ASSESSMENT

A pilot survey of stigma related to infection with hepatitis B and C

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Abbreviations

ECDC	European Centre for Disease Prevention and Control
LSS	Life Satisfaction Score
PHQ-4	Four-Item Patient Health Questionnaire for Depression and Anxiety
WHA	World Hepatitis Alliance
WHO	World Health Organization

Executive summary

Stigma and discrimination are major barriers to the provision of effective care for people living with hepatitis. They can have a negative effect on access and linkage to care and may affect retention in healthcare services and adherence to treatment. The stigma and discrimination faced by this group may constitute a real barrier to the achievement of hepatitis elimination. Up-to-date and comprehensive data on stigma and discrimination related to hepatitis has been lacking, but this information is critical to enable policy makers to formulate informed policies and strategies to reduce stigma and improve the care and quality of life of people living with hepatitis.

The European Centre for Disease Prevention and Control (ECDC) in collaboration with the World Hepatitis Alliance (WHA) developed a survey tool to explore stigma and discrimination experienced by people living with hepatitis. This tool was piloted in nine selected European countries (Bulgaria, Croatia, Cyprus, Denmark, Germany, Portugal, Romania, Spain, United Kingdom) to test the feasibility and acceptability of this approach. The main objectives of the study were to:

- develop a survey tool;
- implement the survey among a sample of adults living with hepatitis B and hepatitis C, or who have lived with hepatitis C;
- obtain data that could help understand hepatitis-related stigma among the surveyed communities;
- learn lessons from the pilot phase to help optimise the methodological approach for future surveys.

A total of 641 valid responses were obtained, with 487 (76%) respondents currently living or previously living with hepatitis C and 169 (26%) living with hepatitis B. Of the 169 respondents with hepatitis B, 15 reported that they also had or previously have had hepatitis C, and of the 169 respondents who were living with hepatitis C or had previously had hepatitis C, 15 reported they also had hepatitis B. The majority of those with hepatitis C reported that they had been cured (92%), with only 41 (8%) reporting they had an active infection. Of those with active hepatitis C infection, 18 (44%) respondents reported they were receiving care or treatment. Of the respondents with hepatitis B, nearly two thirds (62%) reported they were receiving care and/or treatment. Only nine (5%) of those with hepatitis B reported they were also living with hepatitis D.

The results presented relating to stigma and discrimination are from a pilot survey and due to the many limitations of the methodological approach taken they may not be fully representative of the overall situation and should be interpreted with caution. In terms of quality of life, just under half (47%) of all respondents reported their health was very good or good, with this proportion higher among respondents with hepatitis B (56%) compared to those with hepatitis C (individuals with active infection and those who have been cured) (45%). A higher proportion of respondents with hepatitis B who were not on treatment or receiving care, reported better health than those who were being treated or receiving care. This discrepancy may be due to various factors, including the possibility that those on treatment have more serious disease or face challenges with taking the treatment that affects their overall health. Hepatitis C respondents who had been cured reported better health than respondents with active infection, suggesting a positive impact of curative therapy on their health status.

Nearly half of the respondents (46%) considered it difficult to tell others about living with hepatitis B with this more commonly reported among respondents with hepatitis C (57%). Just under half of respondents with hepatitis B (44%) had concerns they could pass hepatitis on to others with this being a much greater concern for those with active or cured hepatitis C (70%). Poor self-esteem related to hepatitis status was much more commonly reported for those with hepatitis C (48%) compared to those with hepatitis B (18%). Over a fifth of those with hepatitis B or C had not told any family members or friends that they had hepatitis. Approximately one in six (17%) of respondents with hepatitis B and one in four (22%) of respondents with hepatitis C reported they had not told their current sexual partner(s) they were living with hepatitis.

Respondents with hepatitis C were more likely than those with hepatitis B to report negative experiences of stigma in relation to family, friends and sexual partners such as being blackmailed, threatened or abused, receiving discriminatory remarks or being excluded from activities. In relation to experiences within the healthcare system, one in four respondents with hepatitis B and a third of those with hepatitis C reported they were worried they would be treated differently from other patients by healthcare staff. A quarter of respondents with hepatitis C and one in seven respondents with hepatitis B reported they even avoided accessing health services when they needed it because they expected to be treated differently. Additionally, hepatitis C respondents were more likely than respondents with hepatitis B to report they had been treated unfairly at work and denied professional opportunities.

Our survey was a pilot study restricted to nine European countries with limited sample sizes in half of them. This restricts the conclusions that can be drawn on the data and the results may not be generalisable across the region or outside of Europe. The limited sample sizes restricted key analyses and a full exploration of the data such as through a disaggregation of the data by settings and across different population groups at high risk of hepatitis B or C infection (e.g. people who inject drugs, migrant populations). We also recognise that some population groups, such as people who inject drugs, were underrepresented in the survey and so our results may not be fully generalisable for the hepatitis populations as a whole. Furthermore, men who have sex with men seem to be over-represented among the respondents and this may have biased the results. We also recognise the unique challenge in assessing stigma among individuals who have only lived with hepatitis C infection for a short period of time before receiving curative treatment. We consider this issue needs much further exploration in future studies.

In summary, the study demonstrated the feasibility of our methodological approach to collect data related to stigma and discrimination and the data collected suggest that hepatitis-related stigma and discrimination may be prevalent within the countries that participated in the pilot. Whilst the study undoubtedly marks an important step towards improving knowledge and understanding in this key area, the limitations of our approach restricted our analyses and the conclusions that may be drawn from the data. Key lessons learnt from the survey include the importance of future studies having a longer period for collecting the data, stronger engagement with a range of non-governmental organisations representing people living with hepatitis and using a broader range of communications to reach study participants. Whilst a study with larger sample sizes and with greater representation across population groups at risk of hepatitis B and C infection is needed, as well as a much greater exploration of stigma among those with hepatitis C, the results from this pilot still provide important information for reflection. Our results suggest that stigma and discrimination may pose barriers in terms of access to hepatitis testing and treatment, which, as well as having a serious impact on the lives of people living with hepatitis, also means that achieving the scale up in services needed to reach the elimination targets will be difficult without targeted action to address stigma.

1 Introduction

Globally, more than 300 million people are living with viral hepatitis and there are more than one million people die each year due to liver disease caused by hepatitis [1]. Effective prevention and control strategies exist, and hepatitis elimination is achievable. However, in order to reduce hepatitis-related morbidity and mortality and achieve the elimination of hepatitis, it is essential to address the barriers to elimination, including the stigma and discrimination faced by people living with viral hepatitis.

Stigma is a multifaceted and intricate phenomenon present across society and experienced differently by each person. It can manifest at individual, interpersonal, organisational, community, and public policy levels, and can lead to internalised stigma, where individuals absorb and believe negative stereotypes about themselves, and enacted stigma, where individuals experience acts of discrimination and prejudice. Additionally, stigma associated with hepatitis can also intersect with other types of discrimination, particularly among groups who are marginalised such as people who inject drugs, migrant populations and sex workers [2]. Stigma around hepatitis is sometimes caused by misunderstandings about how hepatitis is transmitted, and this can drastically affect people's personal and professional lives, as well as their mental health. People living with hepatitis may also be subject to discriminatory practices which frequently impact their work, study, and travel.

In 2014, the World Health Organization (WHO) Member States adopted resolution 67.6 at the World Health Assembly which committed them to review as appropriate, policies, procedures and practices associated with stigmatisation and discrimination, including the denial of employment, training, and education, as well as travel restrictions, against people living with and affected by viral hepatitis, or impairing their full enjoyment of the highest attainable standard of health [3]. Furthermore, the Global Health Sector Strategy on HIV, Viral Hepatitis and Sexually Transmitted Infections, 2022–2030, states that the 2030 targets will not be achieved unless accompanied by efforts to address stigma and discrimination [4]. In the strategy there are specific targets on decreasing the experience of stigma among people living with HIV, hepatitis, and sexually transmitted infections to less than 10% by 2025.

While global tools are available to measure stigma for tuberculosis [5] and HIV [6], similar instruments are lacking for viral hepatitis. Up-to-date information on the stigma and discrimination experienced by people living with viral hepatitis is a critical resource for policy makers to formulate informed policies and strategies to decrease this towards people living with hepatitis and improve their life quality. Furthermore, accurate and recent information on stigma can also contribute to the work of epidemiologists, clinicians, civil society organisations, members of the community as well as academics to monitor trends over time, suggest targeted interventions, and explore the complex dynamics related to viral hepatitis stigma.

We developed a draft survey tool to measure stigma and discrimination experienced by people living with viral hepatitis and piloted this tool in selected countries of the European region to test the feasibility and acceptability of this approach and to collect data from these countries. The pilot project was led through a collaboration between the European Centre for Disease Prevention and Control (ECDC) and the World Hepatitis Alliance (WHA).

