Patient Perspectives Report 2017
Executive Summary

This report gathers the testimony of hepatitis C patients across England, in order to highlight their experiences of living with hepatitis C and accessing care, as well as recommendations, informed by these experiences, of how hepatitis C can be better addressed in England.

The report focuses on three central themes:

Awareness & stigma

There is a lack of awareness of hepatitis C among patients, members of the public and health professionals. Many patients told us they were unaware of basic facts about the virus, such as risk factors, and that this was compounded by the often low levels of awareness among health professionals. As such, many went undiagnosed for long periods of time and, even after being diagnosed, frequently received incorrect or poor-quality advice. Those we interviewed also said that poor awareness of the virus among members of the public caused stigma, which often left patients feeling ashamed and unable to confide in others.

The care pathway: testing, diagnosis and support

Patients were frustrated by the length of time it took for them to receive a test for hepatitis C and want to see more widespread testing. Many patients were only diagnosed by chance, despite possessing clear risk factors. The manner in which they were diagnosed was also a common complaint, with many feeling they were informed in an unacceptable way, or not given enough information upon diagnosis. Patients also felt they were not offered enough support following their diagnosis and during treatment, with a common recommendation being access to counselling and support groups through the NHS.

Treatment & cure

There is a significant difference in patients’ experiences of the old hepatitis C treatments compared with the new direct acting antiviral (DAA) treatments. Experiences of the new drugs were uniformly more positive than with the old treatments, with patients reporting that they are able to continue living their lives as normal during treatment. The old, interferon-based treatments, by contrast, resulted in a range of deeply unpleasant side-effects which caused patients significant distress. However, the lack of access to the new drugs, and the uncertainty of waiting for them to be made available, was a huge source of frustration for those we interviewed.

Key recommendations

For Government:

- A public awareness campaign should be implemented, aimed at tackling stigma around hepatitis C and at encouraging individuals to access testing.
- A national hepatitis C plan for England should be released aimed at increasing the numbers of people tested and diagnosed, in order to facilitate the elimination of the virus in England by 2030.

For commissioners (CCGs, local authorities, NHS England):

- Commissioners should ensure that testing and screening blood for hepatitis C increases in primary care, secondary care and Accident & Emergency, and is routine in sexual health clinics, during antenatal care, and in drug and alcohol services.

Counselling and/or peer support services should be made available to patients with hepatitis C.

For NHS England:

- NHS England should abolish ‘run rates’ for the new hepatitis C treatments and adhere to the principles underlying our health system by providing access to the best cost-effective treatments to all patients who need them.

For health professionals:

- Patients with hepatitis C should be provided with clear and comprehensive information upon diagnosis, for example through information packs co-designed and co-produced with patients.
- All relevant health professionals and drug service staff should be supported in maintaining a working knowledge of hepatitis C, for example by ensuring attendance at blood borne virus training is a core component of all professional development plans.
Foreword

The Hepatitis C Trust was founded in order to ensure that patients’ voices were amplified in the national discussion about the virus. Whilst we have come a long way since the Trust was established back in 2001, significant challenges remain in ensuring that the voices of hepatitis C patients and others affected by the virus are heard.

People with hepatitis C often still face stigma and regularly encounter health professionals who are uninformed about the virus. There are still large numbers of people with hepatitis C across England who remain undiagnosed, putting them at risk of developing serious liver problems. To compound this, due to the cap imposed by NHS England on the number of people who can receive new, more effective drug treatments each year, those people who have been diagnosed often face severe difficulties in actually accessing treatment.

This report is a much-needed reflection of the problems faced by the hundreds of thousands of people across the country who have hepatitis C. Yet it also highlights the opportunities in relation to hepatitis C. The significantly more positive experiences patients have had with the new treatments, compared with the old, interferon-based ones, make it easier than ever for hepatitis C to be eliminated as a public health concern, provided the will is there.

The Hepatitis C Trust wants to see the elimination of hepatitis C as a serious public health concern by 2030; this is eminently achievable. My dream is for there to be no need for The Hepatitis C Trust to exist. I want to be able to close the doors of our organisation, knowing that we have achieved our aim of elimination.

