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# Eliminating Hepatitis C in England

**All-Party Parliamentary Group  
on Liver Health Inquiry Report**

March 2018

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## Foreword: The road to elimination

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Over the course of this inquiry into eliminating hepatitis C, the APPG on Liver Health has heard from experts engaged in every aspect of the hepatitis C care pathway. Our contributors have included patients, leading clinicians, NHS managers, commissioners, third sector service workers, campaigners, senior pharmaceutical industry representatives and national public health policy leads. Without exception, they told us that England will not fulfil its commitment to elimination of hepatitis C by 2030 unless the number of people diagnosed and initiated onto treatment is greatly increased.

The opportunity to eliminate a public health threat like hepatitis C is a truly extraordinary one. Elimination would be a global achievement, relegating hepatitis C to an extremely rare infection alongside other diseases of the past like measles and polio. Despite this, and unlike many other European countries including France, Spain, Germany and Italy, England lacks a national strategy to eliminate this curable and highly infectious virus.

Experts contributing to our inquiry overwhelmingly agreed that the development of a national strategic approach to hepatitis C elimination is essential if England is to have any hope of meeting its goal to eliminate hepatitis C as a public health concern by 2030. Our call for a national elimination strategy is central to this report.

In many parts of the country, great progress has been made in tackling hepatitis C. Yet lack of awareness, sub-optimal testing levels, overly complex care pathways, a fragmented commissioning environment, and short-term treatment funding models all present significant challenges. The lack of national coordination holds England back from bold international leadership on this critical public health issue.

The sections below are intended to serve as a vision for a national elimination strategy, bringing together evidence about progress made in recent years, challenges that remain, and the lived experiences of those with hepatitis C. While it was beyond the scope of this report to develop data-based monitoring targets for our objectives, it attempts to make concrete, action-based recommendations which should be considered central to the national elimination strategy we hope to see developed.

To press forward towards achieving NHS England's ambition to eliminate hepatitis C by 2025 at the latest, five years before the World Health Organization target, there is no time to waste in putting new interventions into practice. To that end, we have not shied away from making bold recommendations, and suggest that all of these should be continually evaluated and adjusted for maximum impact.

With the exceptional context of a deadly virus now being fully curable with easily deliverable, highly cost-effective medicines, there is no excuse for not delivering universal access to treatment. In the coming years, finding those still undiagnosed and living with hepatitis C should be a national ambition. It is our hope and belief that in the very near future, hepatitis C will truly be a relic of the past.

**Sir David Amess MP, Co-Chair**

**Baroness Masham of Ilton, Co-Chair**

**Baroness Randerson, Co-Chair**

**Virendra Sharma MP, Vice-Chair**

**Lord Mancroft, Member**

# Summary

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This report puts forward a series of action-based recommendations to support objectives leading to elimination of hepatitis C. The key areas for suggested improvement are summarised by section below.

## Awareness

Awareness of hepatitis C within the public and at-risk groups remains low, and stigma continues to be a burden for patients. New awareness-raising initiatives should support fewer risky behaviours, increased self-presentation for testing, re-engagement of those previously diagnosed into treatment and decreased stigma. A high-profile, Government-backed awareness campaign should be considered, and awareness messaging should be targeted through novel channels at those who may not consider themselves to be 'at risk'. Awareness-raising messaging should also be developed for specific risk groups based on expert advice regarding the unique considerations for each group. Awareness should be increased among primary care professionals through targeted testing initiatives in primary care and additional resources and support for primary care workers.

## Prevention

To achieve elimination of hepatitis C, we must ensure that numbers of new infections are falling, so that increased testing and treatment initiatives lead to a decline in overall prevalence. Provision of needle and syringe programmes, a service key to prevention of hepatitis C transmission, is currently insufficient and should be increased; funding for opioid substitution therapy should also be protected. Knowledge of transmission risks must be increased through peer programmes and improved support from well-trained and informed service staff. Behavioural interventions to reduce reinfection, which remains a serious challenge to elimination, must be prioritised. Bold outreach and incentives to treat those most likely to transmit the virus should become standard.

## Testing and Diagnosis

Significantly increased numbers of people will need to be tested and diagnosed. Testing in prisons, substance misuse services and sexual health clinics will need to become routine, and more ambitious targets for testing uptake should be set. Testing initiatives should be introduced in non-clinical settings in the community, and testing practices – for instance, type of test conducted and laboratory procurement specifications – standardised nationally.

## Linkage to Care

The time between diagnosis and beginning treatment poses the greatest risk of patients dropping out of the care pathway. Time between diagnoses and initiation of treatment should be decreased by simplifying referral pathways and eliminating the need for additional tests and unnecessary appointments. The ambition should be initiating treatment on the same day as a positive diagnosis.

## Treatment

An increased target of at least 20,000 new treatment initiations per year should be adopted nationally in order to achieve the commitment to eliminate hepatitis C by 2025 expressed by NHS England. Treatment must be made available in community settings, and be flexible and accessible to all patients. Treatment should also be made available to those who are reinfected in line with a 'treatment as prevention' approach.

## **Funding**

A long-term, strategic approach to funding for hepatitis C care and treatment should be developed and supported by a national elimination strategy. The currently ongoing negotiations between NHS England and industry towards such a funding agreement provide an opportunity to embed some of the recommendations of this report. The resulting deal should include effective mechanisms to ensure funds are distributed equitably across different geographies and patient populations so that no one is left behind.

## **Monitoring Progress**

Ambitious local, regional and national targets should be developed as part of a national elimination strategy, and used to drive increases in testing and treatment. Improving the quality and type of data collected on hepatitis C prevalence and incidence is crucial to enabling more efficient allocation of resources and monitoring of progress towards elimination. Additional research on bold, innovative approaches to improvement in hepatitis C care should be conducted, and effective mechanisms to upscale best practice established nationally.

# Background

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## Hepatitis C globally

Hepatitis C is a blood-borne virus (BBV) that primarily affects the liver. It is a major cause of liver cirrhosis and cancer and together with hepatitis B is responsible for two out of three liver cancer deaths globally. The number of liver cancer deaths attributable to hepatitis B or C has increased by 19% between 2006 and 2016<sup>1</sup>. Hepatitis C alone was responsible for 400,000 deaths globally in 2016, mostly from cirrhosis and liver cancer<sup>2</sup>.

Hepatitis C can also have a much broader impact and has been linked to cardiovascular disease, mental health issues, kidney problems, and musculoskeletal pain. It is transmitted through blood-to-blood contact and, contrary to popular myth, cannot be spread via spitting, coughing, sneezing, or other physical contact.

The World Health Organization estimates that 71 million people worldwide are chronically infected with hepatitis C<sup>3</sup>. People infected with hepatitis C often experience few or no obvious symptoms, and people can often live with the virus for many years without being diagnosed, increasing the risk of severe liver damage. Crucially, hepatitis C is preventable, treatable and curable for the vast majority of people. Since 2015, treatments with short durations, limited side-effects and cure rates upwards of 95% have been widely available.

In May 2016, the United Kingdom joined 193 other member states in signing up to the World Health Organization Global Health Sector Strategy (GHSS) on Viral Hepatitis, which commits participating countries to the elimination of hepatitis C as a major public health threat by 2030. This commitment included signing up to targets of an 80% reduction in incident (new) chronic hepatitis C infections and a 65% reduction in mortality from hepatitis C by 2030. The strategy also contains service coverage targets for 2030, including 80% of those eligible being treated and 300 sterile syringe and needle sets distributed per year to improve harm reduction. To move towards elimination, the WHO set interim targets of a 30% reduction in infections and a 10% reduction in mortality by 2020<sup>4</sup>.