This report will present the key findings from the data collected during the pilot study from participating countries. Information relating to the experience of conducting the pilot study and the key lessons learned are also presented in this report.

2 Methods

An advisory group was established to steer the project and provide guidance on the development and implementation of a pilot survey study to collect information on stigma experienced by people living with hepatitis B and C. The group was convened by the World Hepatitis Alliance based on their experience of working in the field of hepatitis and included people with lived experiences and representatives from public health, civil society and community organisations.

The key objectives of the pilot study were:

- To develop a draft survey tool to explore stigma among people living with hepatitis B and C, or people who have lived with hepatitis C;
- To implement the survey tool in selected European countries;
- To undertake an exploration of the data collected in the survey and conduct simple descriptive analyses;
- To refine the survey and protocol after the pilot based on feedback obtained from participating countries and the overall experiences of the pilot.

The questionnaire was developed using adapted questions from a range of different surveys and was based around the questionnaire developed by ECDC, European AIDS Treatment Group and the AIDS Action Europe for the European HIV stigma survey [7]. The HIV questionnaire was developed using two validated HIV stigma instruments: the People living with HIV stigma index [8]; and Positive voices 2017 [9]. The hepatitis questionnaire also included validated questions on health status from the United Kingdom's Office for National Statistics [10] and the Four-Item Patient Health Questionnaire for Depression and Anxiety (PHQ-4) [11].

The questionnaire was divided into the following sections:

- Hepatitis assessment: hepatitis B, C and D status, year of diagnosis, and treatment or care status;
- Demographic information: age, gender, sexual orientation, country of birth, time living in the current country, and self-identification with key populations (migrants, refugees, people who use or have used drugs, people who inject or have previously injected drugs, prisoners or former prisoners, people who have sex in exchange for money or other goods, people living with HIV, people who contracted viral hepatitis through a medical intervention);
- Life satisfaction and mental health: current life satisfaction, current health quality, and mental distress (anxiety and depression);
- Self-stigma: disclosure of hepatitis status, self-esteem because of living with hepatitis, and worries because of living with hepatitis; for those who are/have received care or treatment and/or are cured, questions on the effect of it to the self-stigma were also asked;
- Experiences of stigma and discrimination: from family members, friends, sexual partners and acquaintances; at healthcare settings, including dental care; in professional life; in other situations (e.g., immigration).

The questionnaire was approved by the advisory group and then tested with people with lived experiences and revised considering feedback obtained. The questionnaire was fully translated into the key languages spoken in each of the selected countries. The translated questionnaires were fully reviewed by at least one of the supporting organisations in each participating country. An online survey tool was created based on the questionnaire using REDCap[1] electronic data capture tools with the online database hosted at WHA.

The survey was conducted in nine selected countries (Bulgaria, Croatia, Cyprus, Denmark, Germany, Portugal, Romania, Spain, United Kingdom). These countries were selected based on their interest and availability in being part of the pilot study and their ability to obtain local ethical clearance for undertaking the survey. Data were collected between February and March 2024 for all countries except Portugal, which collected data between March and May 2024. The survey was disseminated with support from local civil societies and community organisations, clinical societies, public health contacts, and gay dating apps (Grindr and Hornet).

All individuals aged ≥18 years old living in the selected countries, who are living with hepatitis B and/or are living or lived with hepatitis C, and agreed to participate in the study were eligible for the survey. Before accessing the questionnaire, the respondents had to provide information on their hepatitis status and country of residence, and were asked to read and accept the consent form (inclusion criteria assessment).

Participation was voluntary and anonymous. No information that could identify or track the respondent was collected. There were no mandatory questions besides the ones for selection criteria. Basic descriptive analyses of

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[1] https://www.project-redcap.org/

the data were undertaken using STATA[2] to describe the results. Results have all been rounded up and presented without a decimal place, so totals for percentages in some tables may exceed 100%.

Following the pilot project, the WHA conducted a short evaluation of the approach among the national contact points who had been engaged with the implementation of the survey in the nine countries. The evaluation consisted of a short questionnaire sent via email that aimed to understand the key limitations of the methodological approach and identify some key lessons learnt during the process.

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[2] https://www.stata.com/

3 Survey responses

A total of 2 104 responses were received from the nine participating countries. Of these responses, 641 met the inclusion criteria and were considered valid. The number of valid responses varied by country, with the greatest number of responses from the United Kingdom (238), Spain (123), Portugal (93) and Germany (89) (Table 1).

Table 1. Number of valid responses to the survey by participating country

Country	Number of valid responses
Bulgaria	31
Croatia	31
Cyprus	1
Denmark	16
Germany	89
Portugal	93
Romania	19
Spain	123
United Kingdom	238

In terms of respondents, 487 respondents reported that they were currently living, or have lived, with hepatitis C and 169 reported that they were living with hepatitis B (Table 2) The majority of those with hepatitis C (92%) reported that they had been cured, with only 41 (8%) reporting they had active infection. Of those with active hepatitis C infection, 18 respondents reported they were receiving care or treatment. Of the 169 individuals with hepatitis B, 104 (62%) reported they were receiving care and/or treatment. Only nine (5%) of those with hepatitis B reported they were also living with hepatitis D.

The age profile of respondents was similar by hepatitis type, with around two thirds of respondents for both hepatitis B and C aged between 40 and 69 years. Nearly three quarters of respondents with hepatitis B (73%) were male and a lower proportion of respondents with hepatitis C were male (59%).

Respondents reported whether they identified as belonging to one or more specific population groups, and of those with hepatitis B, 17% identified as being a migrant, 7% as a person who injects or previously injected drug, 17% as a person living with HIV and just over half 54% as a man who has sex with men. For hepatitis C, the proportion of respondents who were men who have sex with men was lower at 36%, with 7% identifying as a migrant, 23% as a person who injects or previously injected drugs, 7% as a person in prison or a former prisoner and 21% as a person living with HIV.

Table 2. Characteristics of respondents by hepatitis type

	Hepatitis type	
	Hepatitis B (N=169) n (%)*	**Hepatitis C (N=487) n (%)***
Hepatitis status		
Living with hepatitis B	169 (100%)	15 (3%)
Hepatitis D co-infection	9 (5%)	4 (1%)
Living/lived with hepatitis C	15 (9%)	487 (100%)
Cured	11 (7%)	446 (92%)
Active infection	4 (2%)	41 (8%)
Receiving care and/or treatment	104 (62%)	18 (4%)
Demographics		
Age		
18-39	39 (23%)	58 (12%)
40-69	114 (68%)	313 (64%)
70 or over	8 (5%)	35 (7%)
Unknown	8 (5%)	81 (17%)
Gender		

Female (cis or trans)	36 (21%)	132 (27%)
Male (cis or trans)	123 (73%)	289 (59%)
Non-binary	3 (2%)	7 (1%)
Other	4 (2%)	5 (1%)
Unknown	3 (2%)	54 (11%)
Sexual orientation		
Straight/heterosexual	64 (38%)	243 (50%)
Gay or lesbian/homosexual	75 (44%)	147 (30%)
Bisexual	22 (13%)	44 (9%)
Other	2 (1%)	1 (0%)
Unknown	6 (4%)	52 (11%)
Key populations*		
Migrants	29 (17%)	34 (7%)
Persons in prison or former prisoners	2 (1%)	33 (7%)
People who inject or have previously injected drugs	11 (7%)	111 (23%)
People living with HIV	29 (17%)	101 (21%)
Men who have sex with men	91 (54%)	177 (36%)
None	100 (59%)	137 (28%)
Unknown	29 (17%)	89 (18%)