The experiences shared by patients in this report, and the experiences of nurses as set out in the accompanying Nurses’ Perspectives report, highlight the urgent need to raise awareness of the virus, increase the numbers of people being tested and, ultimately, treat more people in order to eliminate hepatitis C as a public health concern in England.
Background

Hepatitis C is frequently misunderstood, with often low levels of awareness and knowledge among health professionals, the public, and even those who are particularly at risk of contracting the virus.

160,000 people in England are estimated to be chronically infected with hepatitis C.

An estimated 50% of people with hepatitis C remain undiagnosed.

Over the last decade, hospital admissions from hepatitis C-related liver disease have nearly tripled and deaths have doubled.

Almost half of people who go to hospital for hepatitis C are from the poorest fifth of society.

In May 2016, the UK Government pledged its support for the WHO’s goal of eliminating hepatitis C as a major public health threat by 2030.

This lack of awareness and knowledge is despite hepatitis C being one of the three main causes of liver disease, which is the only one of the five ‘big killers’ in England where deaths are rising. Deaths caused by hepatitis C have doubled over the last decade, with hospital admissions for hepatitis C-related liver disease having nearly trebled. It is estimated that 160,000 people are currently living with hepatitis C in England. With around half of those undiagnosed, hepatitis C really is a silent epidemic, and represents a significant public health challenge.

The recent introduction of direct acting anti-viral drugs provides the opportunity to eliminate the virus as a major public health threat, in line with the UK’s international commitment, by 2030. These treatments, unlike older interferon-based treatments, have short treatment durations, very high cure rates, and little or no side-effects, making treatment for hepatitis C a considerably less difficult process for patients than in the past.

However, the current state of hepatitis C services in England gives cause for concern from the patient perspective. Although the Government has pledged its support for the World Health Organisation’s goal of eliminating hepatitis C as a major public health threat by 2030, multiple barriers in the system preventing increased numbers of people being tested, treated and cured mean it is hard to see how this will be achieved in England in the current environment.

Access to treatment is still severely restricted, due to an unprecedented national cap on access to the new treatments being imposed by NHS England, despite them having been approved as cost-effective by the National Institute for Health and Care Excellence (NICE). With ‘run rates’ guiding the numbers of people each Operational Delivery Network (ODN) is able to treat each year, the end result is that many patients are being told they are not ill enough for treatment. This has the perverse effect of denying treatment to people who have looked after themselves and delayed liver damage by living healthily, resulting in them being ‘punished’ for living healthier lives. It is also leading some to take drastic measures such as buying generic versions of the drug online.

This report was compiled following nineteen semi-structured interviews with patients, who were identified via existing links with The Hepatitis C Trust. Participants answered questions on how they caught the virus; their experience of testing, diagnosis and (where relevant) treatment; and the quality of information and support they received.

The report maps out some of the main issues affecting people with hepatitis C in England. These issues include the wider health and psychological impacts of living with hepatitis C, the stigma that is attached to the virus, and the stress, uncertainty and anger of having to wait for access to the new treatments. The report concludes with recommendations for key actions to help those suffering with the virus and to ensure continued progress in the journey towards elimination.
Chapter 1: Awareness

Hepatitis C has historically suffered from a lack of awareness, with members of the public, patients and even health professionals often lacking basic knowledge of the virus.

For a number of reasons, it is hugely important that these low levels of awareness and knowledge are increased. With so many people with hepatitis C unaware that they have the virus, raising public awareness is crucial in order to increase the number of people getting tested. Low levels of awareness among health professionals represent another significant barrier to ensuring higher diagnosis rates, with patients who present with symptoms of hepatitis C often being mistakenly diagnosed with other conditions and not offered a test for the virus.

Increasing levels of awareness of hepatitis C is also vitally important in order to help those who have been diagnosed. Better understanding of the virus would likely reduce the stigma that people with hepatitis C encounter, which often arises from misunderstanding and ignorance.

Many of the patients we interviewed said they had little understanding of hepatitis C prior to being diagnosed with the virus. Whilst pre-test awareness levels of hepatitis C were slightly higher among the more recently diagnosed, even certain ‘at-risk’ groups – such as people who inject drugs (PWID) and people who had had a blood transfusion prior to 1991 – had little awareness of hepatitis C before being diagnosed.