These targets are a global baseline, but many countries and regions have developed bespoke elimination strategies with more ambitious targets to address infection within key populations. The WHO Regional Office for Europe has also developed an action plan to guide the implementation of the GHSS in the European Region, which includes the following interim 2020 targets for Europe<sup>5</sup>:

- 50% of people living with chronic HBV and HCV infections are diagnosed and aware of their condition
- 75% treatment coverage of people diagnosed with HBV and HCV infections who are eligible for treatment
- 75% of those at late stage of viral hepatitis-related liver disease (cirrhosis or liver cancer) diagnosed

Data on hepatitis C released in November 2017 by the Polaris Observatory, a public health research firm based in the USA with expertise in epidemiology and disease modelling, show that the UK is not one of the nine countries on course to eliminate hepatitis C by 2030.

Brazil, Egypt, Australia and Georgia are key countries often highlighted as making great strides towards elimination. In Egypt, mass screening initiatives have been implemented, and generic copies of treatments are being sold for under \$200 per course. In Australia, there is universal access to treatment as a result of an AUS\$1 billion investment over 5 years. Germany, Iceland, Japan, the Netherlands, and Qatar are also expected to eliminate hepatitis C by 2030 according to the Polaris data. The UK is among 22 countries categorised as 'working towards elimination'.

Australia, Georgia, and Egypt have developed and implemented detailed national hepatitis C elimination strategies which are often used internationally as models of best practice. Other countries like Scotland, Wales, France, Belgium, and Germany have also developed strategic national approaches to hepatitis C.

**World Health Organization Global Health Sector Strategy on Viral Hepatitis service coverage targets for the elimination of HBV and HCV as public health threats, 2015-2030**

Target areas		Baseline 2015	2020 target	2030 target		
Service Coverage	Prevention	1. Three-dose hepatitis B vaccine for infants (coverage %)	82%	90%	90%	
		2. Prevention of mother-to-child transmission of HBV: hepatitis B birth-dose vaccination or other approaches (coverage %)	38%	50%	90%	
		3. Blood and injection safety (coverage %)	Blood safety: donations screened with quality assurance	89%	95%	100%
			Injection safety: use of engineered devices	5%	50%	90%
	4. Harm reduction (sterile syringe/needle set distributed per person per year for people who inject drugs [PWID])	20	200	300		
	Treatment	5a. Diagnosis of HBV and HCV (coverage %)	<5%	30%	90%	
5b. Treatment of HBV and HCV (coverage %)		<1%	5 million (HBV) 3 million (HCV)	80% eligible treated		
Impact leading to elimination	Incidence of chronic HBV and HCV infections	6-10 million	30% reduction	90% reduction		
	Mortality from chronic HBV and HCV infections	1.46 million	10% reduction	65% reduction		

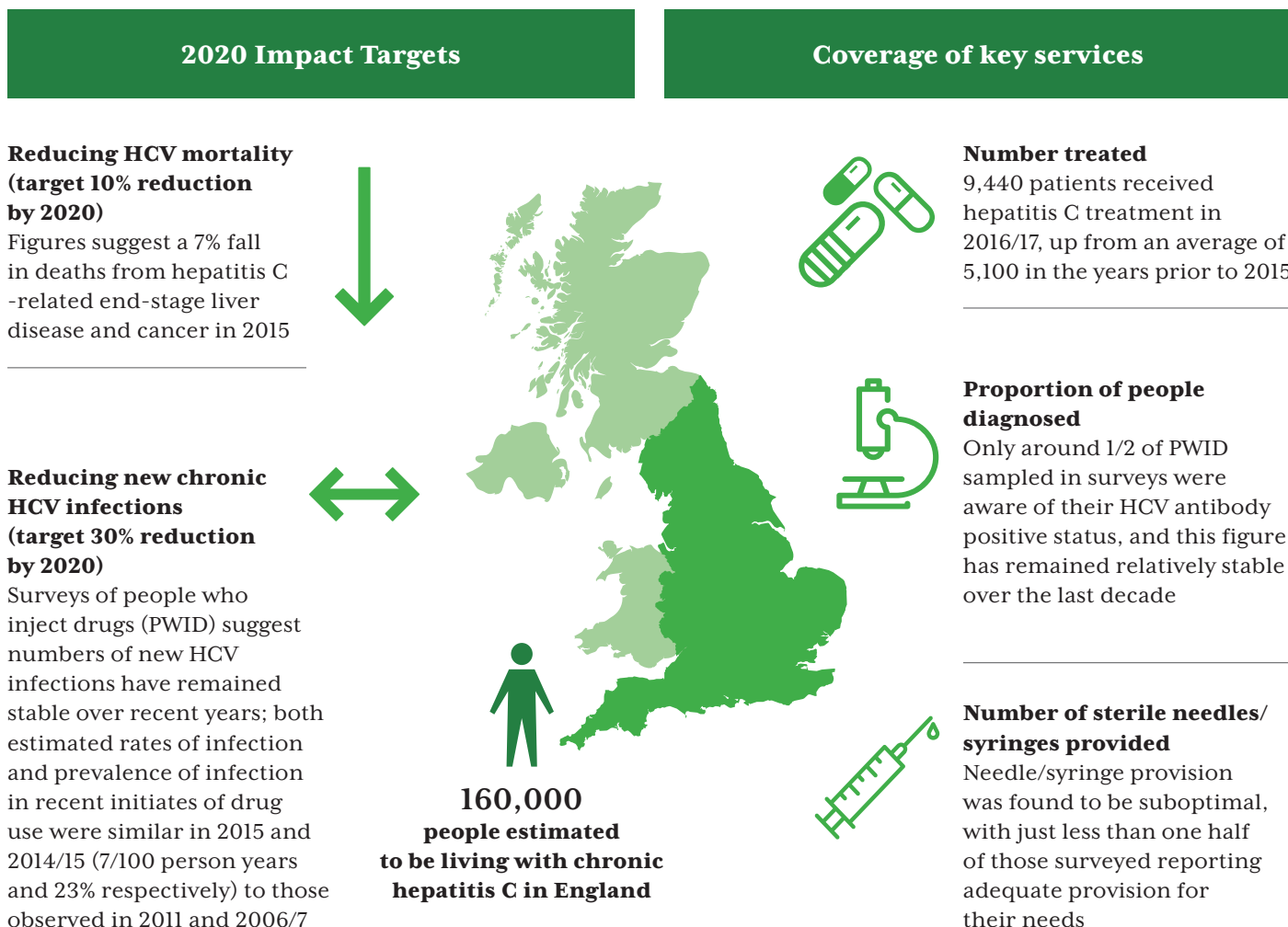
## Hepatitis C in England

In England, around 160,000 people are chronically infected with hepatitis C, with 40-50% remaining undiagnosed<sup>6</sup>. Public Health England data shows that the number of diagnosed infections has been increasing over the past two decades, reaching a peak of 11,605 diagnoses in 2015, reflecting increased testing and treatment targets and initiatives<sup>7</sup>. Testing rates have increased by 18.6% between 2011 and 2015<sup>8</sup>.