**Multiple responses accepted*

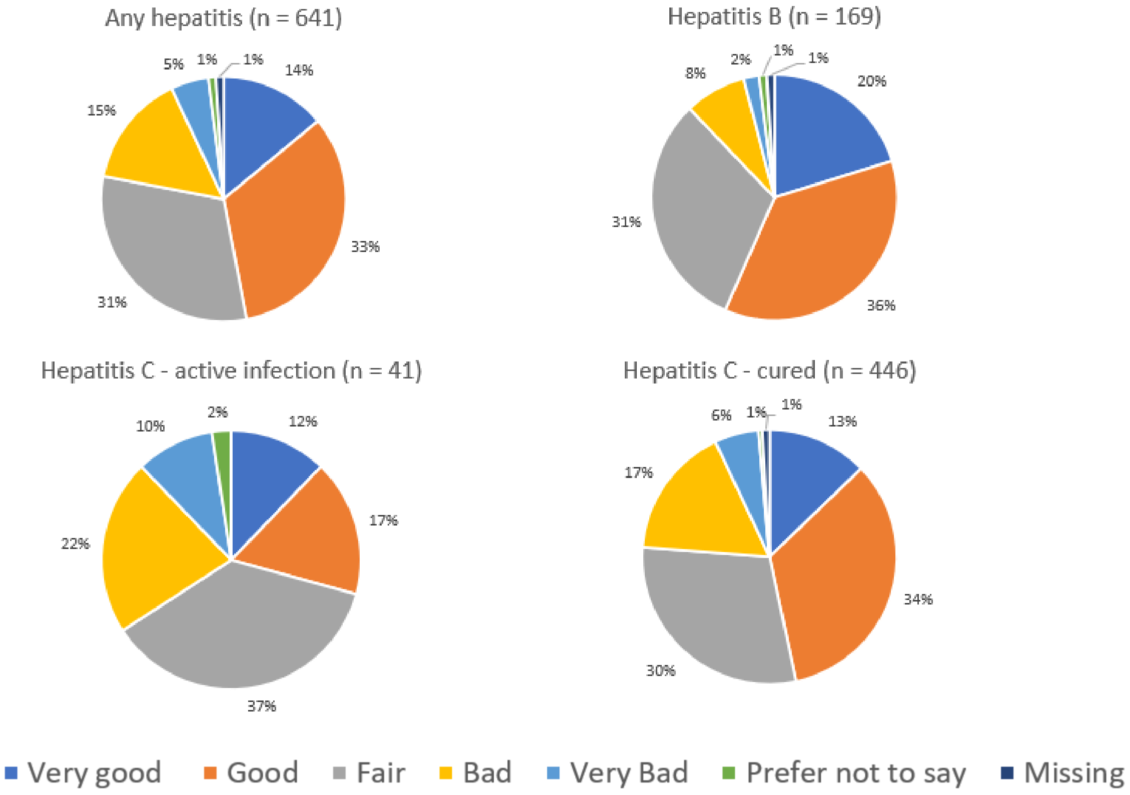
Quality of life

Respondents were asked to provide a life satisfaction score (LSS) between zero and 10 (where zero is not at all satisfied and 10 is completely satisfied) in response to the question: 'Overall, how satisfied are you with your life at the moment?' The average LSS across all respondents with hepatitis was 6.8, which can be compared to an average of 7.1 across European Union (EU) countries for the general population [12]. For hepatitis B, the average score was 7.3, and for hepatitis C (ever) the score was 6.6, with an average score of 5.8 for those with active hepatitis C and 6.6 for those who were cured of hepatitis C.

Respondents were asked to assess their health at the time of completing the survey as good, very good, fair, bad or very bad (Figure 1; Table 3). For all respondents with any type of hepatitis, just under half (47%) reported their health was very good or good, with only 17% of respondents reporting their health as bad or very bad. The proportion reporting that their health was very good or good was higher for all hepatitis B cases (56%) and for hepatitis C cases that had been cured (47%), than for hepatitis C cases with active infection at 29%.

Due to suboptimal sample sizes, it was not possible to disaggregate the data by key population group to explore the differences in reported health status further.

Figure 1. Reported health status of respondents by hepatitis type



For respondents with hepatitis B who were being treated or receiving care, just over half (53%) reported their health was very good or good with only 12% of respondents reporting their health as bad or very bad. For respondents with hepatitis B who were not on treatment or receiving care, the proportion reporting their health was very good or good was higher than those who were being treated or receiving care at 63%. For respondents with hepatitis C who had been cured, just under a half (47%) reported their health was good or very good with this proportion lower for those with active infection (29%). A higher proportion of those with active hepatitis C infection (32%) reported their health was bad or very bad, compared to those who had been cured of their infection (23%).

Table 3. Reported health status by hepatitis type

	Reported health status (%)			
	Hepatitis B		Hepatitis C	
	Treated/ receiving care (n=104)	Neither treated nor receiving care (n=65)	Cured (n=446)	Active infection (n=41)
Very good	19%	23%	13%	12%
Good	34%	40%	34%	17%
Fair	35%	24%	30%	37%
Bad	9%	8%	17%	22%
Very bad	3%	2%	6%	10%
Prefer not to say	0%	3%	1%	2%
Missing	1%	0%	1%	0%

In addition to their responses about their general health status, just over a quarter of respondents (27%) with hepatitis B on treatment or receiving care reported they had markers of depression (e.g. feeling down, depressed or hopeless) during the two weeks prior to completing the survey. For respondents who were not receiving treatment nor care, the proportion with markers of depression was lower than for those receiving care at 18%. For those with hepatitis C who had been cured, around a third (33%) reported markers of depression, with this proportion just over a third for those with active infection (37%).

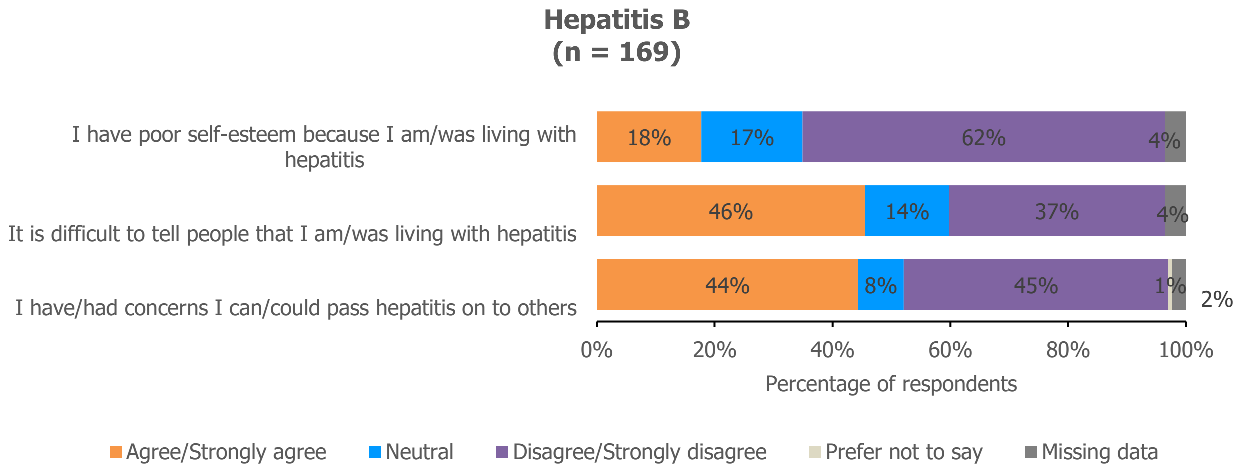
Table 4. Reported markers of depression using PHQ-4 score by hepatitis type

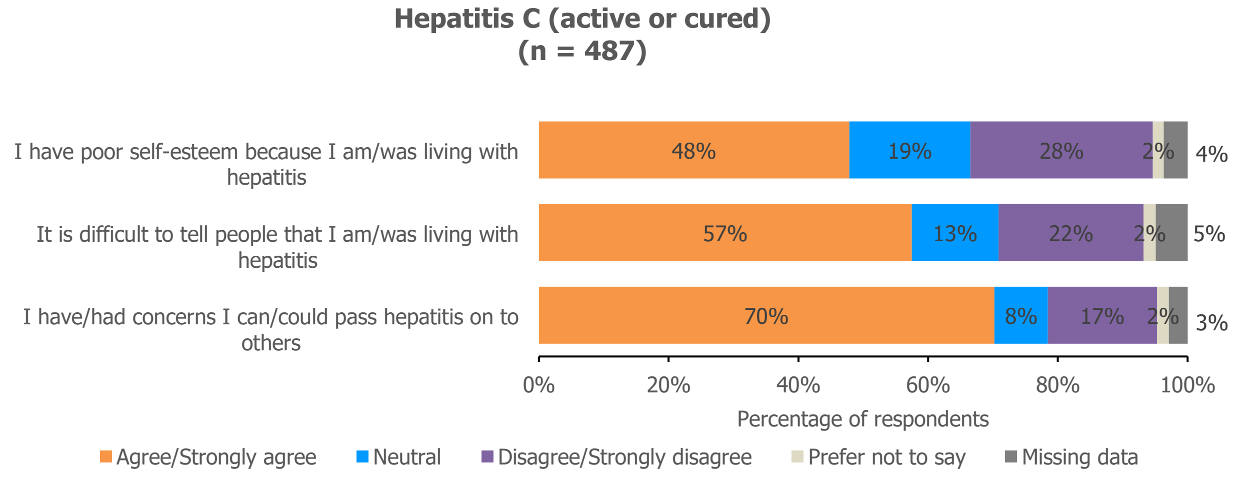
	Depression (using PHQ-4)			
	Hepatitis B		Hepatitis C	
	Treated/receiving care (n=104)	Neither treated nor receiving care (n=52)	Cured (n=383)	Active infection (n=29)
No	67%	79%	62%	51%
Yes	27%	18%	33%	37%
Missing	6%	3%	5%	12%

Reported self-esteem and concerns

Nearly half of the respondents (46%) either agreed or strongly agreed that they consider it difficult to tell others about living with hepatitis B. Around one in six respondents agreed or strongly agreed that they had poor self-esteem related to their hepatitis B status (18%) and just under half (44%) reported they had concerns they could pass hepatitis B on to others (Figure 2). For respondents with hepatitis C (active or cured), a higher proportion (48%) either agreed or strongly agreed they found it difficult to tell others about living with hepatitis, that they had poor self-esteem (48%) and that they had concerns they could pass hepatitis on to others (70%).