One patient who contracted the virus through drug use said that he ‘knew of’ the virus but ‘didn’t know anything about it’ prior to being diagnosed, and had always assumed that it was only related to long-term heavy alcohol use. By contrast, a patient who had contracted the virus through another route believed that hepatitis C could only be contracted by injecting drugs and had therefore not considered himself to be at risk.

Medical professionals’ awareness of hepatitis C was also a concern for the patients we spoke to, particularly awareness and knowledge levels among GPs. A number of patients said that their GP had failed to test them for hepatitis C despite years of presenting common symptoms, and a medical history that clearly put them at risk of contracting the virus. Patient helpline staff from The Hepatitis C Trust also reported frequently speaking to patients who express shock and disbelief that they went so long without being tested despite exhibiting ‘textbook’ symptoms of the virus. The low levels of knowledge among health professionals are not just a factor with GPs. One patient reported an exchange with a nurse who was unclear as to what exactly hepatitis C was, asking the patient if they could go home and ‘Google it’.

Patients also often encountered other support service professionals with low awareness of hepatitis C. One patient we spoke to, who had been the victim of a sexual assault, was not advised to get tested by the support charity they accessed, despite the nature of the assault having put them at serious risk of contracting the virus. The patient was only eventually diagnosed as a result of regular tests they received in relation to a separate condition. We were also told of drug service workers who failed to tell patients that they were at risk of contracting hepatitis C due to a lack of knowledge about the virus.

“I was feeling ill for so many years and didn’t know what it was – I suffered with depression, I’ve had night sweats, nausea, tiredness, memory issues … and going to the doctors, it was always, ‘it’s postnatal depression, it’s this, it’s that’, never hepatitis C. They tested me for every cancer going, I had chest x-rays, an endoscopy, colonoscopy, bronchoscopy, everything… but never for hepatitis C”.

“Awareness needs to be improved. Based on the fact that when I was diagnosed with hepatitis C I’d heard of it and that was it, and given that I fit into a high-risk group, I don’t think that was a good thing, when I’d heard so much about HIV in contrast”.
Awareness in the MSM (men who have sex with men) community of the risks of contracting hepatitis C through unprotected sex were also reported to be low. This is in strong contrast to this community’s awareness of the risks of HIV, thereby clearly highlighting the gap in the levels of public knowledge of the two diseases. The differing levels of stigma around hepatitis C and HIV among MSM was also highlighted, with more awareness and better knowledge of the available treatments resulting in relatively little stigma around HIV. By contrast, stigma is often still attached to hepatitis C, with one patient saying they encountered people who would refuse any physical contact with those who have the virus. The lack of information about hepatitis C aimed specifically at MSM was highlighted as a significant factor in the low levels of knowledge.

Among South Asian patients, awareness levels were also considered to be low. One patient we spoke to said: “After hearing that people who have had medical treatment in places like Pakistan are at higher risk of getting hepatitis C, I decided to get tested and discovered that I had the virus. The problem is, there are lots of people from the South Asian community who are unaware that this is the case and haven’t been tested”. Due to the considerably higher prevalence rates for hepatitis C among the South Asian community in England, it is crucial that this lack of awareness is corrected.

“I don’t think there’s enough information aimed specifically at the risk group of gay men about how hepatitis C is passed on sexually and I don’t think it’s passed on proactively enough; you can find it if you go online and if you look for it but I don’t think it’s there otherwise. Unlike HIV, it’s either not covered at all or mentioned as a side-line, or you’ll see some things online that are overly paranoid and extreme”.

Many patients with whom we engaged were distressed by the length of time it took for them to be tested for hepatitis C, a consequence of the often low levels of awareness and knowledge among many health professionals.

One individual said it took two years from discovering they had raised liver enzymes after a blood test to being tested for hepatitis C, with their condition having been mistakenly (and, to the patient, offensively) ascribed to high alcohol consumption.

A number of patients we spoke to said they had only been diagnosed by chance, despite having clearly been at risk of contracting the virus. One patient was only diagnosed as a result of routine blood tests carried out before a hip replacement operation, despite having experienced symptoms of hepatitis C for around twenty years (which led to her being tested for a number of other conditions, such as diabetes, but not hepatitis C). Another, co-infected, patient was only diagnosed as a result of routine tests undertaken in relation to their HIV status.