Between 2005 and 2014, deaths from hepatitis-C related end-stage liver disease more than doubled<sup>9</sup>. For the first time in 2016, early estimates suggested a notable fall in deaths from hepatitis C related end-stage liver disease and in liver transplants undertaken<sup>10</sup>. This decline has been sustained in provisional figures for 2017<sup>11</sup>. These achievements reflect the positive impact of new treatments combined with NHS England's programme of immediate treatment for those with the most severe liver damage. This success should be celebrated, but it is important to note that it reflects results for only those with the most severe liver damage who have already been diagnosed. Further falls in mortality will require significant action to find those infected decades ago who are unaware of their status and at high risk of cirrhosis and liver cancer.

Until 2014, hepatitis C treatment was primarily injection based, lasted between 24 and 48 weeks, resulted in significant unpleasant side effects and had an overall cure rate of less than 50%. New direct acting antiviral (DAA) treatments first became widely available in 2015. These treatments are tablet-based with a duration of 8-12 weeks, have few side effects, and result in cure rates upwards of 95%.

## Eliminating hepatitis C as a major public health threat in England



In 2015, alongside the widespread introduction of DAA treatments, 22 hepatitis C Operational Delivery Networks (ODNs) were established to co-ordinate cost effective care, data collection and access to treatment across a region. The ODNs operate on a 'hub and spoke' model, with one hospital leading on overseeing treatment in the ODN area. Treatment and prescribing decisions are made within the ODNs by a multi-disciplinary team.

Since their establishment, each ODN has been given a 'run rate' determined by NHS England, essentially a target number of new treatment initiations which is not to be exceeded. ODNs are incentivised via the Commissioning for Quality and Innovation (CQUIN) scheme to treat at least 90% of their run rate target, but not to exceed 100%<sup>12</sup> (increasing to 110% in April 2018<sup>13</sup>). The CQUIN scheme links a proportion of a payment for services provided to the achievement of certain goals. While NHS England has argued that these CQUIN payments should be seen as a 'bonus' incentive, the financial risk of not receiving the payment has in reality been perceived largely as a penalty. Interviews with key ODN staff have showed that the run rates were viewed 'primarily as a cap on treatment and only secondly as a target'<sup>14</sup>.

Initially, this system resulted in waiting lists for treatment in many areas. In the last year, waiting lists in most ODNs have been significantly reduced or eliminated, though they still exist in London. Increasingly, the greatest challenge for ODNs is finding undiagnosed patients and re-engaging those previously diagnosed into care to ensure treatment target numbers are met. This



will become more challenging as time goes on, due to the need to find increasingly hard-to-reach groups who are not in touch with services.

In January 2018, NHS England announced upcoming negotiations with industry intended to reach a new funding arrangement for hepatitis C treatments. The proposed new funding arrangement is intended to support the elimination of hepatitis C in England by 2025 at the latest. The deal promises to agree a role for the pharmaceutical industry in finding currently undiagnosed patients or those previously diagnosed but lost to follow-up and linking them into treatment.

This announcement from NHS England indicates the beginnings of a more strategic approach to hepatitis C care. However, currently England falls behind other European countries which have introduced government-backed national strategies for hepatitis C treatment and elimination. The Government currently maintain they have no plans to release a hepatitis C elimination strategy<sup>15</sup>.

## Key risk factors

Hepatitis C disproportionately affects disadvantaged and marginalised communities, with almost half of people who attend hospital for hepatitis C coming from the poorest fifth of society<sup>16</sup>.

People who inject drugs (PWID) are the group most at risk of becoming infected with hepatitis C, with transmission occurring via shared syringes and other injecting equipment. Approximately 50% of PWID remain undiagnosed, and prevalence of hepatitis C among recent initiates in drug use was found to be 26%<sup>17</sup>. PWID are a key target population for hepatitis C prevention, diagnosis, and treatment initiatives. There is a high prevalence of hepatitis C among people in prison, due to a high population of PWID in prison, as well as unsafe injecting and tattooing taking place within prison.

Men who have sex with men are also at increased risk of infection due to risk of blood-to-blood contact during certain sexual activities, with this risk being particularly pronounced for those who engage in 'chemsex' - the use of recreational drugs in a sexual context, often in a party environment.

There is also a high prevalence of hepatitis C within some South Asian and Eastern European populations in England, due to a high risk of infection from unsafe medical and dental care or unsterile shaving and barbers' equipment. The risk among members of these groups can be hard to assess, due to primary risk factors occurring abroad and depending on frequency of travel to home countries.

Prior to 1991, significant numbers of people contracted hepatitis C via infected blood and blood products. Since September 1991, all blood in the UK has been screened for hepatitis C. Despite national initiatives to trace these people, there are still people who were infected via contaminated blood prior to 1991 who remain undiagnosed. People infected via blood products can be challenging to find and diagnose, as they can be unaware that they previously received a blood transfusion, and usually would not consider themselves to be 'at risk'.

Levels of infection are higher among people who inject image or performance enhancing drugs<sup>[1]</sup>. Hepatitis C is also transmitted via unsterilised needles used in tattoos and piercings, though the risks associated with these transmission routes in the UK are considered relatively low. There is a small risk of transmission from an infected mother to her child at the time of birth.

## Hepatitis C in the devolved nations

All nations in the UK are committed to achieving the elimination of hepatitis C by 2030, though progress towards achieving elimination differs in each. Experts from Scotland and Wales took part in the APPG's inquiry, allowing for a comparison with the approach taken towards hepatitis C in those countries with the approach in England.

Scotland has previously been regarded as a world leader in tackling hepatitis C. Scotland's Hepatitis C Action Plan (2006-2011) and the Sexual Health and Blood Borne Virus Framework (2011-2015, updated for 2015-2020) are seen as good examples of effective frameworks for tackling hepatitis C. Scotland has seen significant increases in the numbers of people diagnosed and treated since 2006. In early 2018, the Scottish Government announced that it would be publishing an elimination strategy later in the year<sup>19</sup>, another encouraging development.

Wales has not historically matched Scotland's pioneering approach to hepatitis C but has taken great strides forward in recent years. In 2015, the Welsh Government released its Liver Disease Delivery Plan, setting out its approach towards hepatitis C, and in 2017 committed to releasing a dedicated hepatitis C elimination strategy, due to be released in 2018. Wales has ambitious treatment targets for hepatitis C, with no limit placed on the number of patients able to access treatment.

Northern Ireland has the lowest prevalence of hepatitis C among the UK nations, with a small proportion of people estimated to be hepatitis C-positive, even when taking into account the country's smaller population. Whilst the potential development of a hepatitis C elimination strategy in Northern Ireland has been stymied by the ongoing suspension of the Northern Ireland Executive, there are still examples of good practice that England can adopt. For example, when a laboratory blood test reveals a sample to be hepatitis C-positive, it is standard practice for the result to be returned accompanied by instructions on next steps (such as how/where to make a referral) and information for the newly-diagnosed patient. This is a good approach to minimising the risk of positive results not being appropriately referred, and one that should be replicated in England.

In the evidence provided at the inquiry sessions, we heard that the freedom for clinicians in Wales to take the lead on making decisions on access to treatment was highly valued. It was felt to be vital that patients could be enrolled straight into treatment following diagnosis, with witnesses saying that treatment restrictions can act as a disincentive to people getting tested in the first place. The development of an elimination strategy in Wales was also praised. A witness closely involved with the hepatitis C treatment programme in Wales said that elimination will not be possible without an overarching strategy to coordinate the many actions and stakeholders involved.

