected for quite a while.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil)**: It is estimated that, in Brazil, there are two million people infected with hepatitis B in the chronic form, and between 3 and 4.5 million infected by hepatitis C. The Brazilian Society of Hepatologia counts on less than 300 members. But it is thought that there are

Explanation of terms

- Alanine aminotransferase (ALT): An enzyme released from liver cells. A blood test that reveals ALT levels above normal may indicate liver damage.
- Aspartate aminotransferase (AST): An enzyme released from liver cells. A blood test that reveals AST levels above normal may indicate liver damage.
- Hepatocellular carcinoma (HCC), or liver cancer, can result from chronic infection with either hepatitis B or C. In areas where hepatitis B is prevalent, the cancer can peak twice at its highest occurrence (among 45 years olds and among 65 year olds).

about 800 specialists in the country. But the number is not sufficient, and the specialised services are unable to receive new patients. The rest of the patients are treated by gastroenterologists, or experts in infection.

- **American Liver Foundation.** There are surprisingly few hepatologists in the United States. The ALF sponsors research awards for young clinicians, to help attract people to the field.
- **Deutsche Leberhilfe e.V. (Germany).** The German healthcare system has a referral system. If family doctors transfer patients to specialists, often punctual treatment (if required) can be guaranteed. However, a family doctor may not take the illness seriously and fail to transfer patients to the appropriate specialist and does not even prescribe treatment. This way patients can remain for many years without treatment, if they do not become active and/or change their family doctor. Some hepatologists can be visited directly. But mostly referrals from a family doctor are required (see also question 2).
- **Selbsthilfe Lebertransplantierter Deutschland e.V. (Germany):** Around 20 in Bremen and surrounding countryside.



Question 4: Access to treatment

- **Hepatitishilfe Mittelfranken e.V (Germany):** Unfortunately, in daily consultation, the numbers of people with hepatitis B who are diagnosed as harmless are too great. Individuals of 45 years of age have the same experience with the diagnosis of HCC.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** Protocols are that only Interferon or lamivudine will be prescribed. Adefovir is not yet approved in Brazil.
- **American Liver Foundation:** Depends on the circumstances, the community, and the patient/doctor resources.
- **Deutsche Leberhilfe e.V. (Germany).** Patients in Germany are usually treated (or not treated) according to international consensus guidelines. Patients with low levels of hepatitis B DNA and normal liver values only very rarely get therapy. Patients with strongly increased liver values and high virus replication are frequently prescribed therapy.
- **Anonymous (US).** I know in our case, treatment wasn't recommended due to the young age of the patients.



Question 5: Communication with patients in the consulting room

- **Hepatitishilfe Mittelfranken e.V. (Germany)**: No—unless you see one of the few physicians in the region who know about lamivudine and/or the ones that still prescribe it.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil)**: In general, there is little information given to patients.
- **Deutsche Leberhilfe e.V. (Germany)**. A lack of time is a particular problem for specialist hepatologists.
- **Anonymous (US)**. Each doctor has their own style. There are no rules about whether how/what they should inform the patient.



Question 6: Effectiveness of medication

- **Hepatitishilfe Mittelfranken e.V. (Germany)**: Effectiveness stands or falls on the experience of the treating physician.
- **Canadian Liver Foundation**: Treatments for this disease are limited, and last only so long before the virus mutates.
- **Berliner Leberring e.V. (Germany)**: The drugs are not very effective. Now that Pegasys is approved, the efficacy of treatment should improve.
- **Deutsche Leberhilfe e.V. (Germany)**. The chances of eliminating all the virus in patients with hepatitis B are almost zero. Many patients, when beginning medication, have difficulties in dealing with their new situation.
- **Anonymous (US)**. I am sure that to their own doctor they do, but to the general population, no.



Question 7: Compliance with medication

- **Hepatitishilfe Mittelfranken e.V (Germany):** Commitment to take or comply with medication can be lacking, usually due to the ignorance of patients. It would better if patients were told about the desirable impact their treatment could have on their blood tests, for example.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** In principle, it is a simple process, as information on medicines are available in the public domain, and updated monthly.
- **Berliner Leberring e.V. (Germany):** Yes, with lamivudine, the compliance is good. But with interferon, it is somewhat more difficult.
- **Deutsche Leberhilfe e.V. (Germany):** Deutsche Leberhilfe e.V. has noted compliance problems with interferon therapy as well as nucleoside/nucleotide analogue-treatments. With interferon, side effects are a major difficulty, although they may be for a limited phase during early stages of treatment. With oral medicines side effects are less of a problem. Rather the danger is that because of the long duration of therapy and apparent minor changes in symptoms, patients become careless and fail to comply with treatment .
- **Anonymous (US):** If you know it is going to possible save your life then the regimen get more important. The more important, the easier it gets taking a needle every other day is difficult.



Question 8: Drug resistance

- **Hepatitishilfe Mittelfranken e.V (Germany):** It depends on whether patients are informed, what is said to them, or what they want to know. However, without such knowledge, the results can be fatal.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** Since the majority have little information, most aren't bothered.
- **Berliner Leberring e.V. (Germany):** As reported in the professional world, mutation can occur.
- **Deutsche Leberhilfe e.V. (Germany):** Enlightened patients, yes. Patients who are less clued up, no.
- **Anonmyous (US)** Sure, wouldn't you be.



Question 9: Access to reimbursement

- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** Patients are referred to hospitals to receive treatment and medicines. A reimbursement system does not exist.
- **Berliner Leberring e.V. (Germany):** Following health reforms in Germany, prescription medicines are refunded. The patient pays the prescription fee.
- **Anonymous (US):** Our treatment was covered by a large local insurance carrier but there are many carriers in the USA each with their own rules.