Figure 2. Reported self-esteem and concerns by hepatitis type

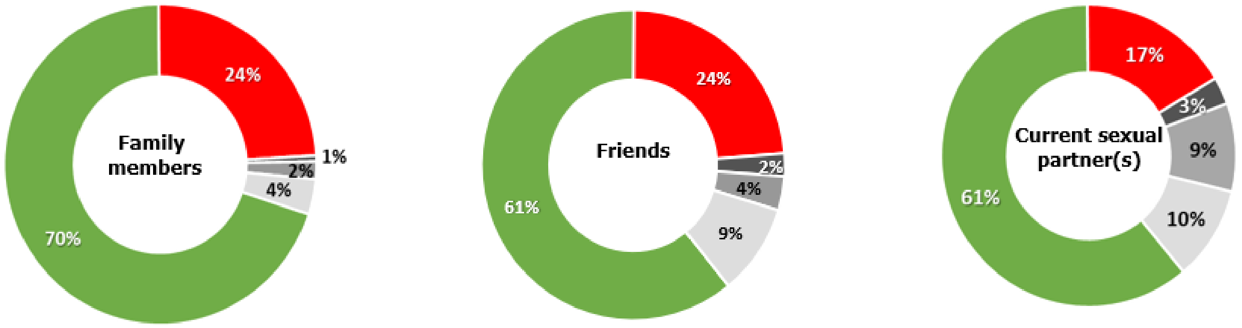




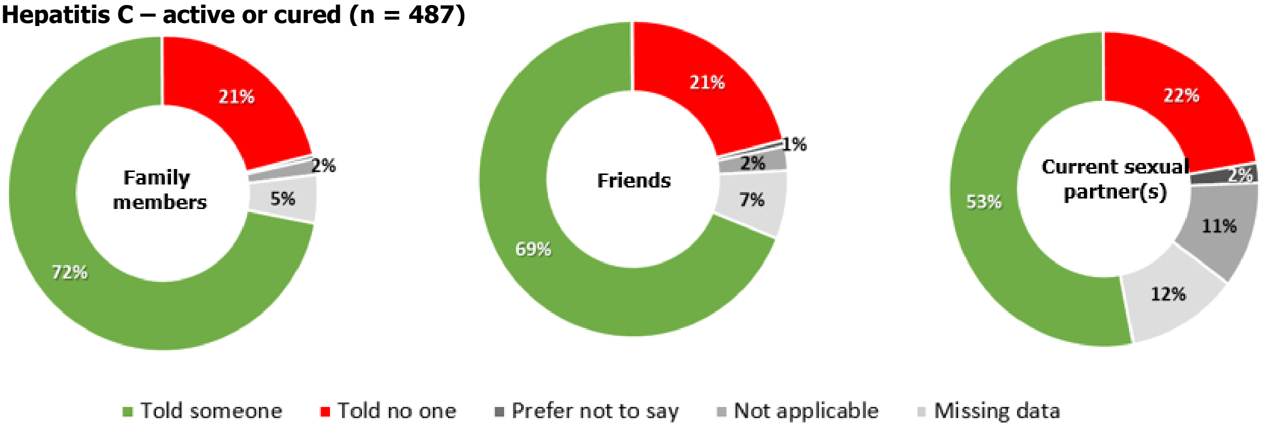
Around a quarter (24%) of respondents had not told a single family member or friend they were living with hepatitis B. Approximately one in six (17%) had not told their current sexual partner(s) they were living with hepatitis B (Figure 3). For respondents with hepatitis C (active or cured), just over a fifth (21%) had not told a single family member or friend they were living with hepatitis C and compared to hepatitis B, the proportion who had not told their current sexual partner(s) was slightly higher at 22%.

Figure 3. Proportion of respondents who have ever told people in their life about their hepatitis status by hepatitis type

Hepatitis B (n = 169)



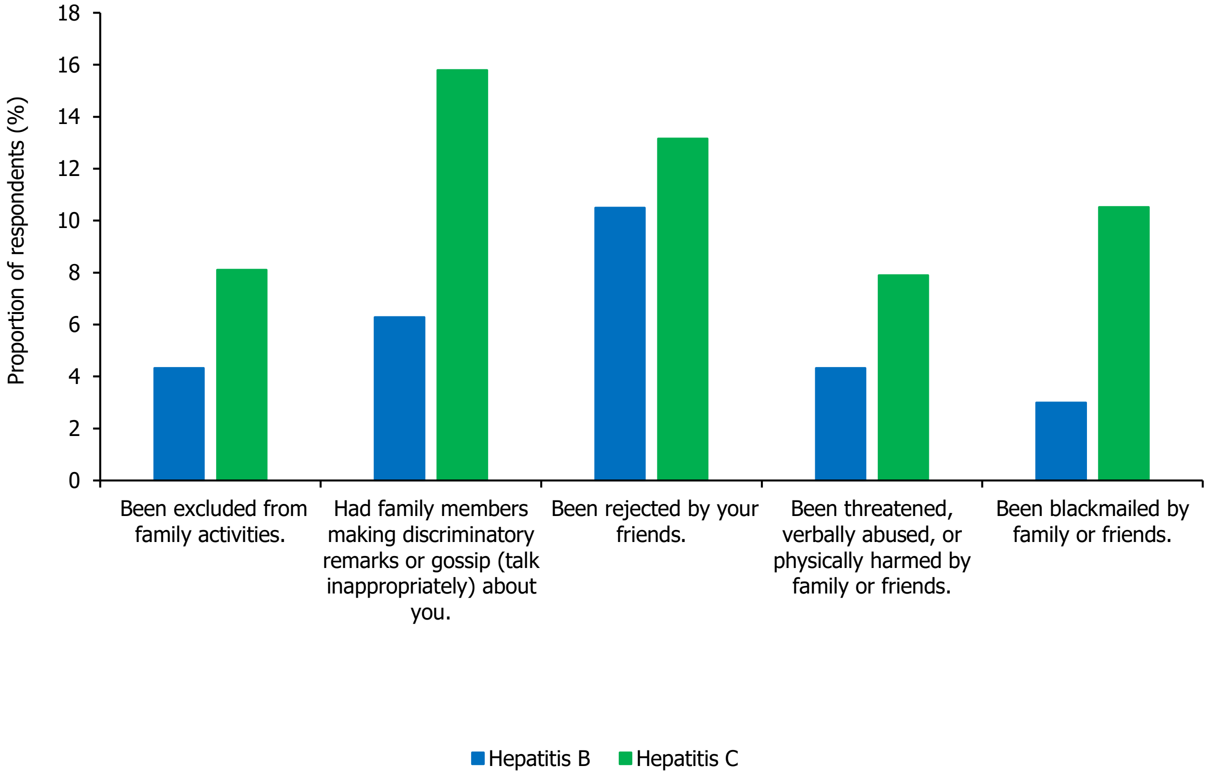
Hepatitis C – active or cured (n = 487)



Experiences of stigma: friends, family and sexual partners

One in ten respondents with hepatitis B reported they had been rejected by friends once or a few times (Figure 4). However, most respondents reported they had never been rejected by friends, blackmailed, threatened or abused, had family members making discriminatory remarks about them or been excluded from family activities. For people currently living with hepatitis C, higher proportions of respondents indicated they had been blackmailed, threatened or abused, had family members making discriminatory remarks about them or been excluded from family activities once or a few times. Around one in six (16%) reported family members had made discriminatory remarks about them and one in eight (13%) reported they had been rejected by family or friends.