Whilst yet to adopt an elimination strategy, Scotland was regarded as being in a strong position in its approach to hepatitis C because of the coordinating and monitoring infrastructure built up over the 12 years since the publication of the Hepatitis C Action Plan. As a result, it was felt that Scotland is in a strong position to take full advantage of the still-relatively-new DAA treatments to drive towards elimination. The current system of delivering treatment in England ensures close monitoring, and efforts are underway to establish a registry of diagnosed patients, which is a positive step. However, as England has not been operating under a national plan over the same period of time, the level of coordinating and monitoring infrastructure is not yet equal to that in Scotland. The comparison with Scotland and Wales therefore supports the case for an elimination strategy in England, to fast-track the development of such infrastructure, and to ensure a strategic, joined-up approach to achieving elimination.

The inquiry also heard that the development of the Hepatitis C Action Plan formulated Scotland's approach to hepatitis C, with the Government "right at the centre providing a helping hand, developing infrastructure and [providing] additional investment in service development". This central role for the Scottish Government, and the very public commitment to hepatitis C elimination from ministers in both Scotland and Wales, demonstrates the positive role governments can play in galvanising action in tackling hepatitis C. This approach is one that could be emulated in England, where the Government has to date played a less central role in efforts to tackle hepatitis C and has been less explicit in its support for the elimination agenda.

However, while there is much that England can learn from the approaches taken in Scotland and Wales, there are still challenges in both countries and areas where England could set an example in its approach towards hepatitis C.

Despite Scotland taking a world-leading approach to hepatitis C in the past, there is a perception among key stakeholders that progress towards elimination has stalled in recent years. Whilst there is no explicit limit on the number of patients able to access treatment in Scotland, in practice budgets do impose a limit. Scottish Government targets for the minimum number of patients to be treated by health boards in 2018/19 have only marginally increased on the targets for 2017/18. A recent inquiry by The Hepatitis C Trust and a cross-party group of MSPs found consensus from experts that Scotland has not been on track to

achieve elimination by 2030, based on current testing and treatment rates<sup>20</sup>.

Likewise, there are ongoing difficulties in Wales. Around 700 patients were treated in 2016/17, short of the Welsh Government target to treat 900 patients per year. With no restrictions imposed on the number of patients able to access treatment, this shortfall reflects the challenge of finding undiagnosed patients. Welsh stakeholders report that ongoing failures to diagnose enough patients risks imperilling progress towards elimination.

The ongoing negotiations between NHS England and the pharmaceutical industry on a new funding deal for hepatitis C therefore offer an opportunity for England to provide a positive example to the devolved nations. If such a deal leads to a significant increase in the number of patients diagnosed and accessing treatment, England will be leading the way in the UK and providing a model for Scotland, Wales and Northern Ireland to follow.

# Awareness

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## Current situation

There are low levels of awareness of hepatitis C within the general public, with 40-50% of those living with hepatitis C remaining undiagnosed. Misconceptions about transmission risks also persist within more informed risk groups; for instance, even PWID who are aware of the risks of transmission via shared needles are often not aware that risk extends to sharing other injecting equipment like water, filters and spoons.

It was reported that the progression of hepatitis C is perceived as very slow, with many not appreciating its seriousness or understanding that infection can lead to liver cirrhosis and cancer. Often, if people are not experiencing immediate, identifiable symptoms, treatment is not seen as a priority. Lingering fears about the effects of old treatments that are no longer in use also prevent people from accepting a test or seeking treatment. These symptoms of low awareness create significant barriers to increased testing, improved linkage to care, and increased treatment numbers.

While experts agreed that awareness-raising initiatives and the advent of curative treatments have assisted in decreasing stigma surrounding hepatitis C in recent years, it remains a major burden. In addition to contributing to social exclusion and isolation, stigma is a key barrier to people presenting for testing or seeking treatment.

It was recognised that while publicity is necessary to increase knowledge in various communities and encourage people to come forward for testing, awareness-raising must be accompanied by resource-backed testing initiatives and universal access to treatment. It was noted that as diagnosis becomes simpler and faster, and treatment is increasingly normalised and delivered in community settings, stigma will naturally lessen, and that increasing awareness should be seen as part of a comprehensive approach to tackling hepatitis C.

**“It starts before the test. The messaging in the community of drug users on the importance of testing is crucial. Hepatitis C kills people, and there is a reluctance to acknowledge that in the drug user community.”**

**Stuart Smith**

*(Head of Drug Services, The Hepatitis C Trust)*

**Objective 1.1: Awareness of hepatitis C within the public is increased, leading to fewer risky behaviours, increased self-presentation for testing, re-engagement of those previously diagnosed into treatment and decreased stigma.**

While experts and former patients in our evidence sessions expressed optimism that awareness of hepatitis C was slowly increasing, all emphasised that there is still insufficient awareness of hepatitis C within at-risk communities and stigma remains high. Patients discussed that understanding of symptoms and consequences of hepatitis C within at-risk groups is limited and that people are often unaware that they have put themselves at risk. Witnesses reported that the perceived risk of transmission and fear of contracting hepatitis C were far lower than perceived risk and knowledge of HIV.

When asked about awareness-raising strategies, many witnesses referenced the impact of the Government-backed national publicity campaigns for HIV in the 1980s, particularly the ‘tombstone’ adverts, and noted that nothing similar on a national scale had ever been tried for hepatitis C. The high level of HIV awareness was partially attributed to these national campaigns and a similar campaign for hepatitis C was strongly advocated. The upcoming negotiations between NHS England and industry, which promise an increased role for industry in outreach and case-finding, offer a renewed opportunity to investigate the value and effectiveness of a high-profile, Government-backed publicity campaign.

Knowledge of new treatments within the patient community is often limited and people are often unaware that they have put themselves at risk. Some of those living with hepatitis C who are still undiagnosed may be from a cohort of people who injected drugs a long time ago, perhaps only once or just a few times, and no longer associate themselves with this community. Other groups with a high prevalence of hepatitis C, like the South Asian community, are also diffuse, less likely to already be accessing health services, and unlikely to consider themselves as ‘at risk’. It was proposed that key messages about hepatitis C could be distributed through popular non-health channels (magazines, dentists, billboards) to raise awareness within hard-to-reach communities.

The importance of an empowered patient perspective was emphasised, with many witnesses highlighting the positive effect of patients sharing their stories through traditional and social media. It was suggested that securing a high-profile celebrity backer with experience of hepatitis C for a national awareness campaign would contribute greatly to its impact.