Question 10: National differences

- **Hepatitisilfe Mittelfranken e.V (Germany):** Although we live in a country with high levels of education, in practice, circumstances are unfortunate. Not least, because the physician in Germany is still considered something of a god. Patients are not thought of as partners, and not much can be done to change this. Sometimes, it is almost better to be uneducated and totally poor. Life then becomes simple.
- **Canadian Liver Foundation:** I have read that Canada has one of the highest survival rates of HCC in the world. Why, we don't know.
- **HepCure (Canada):** Asian, Croatian immigrants, and a very large gay population.
- **Anonymous(US):** Hard to compare one country to the rest of the world. Developing countries versus developed countries, and not all developed countries are equals in the field of medicine.
- **American Liver Foundation:** Yes. All iterations of hepatitis (A, B, and C) are largely 'invisible' diseases in the United States. The funding commitment for research must be greater on the part of legislators, and public awareness must increase.
- **Deutsche Leberhilfe e.V. (Germany):** In Germany after the European consensus guidelines on therapy.



Question 11: On diagnostics tests

[The latter question was posed to some, but not all, respondents]

- **Hepatitishilfe Mittelfranken e.V (Germany):** They can pass on that type of information.
- **Grupo Optimismo de Ayuda a Portadores de Hepatitis (Brazil):** Hepatitis B is difficult to diagnose. Most doctors (not specialists) do not know how to interpret the algorithms to know if patients are infected or cured, or if the infection is acute or chronic. In general, they look for information in our pages on the Internet, to compare the blood test results. In treatment, the situation is even more complicated.
- **Berliner Leberring e.V. (Germany):** Information brochures. In rare cases, groups of self-helps and associations.
- **Selbsthilfe Lebertransplantierte Deutschland e.V. (Germany):** They can pass on that type of information.

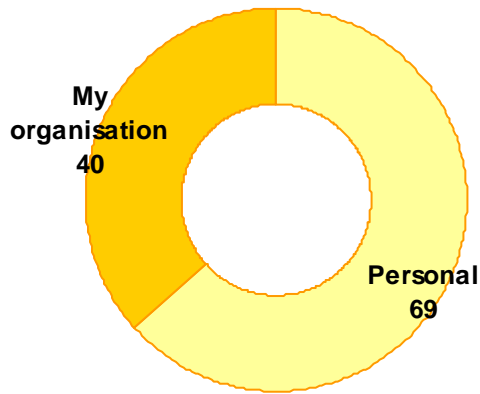


Other

- **Anonymous (US):** We are also conducting Illinois Community Forums to address issues with hepatitis in general. I'm eager to see the outcome of this survey.
- **Deutsche Leberhilfe e.V (Germany).** We are also conducting a survey about the situation of German HBV patients at the moment. So it would be great if you could send us the results of your initiative.



**Survey results:
Profile of respondents**

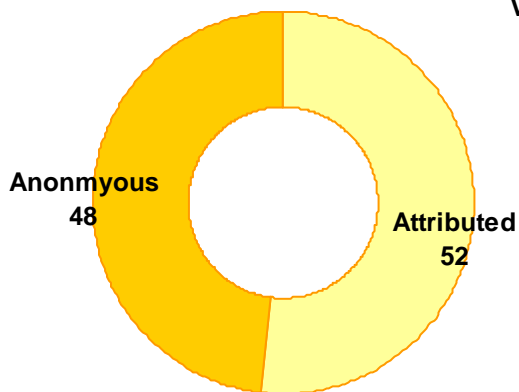


**Whose views are you expressing
in this survey?**

% of respondents
number = 29

Some respondents expressed both
personal views
and the views of their organisations

Source: PatientView hepatitis B survey, March 2005



Views for attribution versus anonymity

% of respondents
number = 29

Source: PatientView hepatitis B survey, March 2005

Speciality areas of respondents

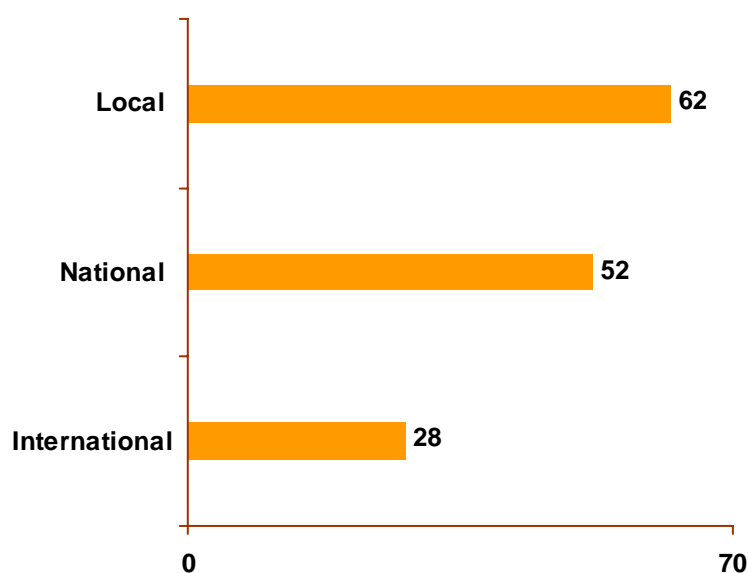
Country	Hepatitis	Liver	Total
Australia	2	-	2
Bangladesh	2	-	2
Brazil	1	1	1
Canada	1	1	2
Denmark	1	-	1
France	1	-	1
Germany	4	4*	5
Italy	1	-	1
Norway	1	-	1
Switzerland	1	-	1
US	6	6	12
Totals	21	12	29

* One German respondent stipulated "all liver diseases"