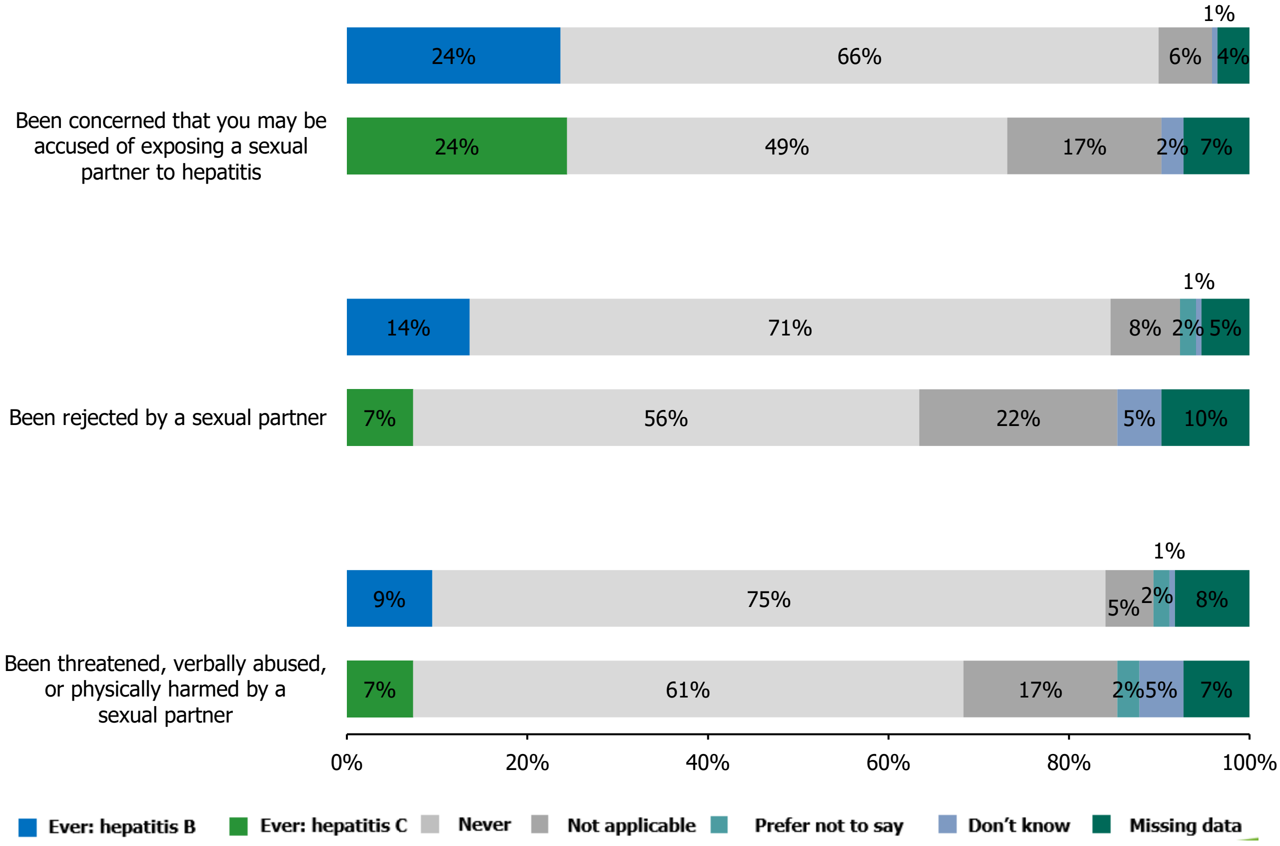
Figure 4. **Experiences of stigma (once or a few times) from friends and family by hepatitis type***



**Hepatitis B n= 169; hepatitis C (active) n= 41.*

Just under a quarter of respondents living with hepatitis B or C (24%) reported that they had ever been concerned they may be accused of exposing a sexual partner to hepatitis, with 66% and 49% of those with hepatitis B and C respectively reporting they had never been concerned about this. One in seven (14%) respondents with hepatitis B reported they had ever been rejected by a sexual partner, with this less commonly reported for those with hepatitis C (7%). Less than 10% of respondents with hepatitis B (9%) or hepatitis C (7%) reported they had ever been threatened, verbally abused or physically harmed by a sexual partner.

Figure 5. Experience of stigma with sexual partners by hepatitis type*

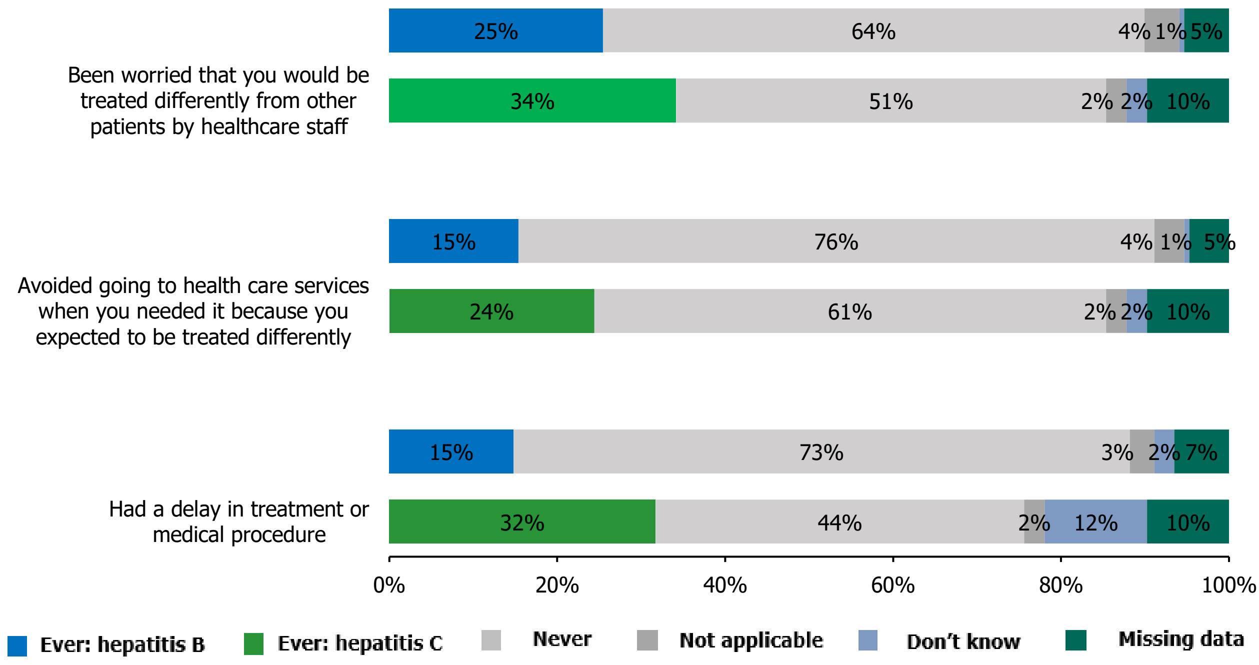


**Hepatitis B n= 169; hepatitis C (active) n= 41.*

Experiences of stigma: healthcare settings

One in four respondents with hepatitis B (25%) and around a third (34%) of those living with hepatitis C reported they were worried they would be treated differently from other patients by healthcare staff (Figure 6). Around one in seven respondents (15%) with hepatitis B avoided accessing healthcare services when they needed it because they expected to be treated differently, with nearly a quarter of respondents with hepatitis C (24%) reporting this. A third of respondents with hepatitis C (32%) reported a delay in treatment or medical procedure with this less commonly reported for individuals with hepatitis B (15%).

Figure 6. Experience of stigma in healthcare settings*

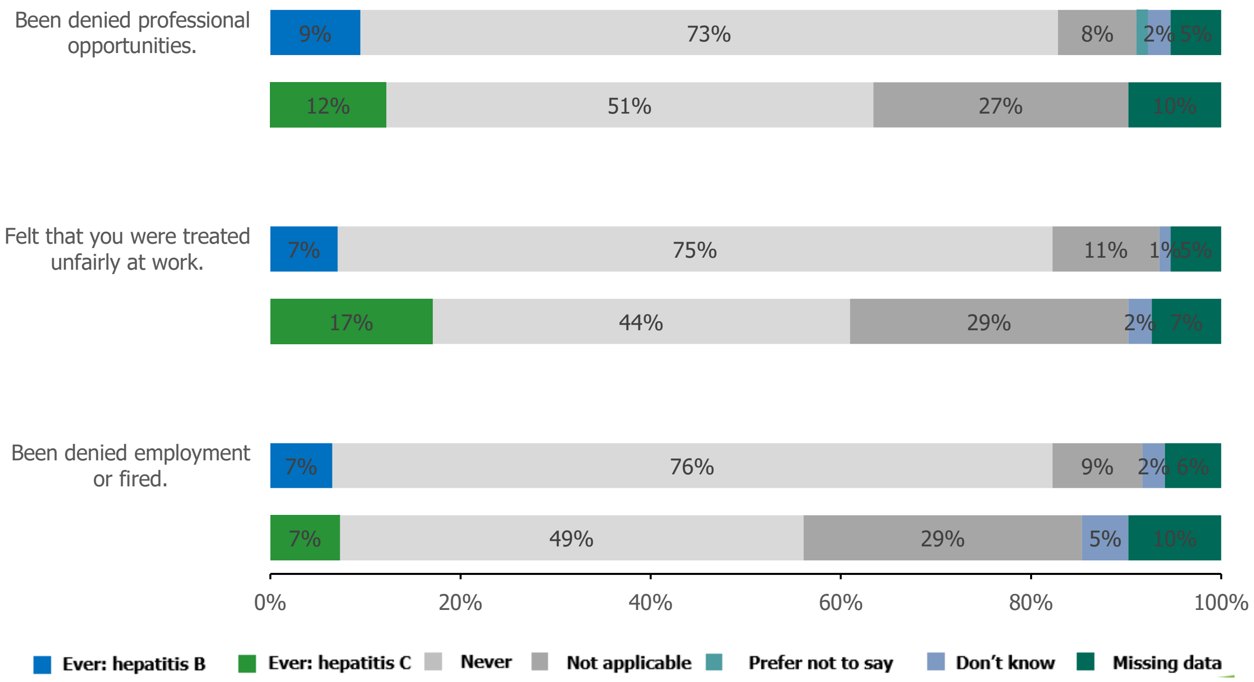


**Hepatitis B n= 169; hepatitis C (active) n= 41.*

Experiences of stigma: workplace settings

One in six respondents living with hepatitis C (17%) reported they felt they had been treated unfairly at work, with this less commonly reported by respondents with hepatitis B (7%). Around one in eight (12%) respondents with hepatitis C reported they had been denied professional opportunities, with this less commonly reported for those with hepatitis B (9%). For respondents with hepatitis B and C, 7% reported they had been denied employment or fired.