Due to a need to develop more sophisticated ways of targeting and reaching previously undiagnosed populations, investment in bold, innovative approaches to targeted awareness-raising could bring significant benefits. Big data or tech-based approaches to improving the profile of those at risk and ensuring awareness-raising messaging reaches them would merit investigation. Data about people who are known to be living with hepatitis C could be processed to glean insights about their behavioural patterns which could improve understanding of how to find those as yet undiagnosed. Combined with known facts about risk groups, these insights could be used to target sponsored awareness-raising messaging via social media or apps.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased awareness within the general public leads to decreased stigma and greater numbers of people getting tested and treated</b></p>	<ul style="list-style-type: none"> <li>• Department of Health and Social Care to commission a pilot investigating the effectiveness of awareness-raising messaging, with the aim of building a business case for a national awareness campaign</li> <li>• A high profile, Government-backed national awareness campaign to be implemented</li> <li>• A media ‘champions’ campaign, encouraging high-profile figures with experience of hepatitis C to talk about their experience publicly, to be implemented</li> <li>• Industry to be incentivised via a long-term strategic funding agreement to invest in national awareness-raising programmes</li> <li>• All awareness-raising publicity to include key messaging conveying the short duration and ease of treatment, as well as the urgency of getting tested and treated as soon as possible</li> </ul>	<p>Department of Health and Social Care, Public Health England, NHS England, industry</p>
<p><b>Increased awareness among people living with hepatitis C who would not consider themselves to be ‘at risk’</b></p>	<ul style="list-style-type: none"> <li>• Awareness-raising publicity to be distributed in schools, airports (specifically on flights to South Asia), in dentists, magazines and on billboards</li> </ul>	<p>NHS England, Department of Health and Social Care, industry</p>
<p><b>Increased awareness within at-risk groups who may be out of touch with services through technology and social media</b></p>	<ul style="list-style-type: none"> <li>• Use of big data for improved profiling of those at risk and targeted advertising on social media and/or apps to be investigated</li> </ul>	<p>NHS England, Department of Health and Social Care, industry</p>

**Objective 1.2: Awareness of hepatitis C among primary care professionals is increased, leading to increased testing in primary care.**

While awareness of hepatitis C among health professionals has been increasing with the advent of new treatments, misinformation about risk factors, symptoms, and treatment options among GPs was still reported as common. Stigma also exists within the healthcare profession, with PWID or others with chaotic, unstable lives sometimes perceived as ‘undeserving’ of expensive treatments and not being appropriately informed of testing and treatment opportunities as a result.

There was recognition among witnesses who are clinical workers that they could do more as professionals, both through advocacy and implementation of innovative local strategies. One witness who is a clinician stated: “we need to stick our head above the parapet and say ‘we will save you a huge amount of money going forwards, give us the tools and the ability to do it’”.

Roadshows and public health meetings to continue educating health professionals are already taking place and should be continued. Opportunities for GPs to access additional information should be readily available as part of continued professional development. Information delivered to clinical and service workers should be reviewed on a regular basis to ensure accuracy in a quickly developing treatment environment. Additionally, signposting towards additional information should be embedded in the care pathway, with notification of positive test results being returned to GPs alongside clear information about specialised guidance and support.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased awareness of hepatitis C among GPs leads to increased testing of at-risk groups and more efficient care pathways</b></p>	<ul style="list-style-type: none"> <li>Targeted testing initiatives to be increased in primary care (e.g. a hepatitis C ‘testing week’ where all bloods taken are also tested for hepatitis C)</li> </ul>	<p>NHS England</p>
	<ul style="list-style-type: none"> <li>Resources on hepatitis C best practice to be produced for primary care workers, for example through health circulars</li> </ul>	<p>Chief Medical Officer, Public Health England</p>
	<ul style="list-style-type: none"> <li>All positive test results to be accompanied by information about where to refer a patient, and contact details for The Hepatitis C Trust for support</li> </ul>	<p>Public Health England</p>

**Objective 1.3: Awareness is increased and stigma is decreased within particular risk groups through targeted initiatives.**

Peer programmes were emphasised by all witnesses as a powerful tool for increasing awareness within at-risk communities. Peer interventions include talks about hepatitis C or ‘buddying’ to appointments, delivered by a former patient from a similar life background alongside their personal story, an approach which is particularly effective in prisons and substance misuse services. A witness with extensive experience delivering healthcare in prisons reported that “the credibility of the peer in the prison setting is so much more than anything a public health expert could deliver”.

In addition to contributing to improved awareness and increased testing uptake, peer programmes also serve to decrease stigma and build community support networks. Normalisation of hepatitis C through peer programmes was highlighted as particularly valuable in prisons, where witnesses reported that anything differentiating inmates from their peers is likely to contribute to social exclusion.

Another significant risk group is the South Asian community, where there is a high prevalence of hepatitis C due to the use of unsterile medical equipment in some South Asian countries. Many members of this community have extensive family links outside the UK, traveling to South Asia often and for lengthy periods of time. This group can also be more difficult to reach as they often have fewer additional support needs, making them less likely to be in touch with services.

A witness who is a leader at an Islamic Centre reported a very low awareness of health risks from unsterile medical equipment in South Asian countries. He reported that hepatitis C is not taken seriously within the South Asian community and that risk of transmission via unsafe medical practices is often ignored, with hepatitis C considered a ‘drug user’s disease’. This witness also stated that he believed stigma was less of a problem than lack of awareness in the South Asian community. In his experience, people in the South Asian community were enthusiastic about coming forward for testing once informed of risk factors.

**“I am a huge advocate of peer programmes in prisons. I say only slightly ironically that the only resource we have in prisons that’s growing is prisoners. A peer model is a very clear opportunity for prisons.”**

**Éamonn O’Moore**  
(National Lead, Health and Justice Team,  
Public Health England)

Awareness-raising specifically targeted at the South Asian community could include talks and community testing in places of worship and schools with large South Asian communities. Production of leaflets and posters translated into Urdu and other South Asian languages to reach those with a language barrier was suggested, as were radio and TV adverts or interviews on Asian media outlets. Friday prayers were noted to be a key opportunity to access large numbers of the South Asian community, with one witness reporting that between 1,000 and 1,500 people regularly attend Friday prayers at his mosque. There was significant uptake and positive feedback from an outreach screening organised by The Hepatitis C Trust in the witness’s mosque.

**“People talk to each other online and in the community about being HIV+. They don’t do that with hepatitis C. It’s a sexualised community that socialises sexually, and having hepatitis C means you are outcast from the group. It’s quite a devastating diagnosis – the stigma is much worse.”**

**David Stuart**  
(Substance Use Lead, 56 Dean Street)

Another significant risk group is men who have sex with men (MSM); the key considerations for this group are unique. It is important to note that MSM communities include out gay and bisexual men and Queer people, who may be easier to target with campaign messages, and more likely to engage well with sexual health clinics/testing services. MSM communities also include large numbers of men who may not identify as “gay, bi or Queer”, may not be fully out, or out at all; many may be from cultural or religious backgrounds that shroud homosexual sex with shame, rejection and stigma.

Active LGBTQ communities are already heavily targeted for sexual health awareness, and many access care regularly. A witness from a leading sexual health clinic in London that is well-frequented by MSM reported that it is “very rare for us to come across someone who hasn’t been to clinic in the last six months”. The approach to awareness-raising from sexual health clinics and campaigns aimed at MSM communities overall is considered highly effective, but oversaturation of campaign messaging surrounding sexual health and HIV within this group can be a challenge, with few of these campaigns explicitly including hepatitis C.

It is important to note that this expert represented a demographic that presented for sexual health screens regularly and there are many MSM who would be very reluctant to access sexual health testing for reasons associated with fear, shame and stigma. Those within this latter cohort of MSM may be difficult to reach with campaign messages and perhaps less likely to access sexual health or testing services.