Geographic remit of respondents

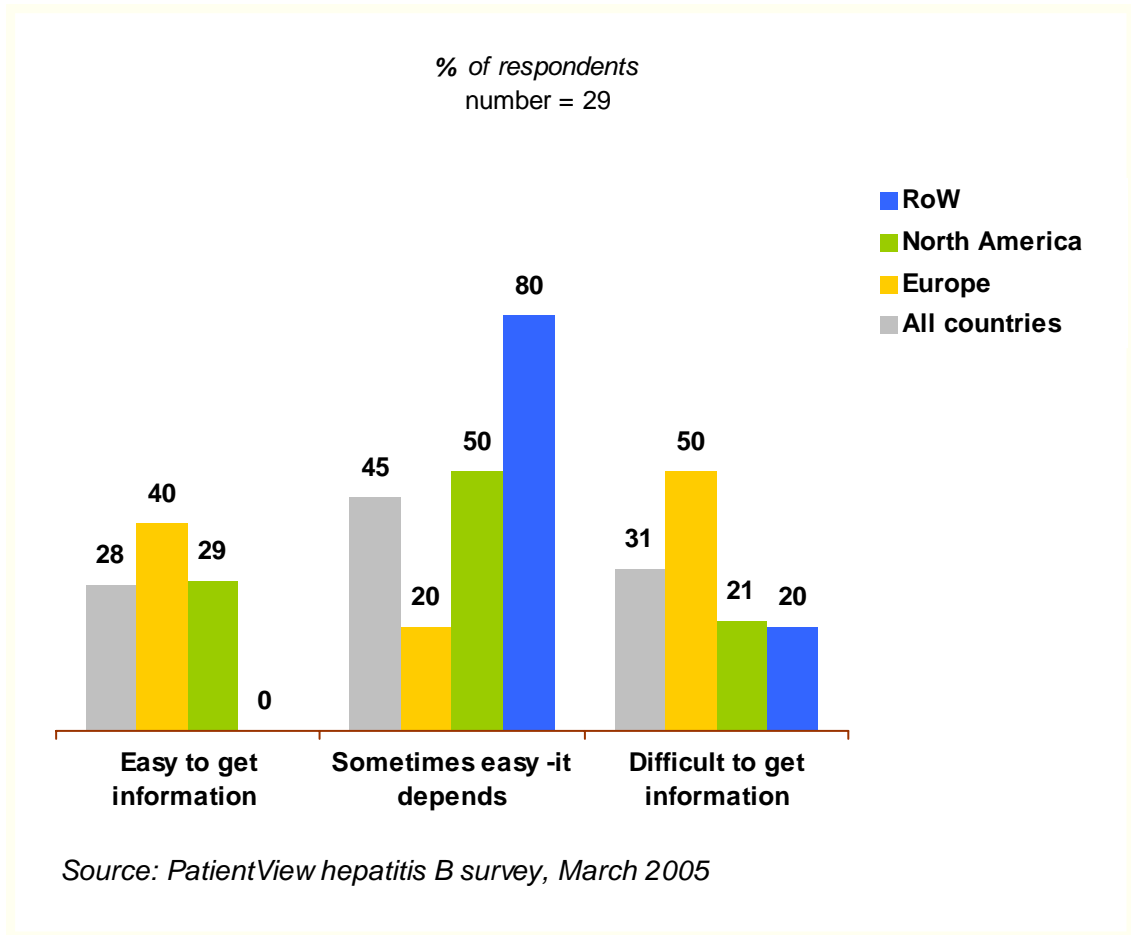
% of respondents
number = 29

Some respondents had more than one remit

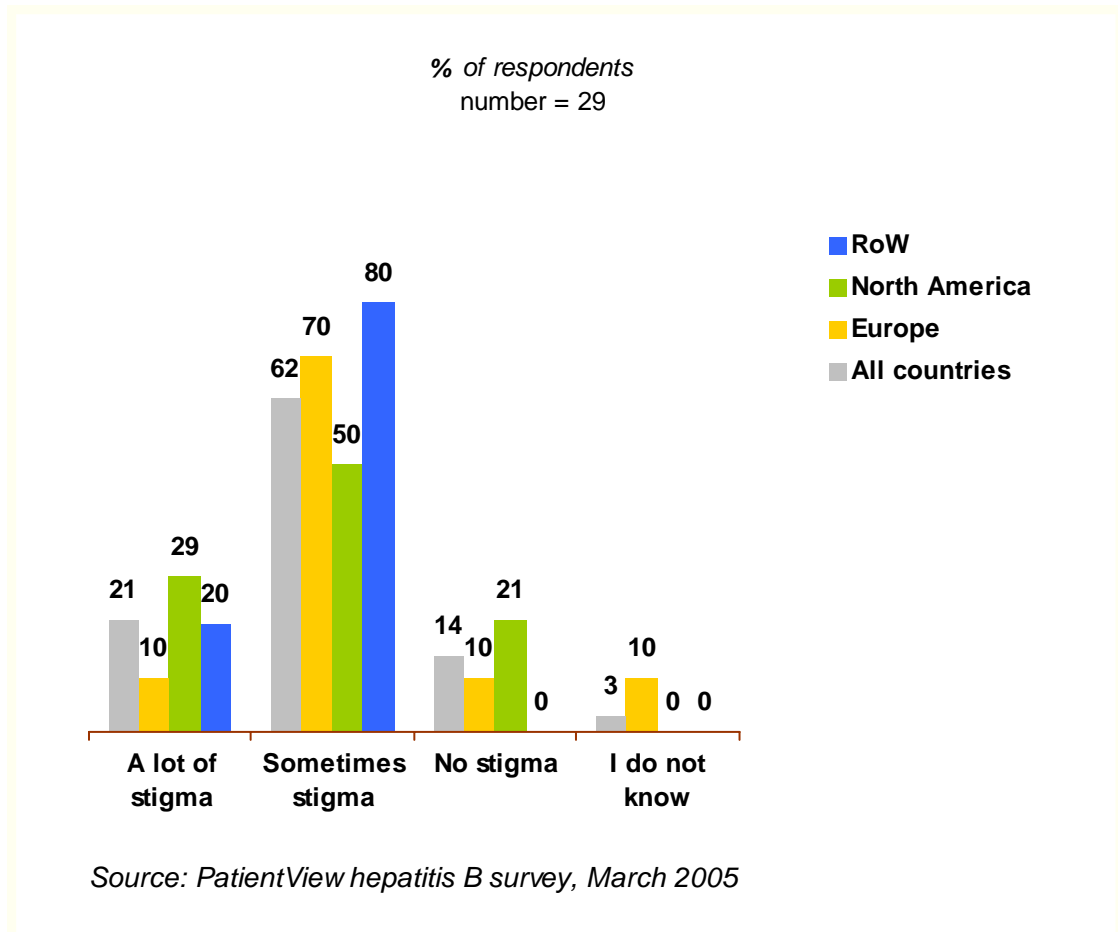


Source: PatientView hepatitis B survey, March 2005

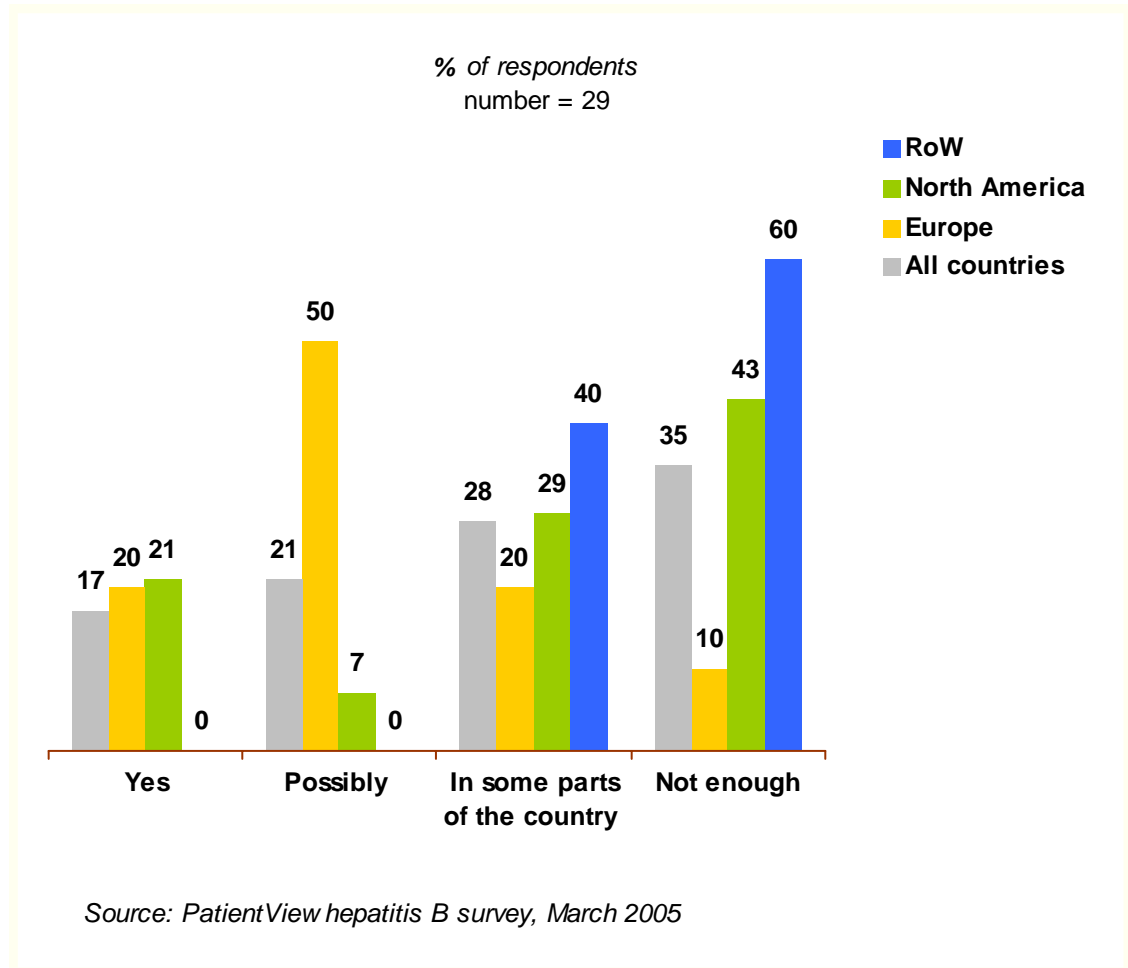