“One of the most frequent areas for improvement cited by patients was increasing levels of testing for the virus, particularly by implementing routine testing – for example, upon first registering with a GP. One patient highlighted the way routine tests are carried out for HIV in areas of high prevalence and advocated this being replicated for hepatitis C.

As well as testing more people for the virus, one patient called for a look-back study to be conducted, with the aim of identifying and finding all those who have been diagnosed with hepatitis C in the past to locate those who may have dropped out of treatment or the care pathway. Similarly, it was suggested...”

Chapter 2: The care pathway: testing, diagnosis and support

“It just needs to be routine, the testing – it took me so long. I never knew that I had had a blood transfusion (I didn’t remember it, it was all part of the post-birth experience), and I’ve never injected drugs and that’s how I thought the majority of people get hepatitis ... Surely the cost of the test is minimal and should be added on as a matter of routine”. 
More hospital departments and GPs need to do testing ... it needs to become more of a routine thing ... adding it on to all those lists of other tests you just generally do when someone is not feeling well is what’s needed.”

“I wanted a doctor to tell me what hepatitis was, what it did, what you needed to do – I wanted answers, not through the internet or phoning The Hepatitis C Trust, but a doctor sitting down with me. It was always so rushed, it never felt like they had long to speak to me”.

Some patients were given the news that they had tested positive for the virus in a manner that they found to be totally unsuitable and which caused them a great deal of distress. One patient said they discovered they had hepatitis C when they received a phone call from their local hospital asking them to attend an appointment “about your hepatitis C” – this was the first the patient had heard of their diagnosis and clearly caused a significant amount of shock and confusion. Another patient was informed that they were hepatitis C-positive by a receptionist, something they described as “a shocking piece of information from someone I didn’t feel was qualified to tell me”.

Levels of support after diagnosis were also a concern for those we spoke to, with many saying that they were dealt with by staff who often could not answer their questions, leading them to rely on the internet or support groups for information. In addition to the delays many patients experienced in receiving a test, many encountered delayed care post-diagnosis, including having to wait a year just to see a consultant or receive a fibroscan to assess the extent of the damage to their liver. Having to wait for such a significant period added to the worry and upset caused by their initial diagnosis, particularly given that they had no idea of the liver damage they were living with at that stage.

A large number of those we spoke to also wanted to see increased access to support through the NHS. Many felt they had to find information and support through organisations like The Hepatitis C Trust – but patients often only discovered this support following a period of uncertainty, distress and fear after their diagnosis. By making access to support available at the time of diagnosis it was felt that some of the psychological strain of testing positive for the virus could be reduced. The type of support most frequently mentioned was counselling, to help patients deal with the psychological strain of being diagnosed.

“I received absolutely no written information. The only information I received was from The Hepatitis C Trust helpline, who sent me a package of information. If it wasn’t for the internet I think I’d be totally stuffed. I’ve never been signposted to any other forms of support like counselling either, and I think at first this would have been helpful”.

Patients also cited the value and importance of peer support, whether from an individual peer support worker or volunteer or as part of a support group. One patient we spoke to highlighted the peer support that is available through The Hepatitis C Trust as an example of good practice, saying “What the Trust does in terms of user-led support, with support from people who’ve been through it themselves – that seems key”. Receiving support from someone who has direct experience of what they are going through can be particularly helpful for patients, and the increased provision of peer support for hepatitis C was strongly supported.

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Patients who were infected with both hepatitis C and HIV (known as co-infection) often contrasted the support they received for HIV with that for hepatitis C, with a general perception that services for HIV are more holistic and comprehensive in their approach than for hepatitis C, and that it is easier to see an HIV specialist than a hepatologist. During hospital appointments, co-infected patients reported, HIV patients are often seen by a consultant physician, whereas hepatitis C patients usually see a nurse.

With regard to treatment, the broader moves within the NHS towards greater shared decision-making with patients relating to their care do not seem to have been wholly adopted in relation to hepatitis C. The majority of patients we spoke to reported experiencing fairly paternalistic interactions with their consultant and of having to push for further information in order to feel properly involved in their own care.