Crucially, stigma surrounding hepatitis C within MSM communities was reported as significantly greater than stigma surrounding HIV. Discussion of HIV status is normalised within the community, but this is not the case with hepatitis C. Witnesses reported that hepatitis C is much more likely to result in social exclusion and “devastating” social consequences, due to the stigma being far greater.

New awareness-raising initiatives for MSM should utilise truly innovative mediums where they are likely to reach a greater proportion of those who are not already engaged with sexual health services and contribute towards decreasing stigma. Awareness-raising messaging through commonly used hook-up apps was proposed.

<b>Desired outcome supporting elimination</b>	<b>Suggested actions</b>	<b>Suggested organisational responsibility</b>
<b>Increased awareness of hepatitis C within the South Asian community</b>	<ul style="list-style-type: none"> <li>Awareness-raising messaging aimed at the South Asian community to be developed, including talks and materials delivered in Urdu and other South Asian languages, outreach in mosques, and messaging through South Asian media channels</li> </ul>	Public Health England, Islamic community organisations
<b>Increased awareness of hepatitis C among men who have sex with men</b>	<ul style="list-style-type: none"> <li>Awareness-raising messaging aimed at MSM communities to be developed, with a focus on innovative, previously untried methods such as publicity via commonly used apps</li> </ul>	Sexual health clinics
<b>Increased awareness of hepatitis C among PWID and people in prison</b>	<ul style="list-style-type: none"> <li>Awareness-raising talks delivered by peers to be commissioned as an integral part of contracts for substance misuse services and in prisons</li> </ul>	NHS and local authority commissioners, NHS England Health and Justice, substance misuse services



**Objective 1.4: Awareness of the short duration and ease of new DAA treatments is increased, dispelling reticence to test and get treated among PWID and people in prison.**

Outdated knowledge about treatments was reported as persistent within patient communities, with many still holding perceptions of treatment related to the older, interferon-based treatment. Patient witnesses emphasised that the PWID community is highly networked and susceptible to culturally transmitted misconceptions.

It was reported that there are still significant fears about the negative effects of the old interferon-based treatments, which included frequent injections and could last up to a year, resulting in cure rates of only around 50%. Historically, the treatments were perceived to be so unpalatable that many patients chose to delay treatment. These fears were replicated through informal networks and were reported as discouraging people from getting tested, with some preferring not to know their status to avoid the choice of whether to get treated.

DAA treatments which are tablet-based, last 8-12 weeks and lead to few side effects are exponentially more palatable for patients. However, knowledge of the new treatments is still relatively low, especially in communities where displacing culturally embedded negative attitudes to the old treatment regime remains a challenge.

Continued expansion of peer programmes and targeted publicity - with messaging deliberately comparing the ease and short duration of new treatments to the old treatments - would contribute to these efforts.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased awareness of the ease and short duration of new DAA treatments among prisoners</b></p>	<ul style="list-style-type: none"> <li>Nationally-approved NHS England Health and Justice publicity highlighting the ease of new treatments to be rolled out across HM prison estate</li> <li>Peer programmes to be commissioned as an integral part of hepatitis C treatment services in commissioning contracts in prisons</li> </ul>	<p>NHS England Health and Justice</p>
<p><b>Increased awareness of the ease and short duration of new DAA treatments among PWID</b></p>	<ul style="list-style-type: none"> <li>Nationally-approved publicity highlighting the ease of new treatments to be rolled out across substance misuse services</li> <li>Hepatitis C peer programmes to be commissioned as an integral part of commissioning contracts for substance misuse services</li> </ul>	<p>Local authority commissioners</p>

# Prevention

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## Current situation

To achieve elimination of hepatitis C, we must ensure that numbers of new infections are falling, so that increased testing and treatment initiatives lead to a decline in overall prevalence. Effective education about transmission risks is crucial to achieving this, especially for PWID and MSM, among whom rates of reinfection are high. In addition to education about transmission risks, needle and syringe programmes (NSP) and opioid substitution therapy (OST) are key to preventing transmission<sup>21</sup>. The effectiveness of these interventions is dependent on their coverage, which is currently insufficient or under threat.

Harm reduction was recognised as a key function of substance misuse services, one which many services are being forced to deprioritise due to lack of resources. Similarly, educating clients about the dangers of reinfection is an important aim of sexual health clinics. Throughout our inquiry, experts repeatedly expressed significant concern about national funding cuts to substance misuse services and sexual health clinics and their impact on prevention efforts for hepatitis C and other BBVs. The funding pressures faced by these services and their critical role in prevention and harm reduction form a worrying backdrop to the interventions discussed below.

## **Objective 2.1: Sufficient injecting equipment and opioid substitution therapy is available to all PWID to support prevention and harm reduction efforts.**

The WHO European Region action plan for hepatitis contains the interim 2020 target of at least 200 sterile injection equipment kits distributed per person per year for PWID, as part of a comprehensive package of harm reduction services<sup>22</sup>. The UK is a party to the action plan, but there is currently no data regarding injection kit provision which is directly comparable to this target.

According to Public Health England, the level of needle and syringe provision is considered ‘adequate’ when the reported number of needles and syringes received met or exceeded the number of times an individual injected. In 2016, only around half (46%) of PWID who injected during the preceding 28 days reported adequate needle/syringe provision<sup>23</sup>. This was significantly worse than in Scotland, where 72% of PWID injecting in the last 6 months reported adequate provision<sup>24</sup>. It seems clear from these data that the current level of needle and syringe provision is not sufficient for maximum prevention of hepatitis C and other BBVs.

Other injecting paraphernalia also present a significant risk of transmission. Evidence from laboratory studies which tested used paraphernalia from injecting drug users found hepatitis C consistently present on swabs, filters, spoons, and in water samples<sup>25</sup>. Sharing of other paraphernalia is also more common due to the misconception of lower or no risk – while 17% of PWID reported sharing of needles and syringes in 2016, this number rose to 39% when including sharing of mixing containers and filters<sup>26</sup>. NICE guidance states that other injecting equipment should be available as part of NSP<sup>27</sup>, but witnesses reported that due to budget pressures, NSP provision is being reduced in many areas. This included both narrower choice of equipment for service users and fewer venues where equipment is accessible.

Another practical prevention method is supporting PWID to transition to opioid substitution therapy (OST), which eliminates transmissions via injection, alongside the social benefits of a sustainable transition away from injecting drug use. Witnesses reported that lack of resource is preventing drug services from encouraging and supporting patients into OST. Service workers discussed the challenges in meeting targets while coping with severe budget cuts, reporting pressure to get people through treatment quickly and an emphasis on abstinence recovery, with a declining cultural regard for long-term OST.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Fewer transmissions of hepatitis C among PWID due to adequate NSP provision and access to OST	<ul style="list-style-type: none"> <li>Public Health England to establish a target for an increase of PWID reporting adequate provision, in line with the WHO 2020 target for NSP</li> <li>Public Health England to monitor and report on this target in its annual 'Shooting Up' report</li> <li>Needles, syringes, and other injecting equipment to be widely available in drug services and sexual health services, particularly in areas identified as having growing infection incidence</li> <li>Funding for NSP and OST in substance misuse services to be protected</li> </ul>	Public Health England, local authorities

**Objective 2.2: Knowledge about prevention is increased in prisons, substance misuse services, and sexual health clinics.**

In addition to the barriers to awareness of hepatitis C discussed in the previous section, lack of in-depth knowledge among service users and staff about transmission risks create additional barriers to prevention. Awareness of transmission risks among PWID is often limited to an understanding that sharing needles can lead to infection, with many not being aware that sharing other injecting equipment like syringes, filters, water, and spoons also presents a risk.