How easily can people in your country get information about hepatitis B and its treatment?



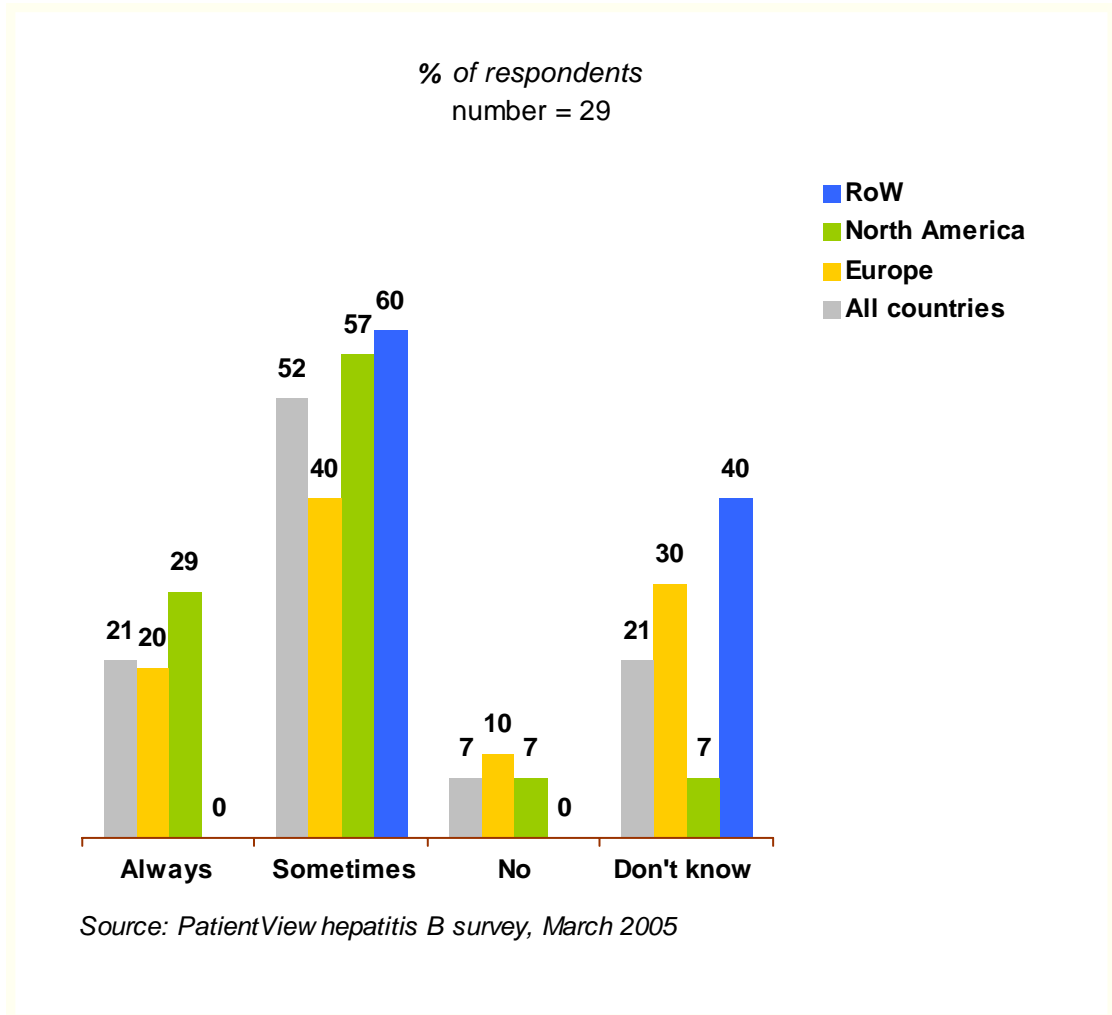
**In your country, do people with hepatitis B experience stigma associated with the condition
(and, if so, does it prevent them from coming forward for treatment?)**