Figure 7. Experience of stigma in workplace settings*



**Hepatitis B n= 169; hepatitis C (active) n= 41.*

Post-survey evaluation

There were a total of eight responses to the post-survey evaluation from five countries (Croatia (1), Germany (2), Portugal (1) Romania (2), Spain (2)). All respondents indicated the questions were easy to understand and also felt the survey covered the key areas relating to stigma and discrimination. Six respondents (75%) indicated they had enough support during the dissemination process for the survey with one respondent reporting they did not have enough support, and the other respondent responded they were not sure. In terms of support that would have helped, the respondent who indicated they needed additional support noted they would have liked more support from other non-Government organisations (NGOs) and from the Ministry of Health.

In terms of challenges, one respondent indicated that it was hard to reach some groups such as people experiencing homelessness. Two respondents indicated that there was not enough time to disseminate the survey. In terms of the reported positive feedback around the survey, one respondent indicated there were lots of positive reactions from their local network and another noted considerable local interest in the survey. Four respondents indicated that the results would be helpful in supporting policy actions and raising awareness. One respondent highlighted the importance of the results in providing a baseline which could be used to measure progress over time following local efforts to tackle stigma and discrimination and could be used to compare the situation across countries.

Respondents were asked about how the survey could be improved in the future and one respondent suggested that there could be greater promotion on social media, and another indicated that future surveys should also consider traditional forms of media to reach individuals who do not use the internet and that in some instances paper copies of the survey could be helpful.

4 Discussion and conclusions

We developed an online survey tool on stigma and discrimination experienced by people living with viral hepatitis and piloted it in nine European countries to test the feasibility and acceptability of this approach and to collect baseline data from these countries. Although the survey as a pilot was conducted over a short period of time, there was still a good uptake with a total of 641 valid responses to the survey. There were many invalid responses received from individuals who had responded to the survey but did not fulfil the criteria for having hepatitis B or C or having had hepatitis C. It is likely that many of these individuals had been reached through media communicated via gay dating apps and this highlights the importance of clearer messaging around who the survey is intended for in the future. Whilst there were some countries with very low numbers of responses, the overall uptake is a clear reflection of the general acceptability of the study among the community and a willingness to participate. Further work is needed with partner organisations to explore the factors contributing to the low number of responses in some countries, although it seems likely that this was largely related to the short time allocated to conduct the study combined with limited community resources to support the rollout in some of the countries.

A total of 487 respondents were currently living or had been living with hepatitis C and 169 reported that they were living with hepatitis B. A high proportion of respondents were male, with this proportion greatest among individuals with hepatitis B (73%). This finding may reflect the large numbers of men who have sex with men who participated in the study, with 54% of respondents with hepatitis B identifying as men who have sex with men, which is much higher than would be expected based on recent modelling work [12]. For hepatitis C, a third of all respondents identified as men who have sex with men, with only 23% of respondents reporting current or past drug use and 7% identifying as a person in prison or with a history of being in prison. Recent analysis estimated the proportion of chronic hepatitis C infection cases among people who inject drugs to be 36%, with this proportion over 70% in 13 countries [13]. These findings certainly suggest a possible bias in sample with an under-representation of some population groups at risk of hepatitis B or C infection, including people who inject/have injected drugs and people in prison and a possible over-representation of men who have sex with men. This over-representation may reflect the success of using gay dating apps to cascade information to the community around the study, but may also reflect the familiarity with such survey tools following on from the ECDC survey on stigma related to HIV that was recently conducted [7].

The majority of those with hepatitis C (92%) reported that they had been cured, with only 41 (8%) reporting they had active infection. The dominance of responses from individuals with cured hepatitis C infection is a potential source of bias and the limited number of respondents with active infection certainly impairs any conclusions that can be drawn from the hepatitis C data. Addressing this imbalance and increasing the sample size of individuals with active infection is a challenge that needs to be carefully considered in subsequent surveys. Of those with active hepatitis C infection, 18 respondents reported they were receiving care or treatment. Of the 169 individuals with hepatitis B, 104 (62%) reported they were receiving care and/or treatment. Only nine (5%) of those with hepatitis B reported they were also living with hepatitis D. The proportion of cases engaged in care or treated for both infections is fairly high and may also reflect a potential bias in the sample with a possible under-representation of the large number individuals in the community who have been previously diagnosed but who are not connected to care. This finding may also reflect the recruitment process for the survey, with many individuals recruited into the study through contact with their treating physician or other healthcare staff they are in contact with in connection with their hepatitis.

In terms of quality of life, less than half of all respondents reported a positive health status with with respondents with hepatitis B having a better reported status than those with hepatitis C. Respondents with hepatitis B who were not on treatment or receiving care reported a better health status than those who were being treated or receiving care. Among respondents with hepatitis C, those who had been cured had a better reported health status than those with active infection. Whilst the questionnaire included a question related to markers of depression, the interpretation of the results are challenging and do not necessarily imply hepatitis is the cause of depression. Future surveys should consider alternative options to explore this issue further.

Half the respondents with hepatitis B or C reported that they found it difficult to tell others about living with hepatitis, with this being slightly more reported for those with hepatitis C. Just under a half of the respondents with hepatitis B had concerns about passing hepatitis on to others, with this being a much greater concern for those with hepatitis C. Poor self-esteem related to hepatitis status was a greater concern for those with hepatitis C compared to those with hepatitis B, and many respondents with hepatitis B or C had not told any family members or friends or their sexual partners that they had hepatitis.

In relation to experiences of stigma in relation to family, friends and sexual partners, a higher proportion of respondents with hepatitis C reported unfavourable experiences compared to those with hepatitis B. In relation to their experiences of accessing healthcare, one in four respondents with hepatitis B and a third of those with hepatitis C reported they were worried they would be treated differently from other patients by healthcare staff, and some reported they had avoided accessing healthcare services when they needed it because of concerns they would be treated differently. An important consideration in the interpretation of our findings relating to experiences of stigma for those living with hepatitis, is that for hepatitis C, the results include only those with active infection of which the sample size is extremely limited and this may affect the reliability of the results. However, these results are in line with the findings from other studies that found stigma in healthcare settings to be an ongoing concern for individuals with hepatitis that may result in the avoidance of care [14].

Our results show differences between respondents with hepatitis B and C in terms of their reported quality of life, self-perception, and experiences of stigma. In general, across all these domains, those affected by hepatitis C reported more negative experiences compared to those with hepatitis B. Some of these differences may relate to chronic hepatitis B being less well understood as a disease compared to hepatitis C which has received much attention since the emergence of the direct acting antivirals that revolutionised the therapeutic landscape for hepatitis C. Whilst a larger study with better representation is needed to fully understand the differences observed, it is possible that the varying experiences of stigma and discrimination between those with hepatitis B and C is partly related to differences in the predominant population groups affected, and the societal perceptions of these groups, as well as the infections themselves. Indeed, stereotypes of certain behaviours associated with some of these population groups that are viewed negatively by societies, such as injecting drug use, can reduce the perceived status of individuals with hepatitis C and result in stigma [15]. Individuals with hepatitis have complex multifaceted health and social needs and it is very likely that there are many other social and individual factors that underly the differences observed, and this deserves further careful disentangling and theoretical study. Indeed, what is clear is that the stigma that surrounds hepatitis B and C is highly complex and shaped by wider political and cultural factors. A study with larger sample sizes that is more representative and which enables disaggregation of the data by population group, geographical area or by other factors would facilitate a deeper exploration of the data that is needed to untangle these differences and gain a greater understanding of stigma.

Our results also indicated difference between individuals with hepatitis B who were on treatment compared to those who were not on treatment, with a higher proportion of those on treatment reporting their health was not so good and reporting markers of depression. This may reflect various factors including the possibility that those who are on treatment have more advanced disease resulting in poorer health, but further research is needed to confirm this. For hepatitis C, those who had been treated and cured reported less markers of depression and a more positive health status compared to those who had not been treated. This finding is consistent with research indicating that the eradication of the virus through treatment not only reduces morbidity and mortality but results in a better quality of life [16].