Misconceptions about transmission risks were reported as common even within communities where overall awareness of hepatitis C was higher than average. There was frequent confusion of transmission risks between HIV and hepatitis C. Fears of sexual transmission, mother-to-child transmission, and transmission from breastfeeding, all of which present a very low risk of hepatitis C transmission, were often exaggerated due to confusion with HIV.

Peer programmes are a highly effective way of delivering accurate knowledge about transmission risks within prisons and drug services. It is also crucial to ensure that workers in prisons and community services are confident in their knowledge of transmission risks and enthusiastic about communicating these to service users.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Prison staff are an effective source of information for prisoners on harm reduction and prevention	<ul style="list-style-type: none"> <li>BBV training to be made compulsory for prison staff</li> </ul>	NHS England Health & Justice, Her Majesty's Prison and Probation Service
Fewer new infections as a result of improved knowledge of transmission risks	<ul style="list-style-type: none"> <li>Peer programmes to be commissioned as an integral part of hepatitis C treatment services in commissioning contracts for substance misuse services and in prisons</li> </ul>	NHS England Health and Justice

**Objective 2.3: All those diagnosed are educated about transmission risks, leading to reduced reinfection rates.**

Reinfection within key risk groups, particularly PWID and MSM, remains a serious challenge to elimination. Improved educational interventions surrounding the risks of reinfection should be seen as key to reducing infection rates.

A 2016 study of MSM who were diagnosed with hepatitis C and cleared the virus found that 25% were subsequently reinfected within two years<sup>28</sup>. A witness from a sexual health clinic reported that within the last decade there has been a concerted shift within sexual health clinics to create teams of health advisors who are trained to discuss behavioural change with those who are diagnosed, ensuring that they can have a positive sex life without getting reinfected. The steadily declining rate of new HIV diagnoses in sexual health clinics has been partly credited to effective behavioural interventions to prevent infection.

However, education about the risks of reinfection surrounding hepatitis C was said to be a particular challenge due to the varied and unique infection risks within the MSM community, described by one witness as a “sexualised community that lives online”. Chemsex – the use of recreational drugs in a sexual context, often in a party environment – presents multiple transmission risks via drug paraphernalia, household paraphernalia, sex toys/equipment, and sexual contact<sup>29</sup>. Even if individuals present to staff at sexual health clinics and are interested in effective prevention tactics, staff may find it difficult to caution people about every potential risk. A witness said it would be “impossible for any clinician to dispense that information in one session”, instead emphasising the need for continued community dialogue around reinfection and re-testing.

**“Every member of frontline staff who will have contact with hepatitis C infected patients should have training on how to have conversations about behavioural change to prevent reinfection. Otherwise you have the same population presenting again and again.”**

**David Stuart**  
(Substance Use Lead, 56 Dean Street)

Studies of reinfection rates among PWID who continue injecting or relapse following treatment have returned varied results with differing methodologies, but reinfection rates of between 2.5% and 25% have been reported<sup>30</sup>. Reinfection rates among PWID were found to be significantly higher in areas where there was a high prevalence of hepatitis C among the local PWID population, supporting the value of a ‘treatment as prevention’ approach<sup>31</sup>.

Witnesses emphasised that every specialist, GP, and service worker who delivers testing and treatment should have the appropriate knowledge and skills to discuss the risks of reinfection with a patient and make them aware of support services to sustain behavioural change. It was suggested that monitoring of reinfection rates and targets for lowering reinfection should be included in service specifications for substance misuse and sexual health services. It was also suggested that a discussion of reinfection risks should be part of the standard protocol of a final clinical appointment where a patient receives confirmation of a cure result.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Fewer reinfections due to improved knowledge of transmission risks	<ul style="list-style-type: none"> <li>Peer programmes delivering messaging about prevention to be expanded and included as an integral part of hepatitis C care in commissioning contracts for drug and alcohol and sexual health services</li> <li>Drug and alcohol and sexual health service workers to be trained to deliver behavioural intervention messages to prevent reinfection</li> <li>Commissioning guidance to be developed to ensure local authority commissioners understand the importance of hepatitis C prevention</li> </ul>	<p>Local authority commissioners</p> <p>Local Government Association, Public Health England</p>

**Objective 2.4: New, innovative approaches to prevention lead to a decline in hepatitis C transmissions.**

A ‘treatment as prevention’ approach was mentioned by many witnesses, and offers a bold new framework for prevention efforts. Such an approach would seek to treat large numbers of actively injecting drug users and others currently engaged in the riskiest behaviours in an attempt to prevent as many onward transmissions of the virus as possible. This approach was cited as desirable, but few examples of deliberate, active outreach to treating PWID were cited in practice. Historically, financial CQUIN targets mandating follow-up and data collection on reinfection also disincentivised treatment of actively injecting PWID with chaotic lives, though this CQUIN is no longer mandatory.

A pilot project of a ‘treatment as prevention’ approach is currently taking place at NHS Tayside in Scotland, with the health board attempting to dramatically decrease the number of actively injecting drug users living with hepatitis C. NHS Tayside has as its goal a reduction of hepatitis C in the PWID population from over 30% to below 10%. Their models indicate this would result in a corresponding decline in transmission from 10% to below 1%, leading to effective elimination of the virus. NHS Tayside estimates this can be achieved within 2-3 years.

This approach also makes use of cash or voucher incentives for patients to bring other PWID in their immediate network to get tested and treated, with a goal of eliminating hepatitis C within clusters of people who are likely to transmit to each other. Fewer transmissions would also result in medium-term cost savings, which can be reinvested into additional case-finding.

A ‘treatment as prevention’ approach would also lead to increased emphasis on innovative testing practices in settings where high populations of PWID and potential transmissions present themselves. For instance, witnesses suggested that randomised or universal testing for people in police custody may be an opportunity to access a population at high risk of transmission.

Bold prevention measures like drug consumption rooms would provide an opportunity to significantly reduce hepatitis C transmissions for their users. While such measures are controversial and unlikely to be introduced imminently, it is crucial that we display bold ambition in considering the full range of options for harm reduction within marginalised populations.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Lower transmission rates among PWID due to increased targeting of testing and treatment at actively injecting PWID</b></p>	<ul style="list-style-type: none"> <li>A ‘treatment as prevention’ approach to be upscaled, targeting actively injecting drug users for treatment to prevent onward transmission</li> <li>NSP providers to be commissioned to engage, test, and treat PWID</li> </ul>	<p>NHS England, Operational Delivery Networks, local authority commissioners</p>
<p><b>Safer injecting practices due to harm reduction initiatives in the community</b></p>	<ul style="list-style-type: none"> <li>More radical methods of prevention like drug consumption rooms to be explored</li> </ul>	<p>Department of Health and Social Care</p>

# Testing and Diagnosis

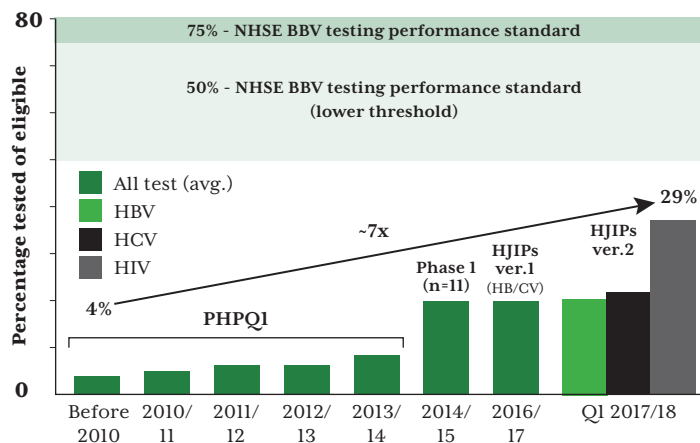
## Current situation

If England is to eliminate hepatitis C by 2030 or earlier, significantly increased numbers of people will need to be tested and diagnosed. Increasing new diagnoses will become more challenging in the coming years, as most historically infected patients who were aware of their status and in contact with services have now been treated. The challenge is quickly becoming finding those previously undiagnosed, as well as re-engaging those previously diagnosed who have never been treated.