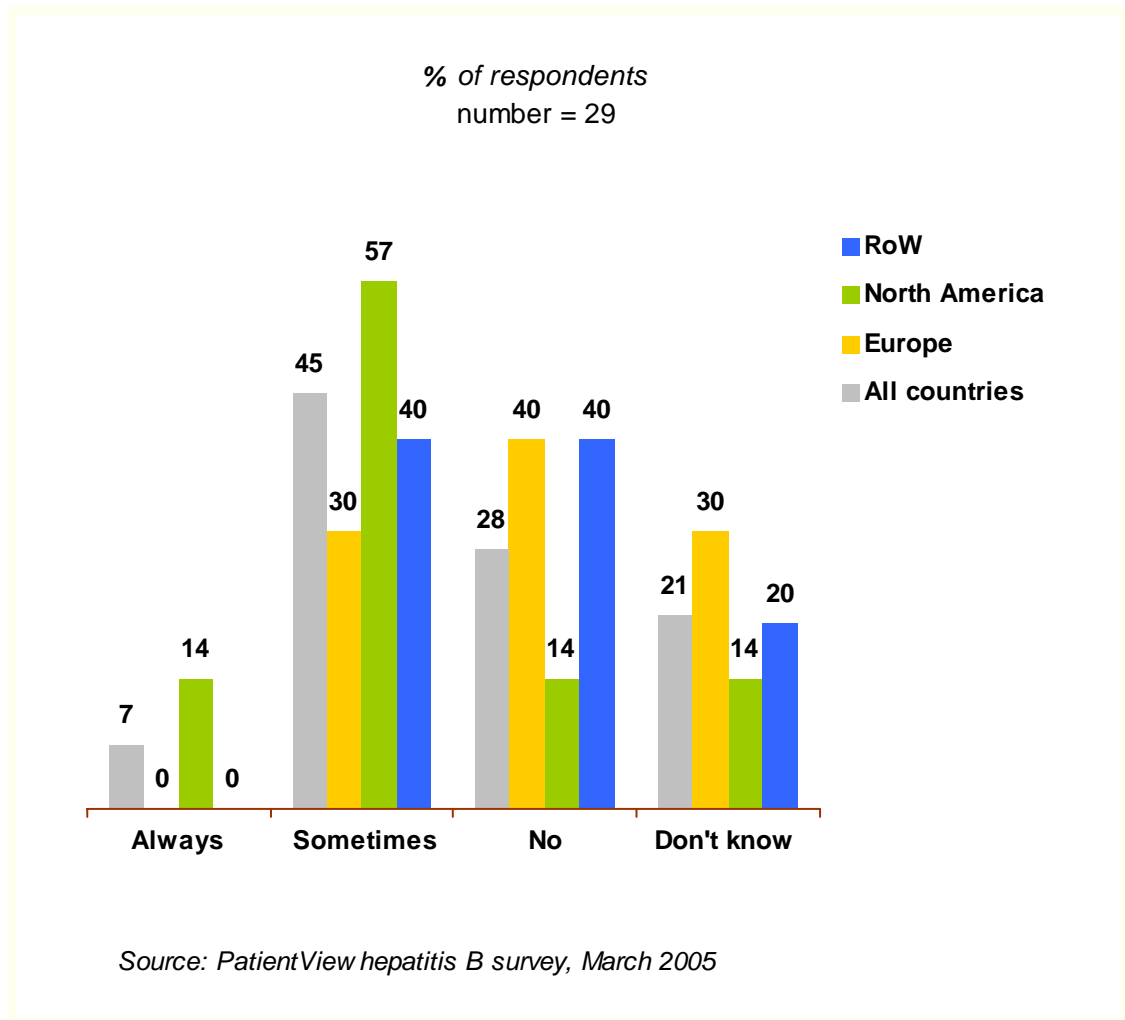
Do you think that your country has enough specialist hepatologists to ensure that patients with hepatitis B receive treatment quickly?