We recognise many limitations in our approach to gather information on stigma and discrimination related to hepatitis. Firstly, our study was restricted to a selection of European countries so the results may not be generalisable to other countries in the region or outside of Europe. Secondly, our survey was a pilot study that was conducted over a short time and this restricted the possibility to reach larger sample sizes and the limited sample sizes obtained in half of the participating countries restricts the conclusions that can be drawn on the data from these countries. In particular, the limited number of respondents with active hepatitis C infection is a key issue that needs to be carefully addressed in future surveys. The limited sample sizes restricted some key analyses and a full exploration of the data. Indeed, it is critical that data on stigma and discrimination are disaggregated by settings and across different population groups (e.g. men who have sex with men, migrant populations) in order to enable a fuller understanding of the situation.

Further, some of the population groups including people who inject/have injected drugs and people who are in prison, or who have experience of being in prison, were under-represented in the survey and the results may not be fully generalisable for the hepatitis populations as a whole. Indeed, there is a relative over-representation of respondents who identified as men who have sex with men and this may have biased the results. The study would have benefited from having the time to ensure stronger engagement with a range of NGOs representing people living with hepatitis and using a broader range of communication tools to reach study participants and increase the sample size. Future development of the survey to include questions that would enable a greater understanding of how long an individual was living with hepatitis C infection before being cured is important, as this was another limitation of our survey. Recall bias for individuals who were infected with hepatitis C but subsequently cured many years ago may have affected some of the results from this group of respondents and warrants greater exploration in future studies through a more granular analysis of the data.

In summary, the data collected through this pilot survey are subject to important limitations of the study design, but our results suggest that hepatitis-related stigma and discrimination may be prevalent within the countries that participated in the pilot. The implementation of this pilot study marks an important step towards helping to improve knowledge and understanding in this key area. Whilst further research is needed to gain a fuller understanding of the factors related to hepatitis stigma, our results suggest that stigma and discrimination may pose barriers in terms of access to hepatitis testing and treatment. Achieving the scale up in services needed to reach hepatitis B and C elimination targets will be difficult without targeted action to address stigma and discrimination. A wider rollout of the study is planned by the WHA that will take place across more countries. In order to achieve a broader and deeper exploration of this topic, this study will need to take on board some of the key lessons learnt from this pilot. These include the importance of ensuring a longer time period for rollout of the survey tool, strong engagement with key stakeholders working with people with hepatitis, especially people who inject/have injected drugs, and a broader range of communications to reach individuals.

Whilst a study with larger sample sizes, especially for individuals with active hepatitis C infection, and with greater representation across key population groups is clearly needed, the results from this initial pilot still provide important information for action. Indeed, the findings of stigma and discrimination in relation to healthcare warrant further exploration through research to understand whether these relate to gaps in education and knowledge that could be addressed through targeted training of healthcare professionals. Further research is also needed to help to identify gaps in the understanding around hepatitis among local communities to effectively tailor any local efforts combatting misconceptions that exist around hepatitis.

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Annex 1. Questionnaire survey tool

European Region Survey to Explore the Experiences of Living with Hepatitis B and/or Hepatitis C

The World Hepatitis Alliance (WHA), in collaboration with the European Centre for Disease Prevention and Control (ECDC), is working to understand the experience of stigma and discrimination* of people living with hepatitis B and C in the European region**. This survey is the first survey of stigma and discrimination related to hepatitis to be conducted in the region. We hope the information collected through this survey will help policy makers formulate informed policies and strategies to reduce stigma and discrimination among people living with hepatitis and improve the quality of life for people with hepatitis. The results of the survey will also enable the monitoring of trends over time, help identify targeted interventions to tackle stigma and discrimination, and explore the complex dynamics related to viral hepatitis stigma.

If you are **18 years of age or older** and **living with hepatitis B and/or hepatitis C**, or have ever had hepatitis C, then you can help out by answering this survey. The survey should take around 10 minutes to complete. Please note that the survey is anonymous, confidential, and no information will be collected that allows for the identification of participants. All data collected as part of the survey will be handled in strict accordance with the General Data Protection Regulation (GDPR) guidelines.

We are aware that some of the questions are sensitive. Please do not answer any question that you feel uncomfortable with. If you would like further support, please click the link at the end of the survey to find a list of local organisations working with people who have hepatitis B and hepatitis C that you can contact.

**Please check the WHA's report on stigma and discrimination if you want to learn more about it.*
***Countries within the European Region: Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czechia, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Moldova, Monaco, Montenegro, Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, Russia, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Turkmenistan, Ukraine, United Kingdom, Uzbekistan, and Vatican City.*

- Are you 18 years of age or older? Yes / No (*exit survey***)
- In which country do you live now? (Countries list; *if outside of the European region, exit survey***)
- Do you agree to participate in this survey? Yes (*enter survey*) / No (*exit survey***)

SECTION A	
A1: Are you living with hepatitis B?	Yes [] No [] Don't know [] Prefer not to say [] *If no, don't know, or prefer not to say, go to question A2.*
A1.1: Are you also living with hepatitis D?	Yes [] No [] Don't know [] Prefer not to say []
A1.2: In which YEAR were you first diagnosed with hepatitis B?	Drop down Prefer not to say []
A1.3: Are you currently receiving care for hepatitis B?	Yes, I am receiving care but am not on antiviral medication [] Yes, I am receiving care and am taking antiviral medication [] No [] Don't know [] Prefer not to say []
A2: Are you living with hepatitis C, or have you previously had hepatitis C?	Yes, I am currently living with hepatitis C [] Yes, I have had hepatitis C, but due to treatment, I am not longer living with it [] Yes, I have had hepatitis C, but my body has spontaneously cleared it and I am no longer living with it [] No, I have never been diagnosed with hepatitis C [] Don't know [] Prefer not to say [] *If no, not currently living with hepatitis C, don't know, or prefer not to say AND answered no, don't know, or prefer not to say in question A1, exit survey***.* *If no, not currently living with hepatitis C, don't know, or prefer not to say AND answered yes in question A1, go to section B1.*
A2.1: In which YEAR were you first diagnosed with hepatitis C?	Drop down Prefer not to say []
A2.2: Are you currently being treated for hepatitis C?	Yes [] No [] Don't know [] Prefer not to say []
SECTION B	
B1: How old are you? (In years old)	10-year AGE Groups Prefer not to say []
B2: How do you identify your gender?	Female (including transwoman) [] Male (including transman) [] Non-binary [] In another way [] Prefer not to say []

B3: Is this the same gender you were assigned at birth?	Yes [] No, it was female [] No, it was male [] Prefer not to say [] *If informed "Female (including transwoman)" in question B2, the option "No, it was female" in question B3 will not be shown.* *If informed "Male (including transman)" in question B2, the option "No, it was male" in question B3 will not be shown.*
B4: Which of the following best describes how you think of yourself?	Straight / Heterosexual [] Gay or Lesbian / Homosexual [] Bisexual [] Other. Please, specify ______ Prefer not to say []
B5: What is your country of birth?	Drop down menu Prefer not to say []
B6: How long have you lived in [[*country answered in front page*]]?	Less than 1 year [] 1-5 years [] More than 5 years [] Prefer not to say []
B7: Do you self-identify as a member of any of these groups? (Please, tick all that apply)	Migrants [] Refugees [] People who use or have used drugs [] People who inject or have previously injected drugs [] Prisoners or former prisoners [] People who have sex in exchange for money or other goods [] People living with HIV [] None of the above [] Prefer not to say []
SECTION C	
C1: Overall, how satisfied are you with your life at the moment? (*(Place a mark on the scale above)*	Scale 0-10 *Where 0 is not at all and 10 is completely* Prefer not to say []
C2: In general, how would you say your health is **TODAY**?	Very Good [] Good [] Fair [] Bad [] Very Bad [] Prefer not to say []
C3: During the past two weeks, have you often been bothered by 1. feeling nervous, anxious or on edge? 2. not being able to stop or control worrying? 3. feeling down, depressed, or hopeless? 4. little interest or pleasure in doing things?	Choice for each question: Not at all [] Several days [] More than half the days [] Nearly every day [] Prefer not to say []
C4.1: Who have you told that you are living with hepatitis B? Family member(s) Current sexual partner(s) Friend(s) Healthcare staff Co-worker(s) Previous/other sexual partner(s) Other people. Please, specify […] *[only for those who answered "Yes" they are living with hepatitis B in question A1]*	Choice for each question: None [] One or two [] Several [] The majority [] All [] Not applicable [] Prefer not to say []