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"I would like to see an NHS group run by a psychotherapist or trained counsellor who could have contact with the hepatitis C team - nurses etc. - who could relay anything back. Especially when treatment has finished, even if you’ve failed - it’s like a door closes on you, it feels like the NHS aren’t interested”

"It has been much easier to ring up and get an HIV appointment really quickly, but I’m always told there are hundreds of people waiting to see the hepatologist and I can’t get one. Hepatitis C is nothing like HIV when it comes to the services for patients; there’s a big difference”.

Chapter 3: Treatment & cure

Overwhelmingly, the patients who had access to the new direct acting antiviral (DAA) treatments reported having a much more positive experience than those who were treated with older interferon-based treatments.

"I started the [old] treatment in 2013. I had to stop treatment a few weeks in though because my health had deteriorated so much - I couldn’t raise my arms. I was covered in spots. I had also been bleeding from the nose quite seriously for four days. Every time I had previously raised the issue with the nurse, all she would say is ‘that happens’.

With the new treatments causing significantly fewer side-effects than the older treatments and having shorter treatment durations, adherence rates are much higher and patients spoke of their excitement at being able to access these new, ‘game-changing’ drugs.

The Hepatitis C Trust’s patient helpline staff reported that patients who have experience of both old and new treatments are significantly more positive about the newer drugs, with people able to carry on working and many patients saying that their lives could continue as normal while undergoing treatment. This not only has a wider socioeconomic benefit, but also means that patients are able to maintain self-esteem and confidence levels, and are not left with the additional mental health impact of having to give up employment.

People who had experienced interferon-based treatments reported a wide variety of unpleasant side-effects – including depression, psoriasis, nosebleeds, breathing problems, fatigue, and chronic pain. Frequently, the severity of these side-effects led patients to cease treatment early, preferring to live with hepatitis C rather than go through the suffering and hardship associated with treatment.

By contrast, those who had experience of the new DAA treatments reported little or no side-effects and felt improvements in their health soon after commencing treatment. The only frequent complaint associated with the new treatments is the problem of gaining access to them.

The lack of access to the new treatments is a consequence of the cap
imposed by NHS England on the number of people who can be treated. With local areas having different criteria for treatment, there was a sense that a ‘postcode lottery’ exists which means that those who live in an area with a high prevalence of hepatitis C are more likely to face long waits for treatment. This sense of a postcode lottery also extended to support services, with one patient describing the contrasting availability of support in the two areas they had lived in as “amazing.”

“Fatigue and a degree of depression never left throughout the [interferon] treatment. It felt like chemotherapy; everything tasted of chemicals. I started Harvoni/ribavirin in May 2014, on a 24-week trial. The experience of the medication itself was totally unproblematic, despite the fact I was ill at the time with cirrhosis. There were no discernible side effects at all. I felt a genuine improvement from early on”.

Of those patients who had been refused treatment with the new generation of DAA drugs, the largest cause of frustration was the uncertainty around access to the new treatments, and what some felt was an arbitrary test of whether patients should be provided or denied the drugs. A lack of clarity about the criteria for treatment was exacerbating a stressful situation with many patients feeling that those who ‘shout loudest’ are treated first. Some of those we spoke to were angry that their condition would have to worsen before they would be eligible for treatment, especially as some felt they were being punished for having taken care of their health in order to minimise the damage to their liver.

Patients also spoke of their frustration at the current criteria for accessing treatment. Basing access to treatment purely on the condition of a patient’s liver fails to acknowledge the wider health impacts of the virus, they said, and a number of those we interviewed said that the criteria needs to change to reflect this. These health impacts include other physical problems, but also the psychological effect of being infected with the virus. One patient was concerned that their liver would be deemed “too healthy”, therefore delaying access to treatment, despite them suffering other physical health problems as a result of the virus.

“Something that has niggled with me is that I was speaking to my HIV/hepatitis C consultant, who also runs a clinic in Glasgow, and she said to me, ‘if you were a patient in Glasgow, I would be able to write you a prescription for Harvoni’. So that makes it more frustrating, that there’s a postcode lottery and then a lottery in terms of nations within the UK”.

Many patients who are on a waiting list for the new drugs report being unaware as to how long they will have to wait – with no knowledge as to whether it will be a matter of weeks, months or even years. The psychological effects of not knowing how long they will be waiting can be considerable, particularly with the knowledge that the health impacts of the virus are likely to worsen during the waiting period.