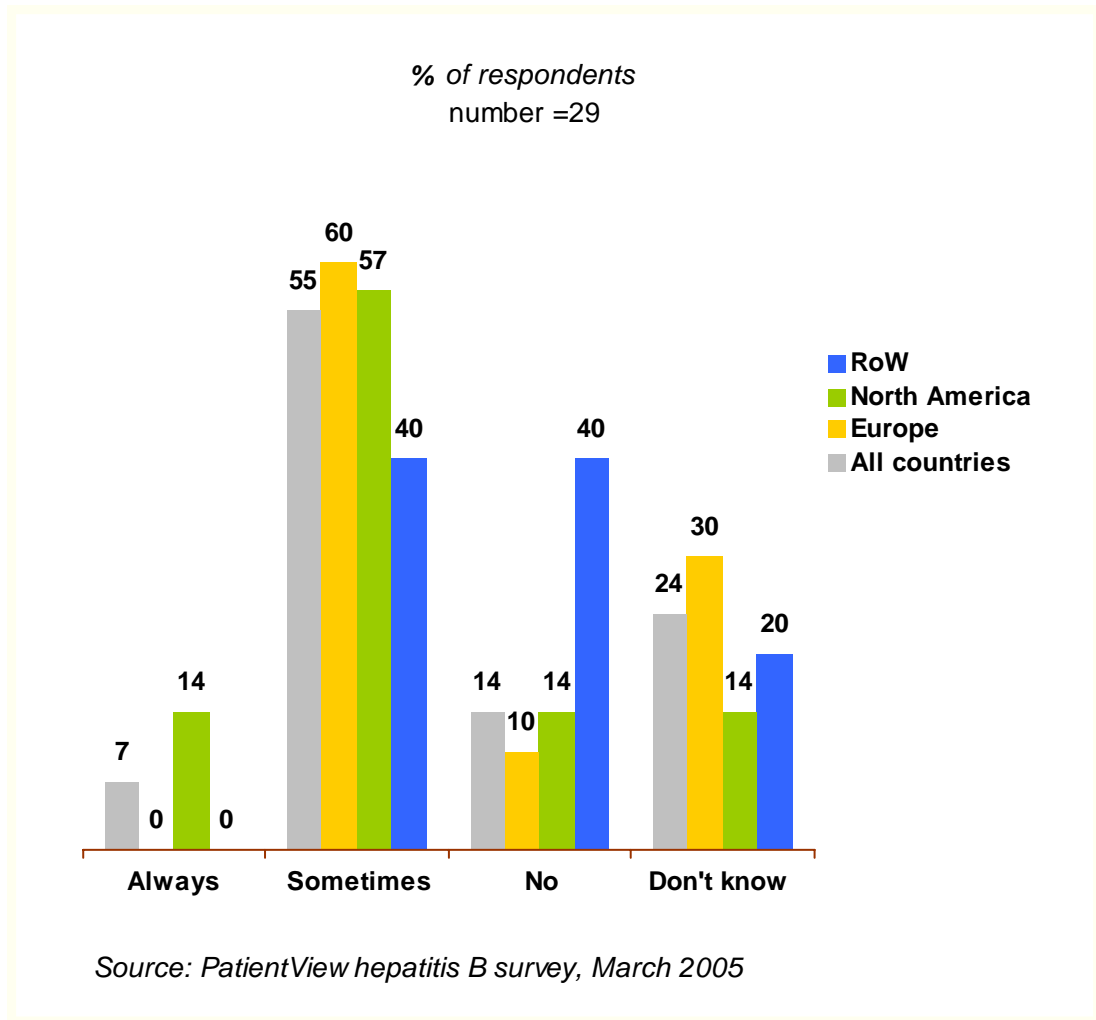
Once a patient with hepatitis B has a consultation with a hepatologist, is treatment readily prescribed?



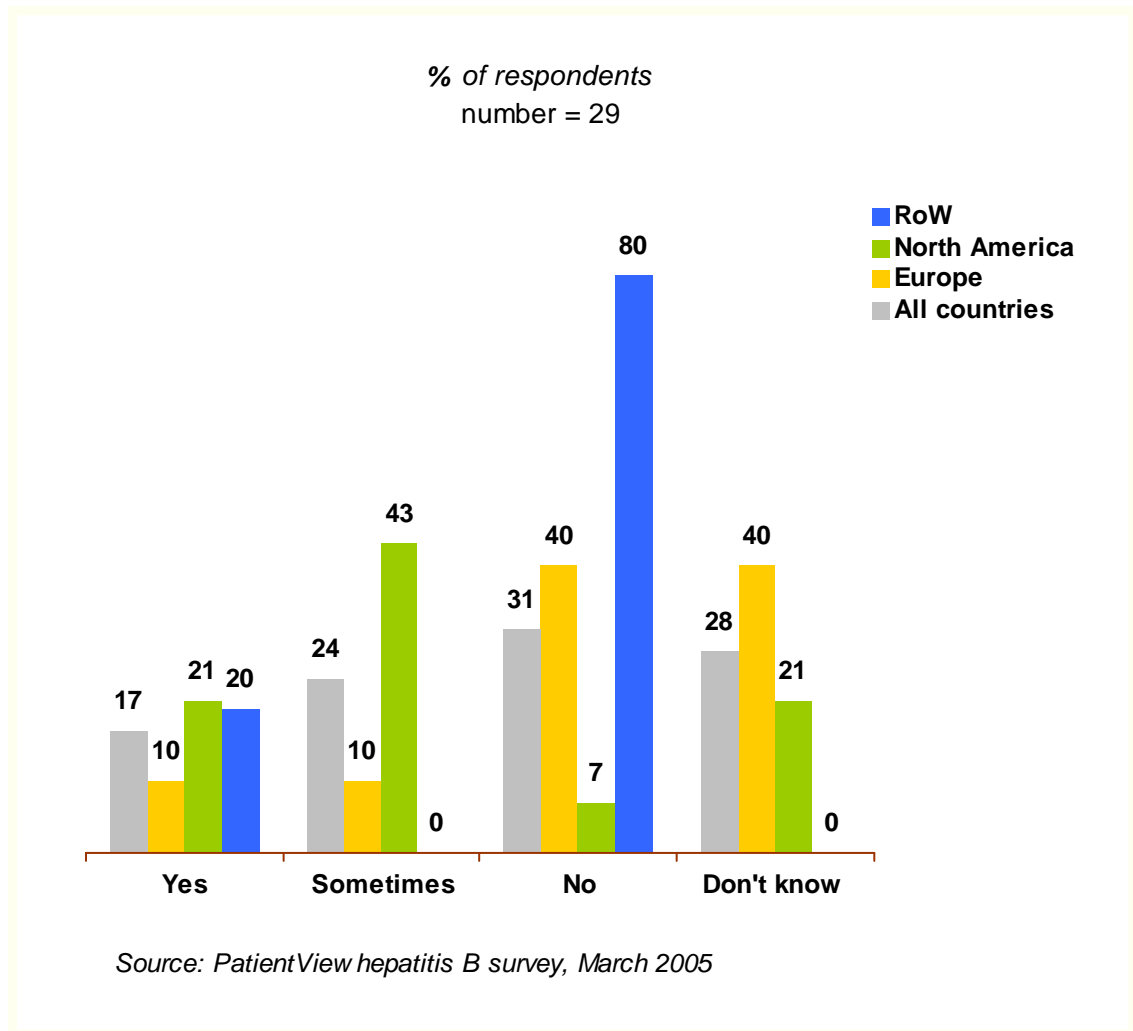
Do hepatologists inform patients with hepatitis B about all possible treatment options?