C4.2: How does living with hepatitis B make you feel? I have poor self-esteem because I am living with hepatitis B It is difficult to tell people that I am living with hepatitis B I have concerns I can pass hepatitis B on to others *[only for those who answered they are living with hepatitis B in question A1]*	Choice for each question: Strongly disagree [] Disagree [] Neutral [] Agree [] Strongly agree [] Prefer not to say []
C4.3: Please complete the following statements based on your experience since starting hepatitis B treatment: My life is… My self-esteem is… My relationships with others are… My comfort with telling others I am living with hepatitis is… My worry about passing hepatitis on to others is… *[only for those who answered that they are currently being treated for hepatitis B in question A1.3]*	Choice for each question: Much worse [] Worse [] Unchanged [] Better [] Much better [] Prefer not to say []
C5.1: Who have you told that you are living with hepatitis C? Family member(s) Current sexual partner(s) Friend(s) Healthcare staff Co-worker(s) Previous/other sexual partner(s) Other people. Please, specify […] *[only for those who answered "Yes, I am currently living with hepatitis C" in question A2]*	Choice for each question: None [] One or two [] Several [] The majority [] All [] Not applicable [] Prefer not to say []
C5.2: How does living with hepatitis C make you feel? I have poor self-esteem because I am living with hepatitis C It is difficult to tell people that I am living with hepatitis C I have concerns I can pass hepatitis C on to others *[only for those who answered "Yes, I am currently living with hepatitis C" in question A2]*	Choice for each question: Strongly disagree [] Disagree [] Neutral [] Agree [] Strongly agree [] Prefer not to say []
C5.3: Please complete the following statements based on your experience since starting hepatitis C treatment: My life is… My self-esteem is… My relationships with others are… My comfort with telling others I am living with hepatitis is… My worry about passing hepatitis on to others is… *[only for those who answered that they are currently being treated for hepatitis C in question A2.2]*	Choice for each question: Much worse [] Worse [] Unchanged [] Better [] Much better [] Prefer not to say []
C6.1: Who have you told you were living with hepatitis C? Family member(s) Current sexual partner(s) Friend(s) Healthcare staff Co-worker(s) Previous/other sexual partner(s) Other people. Please, specify […] *[only for those who answered they have had hepatitis C, but are not longer living with it in question A2]*	Choice for each question: None [] One or two [] Several [] The majority [] All [] Not applicable [] Prefer not to say []
C6.2: How did living with hepatitis C make you feel? I had poor self-esteem because I was living with hepatitis C It was difficult to tell people that I was living with hepatitis C I had concerns I could pass hepatitis C on to others *[only for those who answered they have had hepatitis C, but are not longer living with it in question A2]*	Choice for each question: Strongly disagree [] Disagree [] Neutral [] Agree [] Strongly agree [] Prefer not to say []

C6.3: Please complete the following statements based on your experience since you were cured of hepatitis C: My life is… My self-esteem is… My relationships with others are… My comfort with telling others I was living with hepatitis is… My worry about passing hepatitis on to others is… *[only for those who answered they have had hepatitis C, but are not longer living with it in question A2]*	Choice for each question: Much worse [] Worse [] Unchanged [] Better [] Much better [] Prefer not to say []
SECTION D.1 *[only for those who answered they are living with hepatitis B in question A1]*	
D1.1: Have you experienced in the last 12 months any of the following **because you are living with hepatitis B**? *Some of these questions are sensitive, remember that you do not have to answer any questions that you don't want to.* In the last 12 months, have you experienced any of the following from family and friends **because you are living with hepatitis B**? 1. Been excluded from family activities. 2. Had family members making discriminatory remarks or gossip (talk inappropriately) about you. 3. Been rejected by your friends. 4. Been threatened, verbally abused, or physically harmed by family or friends. 5. Been blackmailed by family or friends. In the last 12 months, have you had any of the following experiences with healthcare (excluding dental) **because you are living with hepatitis B?** 6. Felt afraid to go to health care services because someone may learn your hepatitis B status. 7. Avoided going to health care services when you needed it because you expected to be treated differently. 8. Been worried that you would be treated differently from other patients by healthcare staff. 9. Heard health care staff gossiping (talking inappropriately) about you. 10. Generally felt that you were not treated well in a healthcare setting. 11. Been refused healthcare. 12. Had a delay in treatment or medical procedure. 13. Been tested for hepatitis B without your consent. In the last 12 months, have you had any of the following experiences with dental care **because you are living with hepatitis B?** 14. Felt afraid to go to dental services because someone may learn your hepatitis B status. 15. Avoided using dental services when you needed them because you expected to be treated differently. 16. Been worried that you would be treated differently from others by a dentist or dental healthcare staff. 17. Been refused dental care. In the last 12 months, have you had any of the following experiences **because you are living with hepatitis B?** 18. Felt that you were treated unfairly at work. 19. Been denied educational opportunities. 20. Been denied professional opportunities. 21. Been denied employment or fired. 22. Been denied entry, stay and/or residence in a foreign country. 23. Been refused protection by the police. 24. Felt scared to be in public places. 25. Been rejected by a sexual partner. 26. Been threatened, verbally abused, or physically harmed by a sexual partner. 27. Been threatened or physically harmed by someone (other than friends, family or sexual partner). 28. Been verbally harassed by someone (other than friends, family or sexual partner). 29. Been blackmailed by someone (other than friends and family). 30. Been concerned that you may be accused of exposing a sexual partner to hepatitis B.	Choice for each question: Never [] Once [] A few times [] Often [] Not applicable because they don't know that I am living with hepatitis [] Not applicable due to other reasons [] Don't know [] Prefer not to say []

SECTION D.2 *[only for those who answered they are currently living with hepatitis C in question A2]*	
D1.2: Have you experienced in the last 12 months any of the following **because you are living with hepatitis C**? *Some of these questions are sensitive, remember that you do not have to answer any questions that you don't want to.* In the last 12 months, have you experienced any of the following from family and friends **because you are living with hepatitis C**? 1. Been excluded from family activities. 2. Had family members making discriminatory remarks or gossip (talk inappropriately) about you. 3. Been rejected by your friends. 4. Been threatened, verbally abused, or physically harmed by family or friends. 5. Been blackmailed by family or friends. In the last 12 months, have you had any of the following experiences with healthcare (excluding dental) **because you are living with hepatitis C?** 6. Felt afraid to go to health care services because someone may learn your hepatitis C status. 7. Avoided going to health care services when you needed it because you expected to be treated differently. 8. Been worried that you would be treated differently from other patients by healthcare staff. 9. Heard health care staff gossiping (talking inappropriately) about you. 10. Generally felt that you were not treated well in a healthcare setting. 11. Been refused healthcare. 12. Had a delay in treatment or medical procedure. 13. Been tested for hepatitis C without your consent. In the last 12 months, have you had any of the following experiences with dental care **because you are living with hepatitis C?** 14. Felt afraid to go to dental services because someone may learn your hepatitis C status. 15. Avoided using dental services when you needed them because you expected to be treated differently. 16. Been worried that you would be treated differently from others by a dentist or dental healthcare staff. 17. Been refused dental care. In the last 12 months, have you had any of the following experiences **because you are living with hepatitis C?** 18. Felt that you were treated unfairly at work. 19. Been denied educational opportunities. 20. Been denied professional opportunities. 21. Been denied employment or fired. 22. Been denied entry, stay and/or residence in a foreign country. 23. Been refused protection by the police. 24. Felt scared to be in public places. 25. Been rejected by a sexual partner. 26. Been threatened, verbally abused, or physically harmed by a sexual partner. 27. Been threatened or physically harmed by someone (other than friends, family or sexual partner). 28. Been verbally harassed by someone (other than friends, family or sexual partner). 29. Been blackmailed by someone (other than friends and family). 30. Been concerned that you may be accused of exposing a sexual partner to hepatitis C.	Choice for each question: Never [] Once [] A few times [] Often [] Not applicable because no one knows that I am living with hepatitis [] Don't know [] Prefer not to say []
Is there anything you would like to share with us?	[Open-text box]

Exit message for those who have completed the survey:

****Exit message for those who did not meet the eligibility criteria because they are younger than 18 years old and/or do not live in one of the listed countries and/or do not consent to participating in the survey:**

We regret to inform you that you do not meet the eligibility criteria for participation in our survey. We appreciate your interest.

For individuals living with hepatitis B and/or hepatitis C, we have compiled a list of organisations that offer valuable support. Please feel free to explore the WHA's member listings for access to these resources. https://www.worldhepatitisalliance.org/our-members/member-listings/

*****Exit message for those who did not meet the eligibility criteria because they neither have hepatitis B nor hepatitis C:**

We regret to inform you that you do not meet the eligibility criteria for participation in our survey. We appreciate your interest.

If you want to know more about hepatitis B and/or hepatitis C, we have compiled a list of organisations that offer valuable support. Please feel free to explore WHA's member listing for access to these resources. https://www.worldhepatitisalliance.org/our-members/member-listings/

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