Some patients have taken matters into their own hands, with The Hepatitis C Trust helpline staff reporting contact with several patients who have obtained generic versions of the new drugs online. Although the cost of buying generic drugs is a tenth or less of what the NHS is paying, this is only an option for some people and it is only through increased access to the drugs on the NHS that others will be able to receive treatment. Furthermore, buying over the internet exposes patients to substandard, fake or even physically harmful drugs.

“I was told this year that I’m not sick enough to get treatment, that I have to be patient. I have looked after myself so carefully and that’s partly why my liver isn’t too damaged, and I received this through a blood transfusion, and yet it feels like I’m being punished for this”.

Key recommendations

For Government:

Patients told us: Public awareness of hepatitis C needs to be increased in order to tackle stigma and reach at-risk groups.

- Patients often had very little knowledge of hepatitis C before being diagnosed and some did not realise they were part of an ‘at-risk’ group.
- Many people with hepatitis C were reluctant to tell people about their diagnosis due to the stigma attached to the virus, which is often a result of misinformation.

The Hepatitis C Trust recommends: A public awareness campaign should be implemented, aimed at tackling stigma around hepatitis C and at encouraging individuals to access testing.

Patients told us: We have to increase the numbers of people diagnosed and treated if we want to eliminate hepatitis C.

- Chances to test and diagnose people are still being missed, and more has to be done to increase testing, diagnosis and treatment.
- Patients felt that there was a lack of a coherent strategy for tackling hepatitis C in England, with too many diagnosed by chance and very variable experiences of linkage to care.

The Hepatitis C Trust recommends: A national hepatitis C plan for England should be released aimed at increasing the numbers of people tested and diagnosed, in order to facilitate the elimination of the virus in England by 2030.

For commissioners (CCGs, local authorities, NHS England):

Patients told us: Tests for hepatitis C need to be offered more frequently.

- Routine testing, particularly among at-risk groups, would be a highly effective measure to identify and treat patients with an undiagnosed infection of hepatitis C.
- Providing testing in other services, such as Accident and Emergency departments, increases the likelihood of finding and diagnosing patients who are not engaged with health services.

The Hepatitis C Trust recommends: Commissioners should ensure that testing and screening blood for hepatitis C increases in primary care, secondary care and Accident & Emergency, and is routine in sexual health clinics, during antenatal care, and in drug and alcohol services.

Patients told us: More support should be provided post-diagnosis and during the treatment pathway.

- People with hepatitis C often felt they had to seek support themselves, or from patient organisations, rather than being offered support through the NHS.
Many patients felt it would have been useful to have received ‘peer support’ from someone who had previously had hepatitis C and been treated.

**The Hepatitis C Trust recommends:** Counselling and/or peer support services should be made available to patients with hepatitis C.

**For NHS England:**

**Patients told us:** Treatment should be made available to everyone who has been diagnosed with hepatitis C.

- The current cap on the number of people able to access the new treatments each year is an unprecedented decision by NHS England.
- The restrictions are causing significant distress, frustration and uncertainty for patients.

**The Hepatitis C Trust recommends:** NHS England should abolish ‘run rates’ for the new hepatitis C treatments and adhere to the principles underlying our health system by providing access to the best cost-effective treatments to all patients who need them.

**For health professionals:**

**Patients told us:** More information needs to be provided upon diagnosis.

- Many hepatitis C patients say they were not given enough information when they were diagnosed, which often led them to access unreliable information on the internet.
- Providing information upon diagnosis would also help to ease patients’ worries and help them to better navigate the care pathway.

**The Hepatitis C Trust recommends:** Patients with hepatitis C should be provided with clear and comprehensive information upon diagnosis, for example through information packs co-designed and co-produced with patients.

**Patients told us:** Awareness and knowledge of hepatitis C needs to be improved among many health professionals.

- Many patients had ‘textbook’ symptoms of hepatitis C but were not diagnosed due to the low levels of knowledge about the virus among health professionals.
- People with hepatitis C report frequently receiving poor advice and support from health professionals.

**The Hepatitis C Trust recommends:** All relevant health professionals and drug service staff should be supported in maintaining a working knowledge of hepatitis C, for example by making attendance at blood borne virus training a core component of all professional development plans.