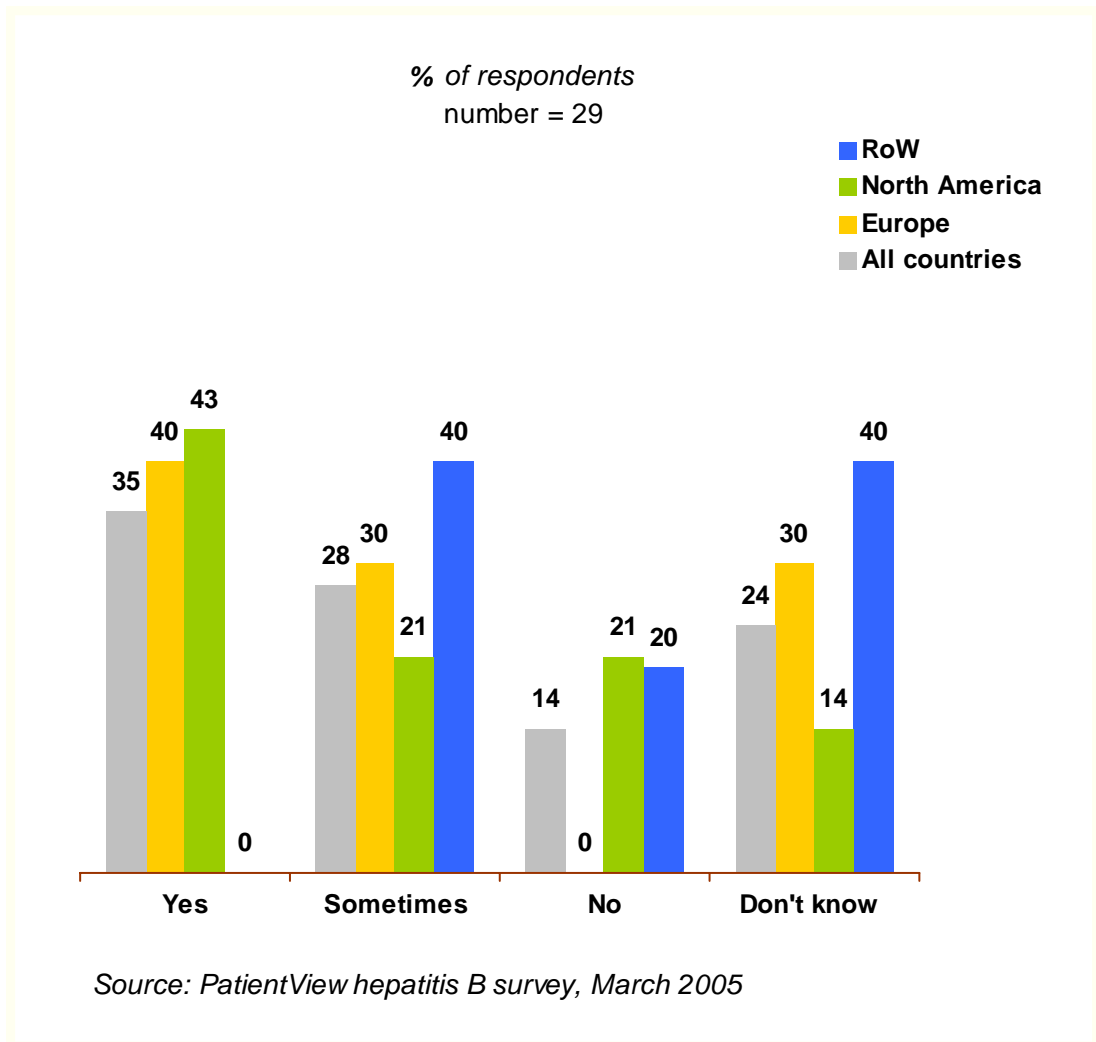
Do patients with hepatitis B (with whom you are familiar) report that their therapy for the condition is effective?



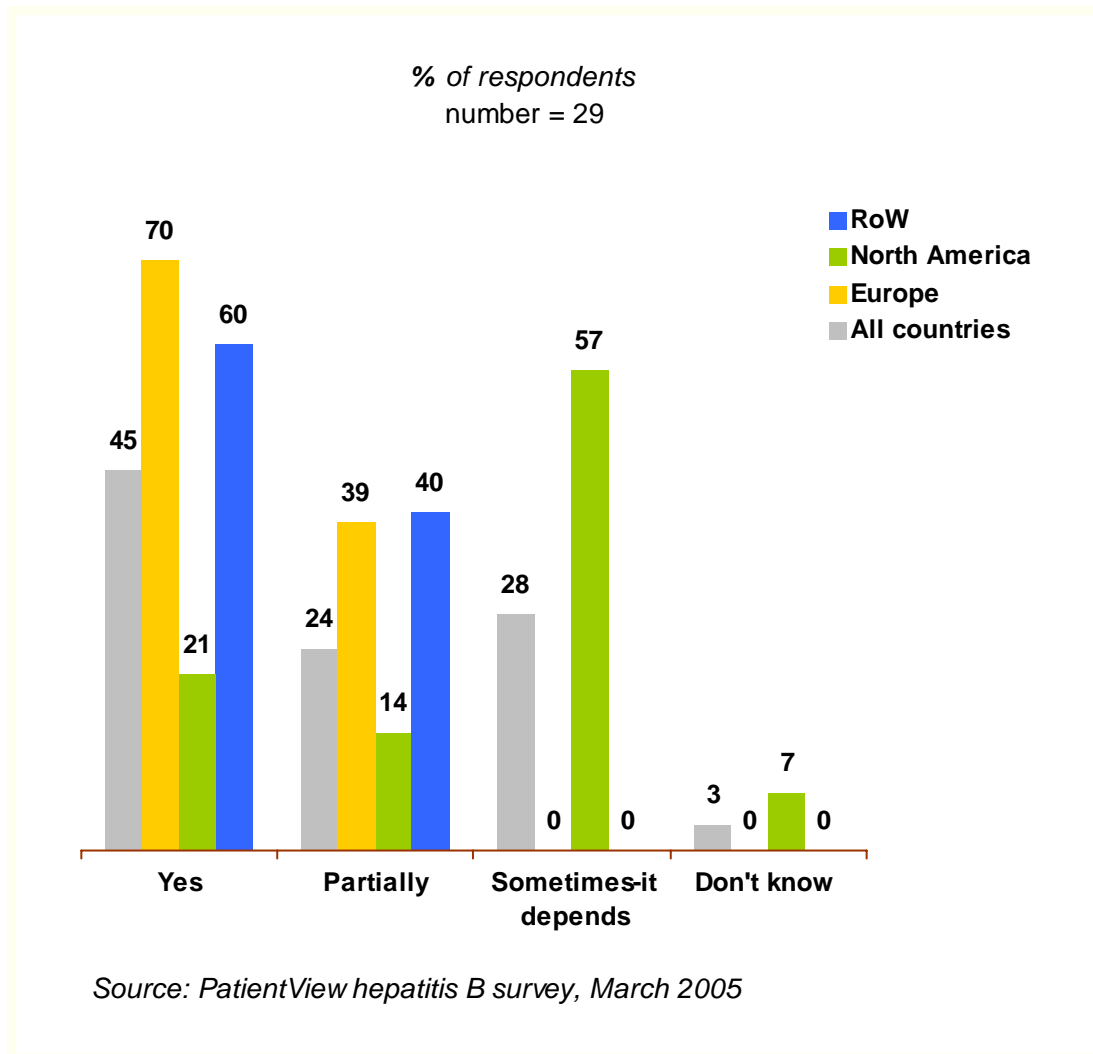
Are hepatitis B treatment regimes easy for patients to comply with?



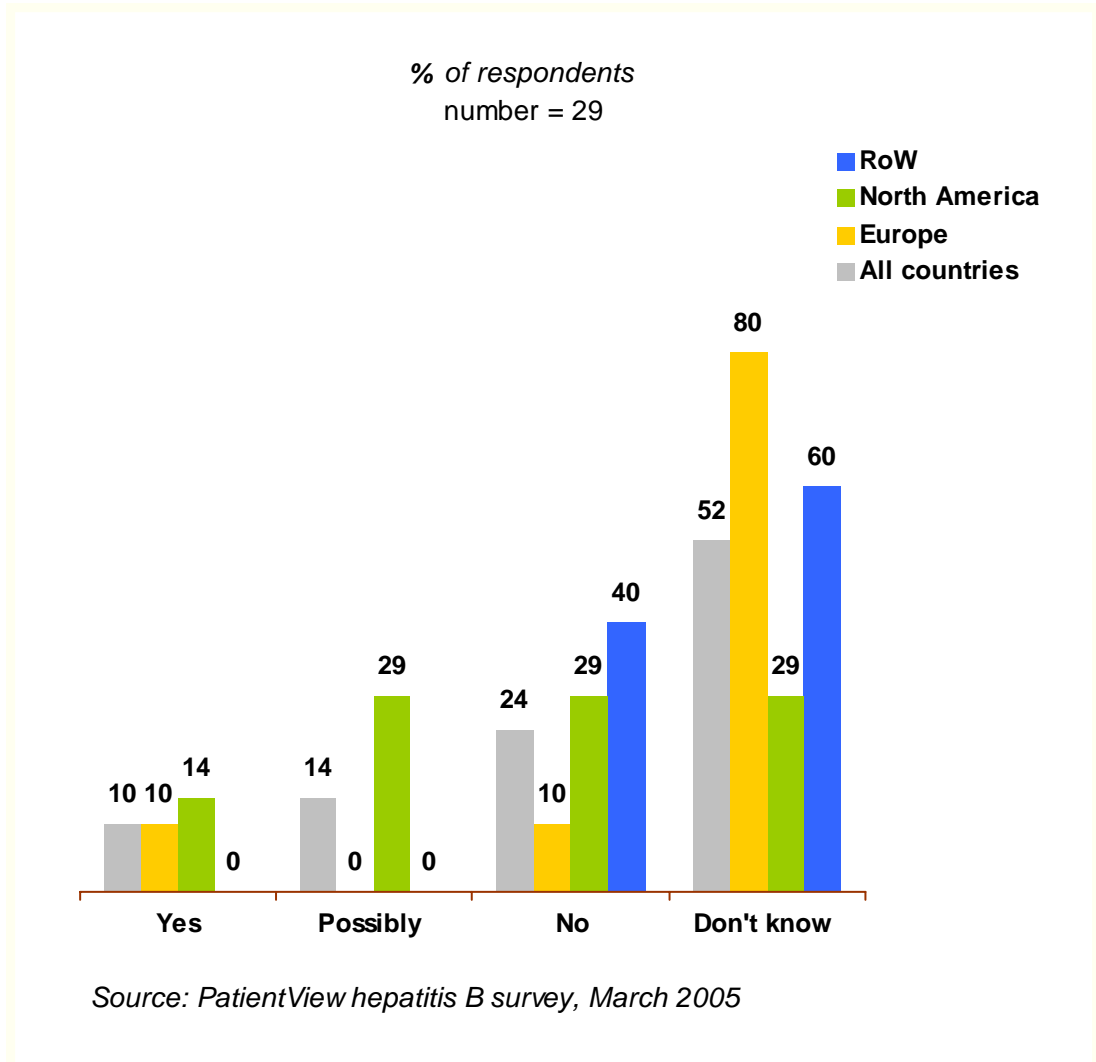
Are patients with hepatitis B (with whom you are familiar) concerned about resistance of the hepatitis B virus to treatment regimes?



Do patients with hepatitis B in your country usually have their prescribed treatment paid for by their healthcare system?



Are there any exceptional circumstances in your country that make the treatment of hepatitis B different compared to the rest of the world?



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