Testing in prisons, substance misuse services, and sexual health clinics will need to become routine, and more ambitious targets for testing uptake should be set. Increased outreach and testing in other community settings with potentially higher concentrations of at-risk groups will be required, alongside greater strategic co-ordination of testing practices and upscaling of best practice.

### Objective 3.1: All those at risk who engage with local services are offered a hepatitis C test.

#### Average blood-borne virus (BBV) testing rates in the English prison estate by financial year.



Average blood-borne virus (BBV) testing rates in the English prison estate by financial year. PHPQI: Public health prison quality indicators; HJIPs: Health and justice indicators of performance (HJIPs ver. 1: before data quality improvement).

Source: Public Health England and NHS England

Prisons, substance misuse services, and sexual health services have traditionally been the key settings to offer hepatitis C testing to high concentrations of at-risk populations. People in touch with these services are highly likely to have put themselves at risk for transmission, and the aim in these settings should be universal testing and regular re-testing of all service users. There are unique challenges and missed opportunities in each of these settings.

The intention to introduce universal opt-out testing for BBVs in prisons was first announced in 2013, and full implementation began in April 2017. Despite this welcome development, uptake of testing and treatment in prisons is still highly varied. Some prisons, like HMP Wandsworth, are regularly achieving testing rates approaching 80% of new receptions, while in others barely 10% of new receptions are being tested for hepatitis C.

Good partnership work between Public Health England, NHS England Health & Justice, HM Prisons and Probation

Service and the Ministry of Justice was reported, and a high level of engagement with hepatitis C issues from ministers with responsibility for prison health was noted. However, due to variation in practice as well as funding and staff pressures, a large amount of responsibility for effectively delivering hepatitis C care in prisons continues to rest on the shoulders of prison governors, with uptake of testing and treatment often correlated with governors' personal commitment. Prison health staff are not routinely trained on BBVs, often relying on prison in-reach teams to deliver hepatitis C care. Although there is a large range of guidance on delivering opt-out testing in prisons, we would recommend more explicit guidance on the wording used, with studies showing a large variation in uptake depending on how the test is offered.

Currently, NICE guidance on the physical health of people in prison recommends screening for BBVs in first reception, as this is an important time to understand the urgent and immediate health needs of people newly entering prison. Public Health England has suggested that second reception (48-72 hours after reception into prison) may be a more appropriate time to deliver BBV testing, due to first reception being a stressful and difficult time where key messages may be lost. Some prisons are

pursuing this approach; in some cases, a test is offered in first reception, with an intention to deliver the test in second reception. However, staffing and funding challenges sometimes prevent new inmates from accessing second reception screening.

The need to re-offer testing to prisoners who may have refused a test or been infected in prison was mentioned, and though this is part of the official approach of the opt-out testing programme, there was a recognition that pressure on resources sometimes prevents tests from being re-offered.

Staffing and funding cuts present a significant challenge to delivering hepatitis C testing in local authority commissioned services like sexual health clinics and substance misuse services. Substance misuse services are commissioned by local authorities from within their public health grants, which are being cut to varying degrees across the country. The inquiry heard reports of budgets being cut mid-contract, further squeezing all but core drug treatment services. Significant funding pressures have a clear negative impact on testing rates, referrals into treatment, and staff training and development.

Even within local authorities where funding for delivery of testing is protected, funding for specialist BBV nurses is often lost, meaning BBV testing is no longer delivered with the same level of expertise in local services. As a result, hepatitis C testing is becoming incorporated as one part of the job of general service workers, who may lack specialised skills catering to the unique clinical needs of target populations (for instance, injecting drug users whose veins may be difficult to access for blood samples).

**“[MSM in the chemsex community] might be the highest risk cohort for hepatitis C in the developed world. They want to come and get tested, and we’re having to refuse them care.”**

**David Stuart**

*(Substance Use Lead, 56 Dean Street)*

uniquely engaged with frequent testing at clinics where they feel supported. Since these clinic closures, there has been overcrowding in the remaining clinics, creating a lack of places for those high-risk users to whom regular testing is key.

Broader funding and workforce issues were also a significant challenge for sexual health services, with witnesses highlighting that six sexual health clinics had closed in London over the months preceding the inquiry. It was said that there was a Government expectation that the effect of the closures should be mitigated by encouraging at-home testing kits as a cost-saving measure. However, witnesses emphasised that people in MSM communities who are engaging in high risk activities like chemsex parties are currently a population recently updated clinical guidelines recommend that all PWID accessing treatment services are tested for hepatitis C at first assessment, and that repeat testing should be considered when the risk of exposure continues. When the risk of exposure is assessed as high, testing should be carried out up to twice a year<sup>29</sup>. However, Public Health England reports that frequency of testing is currently inadequate. In England, the National Drug Treatment Monitoring System (NDTMS) found that among those who have ever injected drugs and who are in treatment for their drug use, the proportion who had been offered and accepted a hepatitis C test was 65% in 2016<sup>33</sup>. The proportion of PWID offered a test at the beginning of their most recent treatment period was high at 96%, but uptake much lower with 67% accepting the offer of testing<sup>34</sup>. Levels of repeat testing were considered to be significantly sub-optimal, with 44% of those previously tested but currently unaware of their status reporting that their last test was more than two years ago<sup>35</sup>.

Witnesses to our inquiry reported that in many services only people who identified themselves as a current or former injecting drug user were offered a test (as opposed to those who may be in the services for alcohol or other substance misuse), supported by the fact that data referenced above on testing offers in substance misuse services is collected only for those identified as ‘at risk’ based on their injecting drug use. Witnesses stated that this continued to perpetuate stigma within services, contributing to lower levels of test uptake, and suggested that a universal offer of testing to all service users would be more appropriate.

Multiple experts suggested the introduction of universal opt-out testing in substance misuse services, with monitoring systems and targets for test offers and uptake put in place as part of commissioning contracts. One witness cited an initiative within Addaction Cornwall where each staff member was given a target to test 10 people in a month, which produced an extremely high testing rate within the service. Another example was given of a commissioning contract in London where 95% of the budget was given to the provider for core services and each additional percentage point was tied to various outcomes. One of

**“I walk into many drug services around the country and it’s chaos. They’re being asked to do so much with so little resource. I’m not sure how many of them can even feasibly have it on their priority list to discuss hepatitis C with clients.”**

**Stuart Smith**

*(Head of Drug Services, The Hepatitis C Trust)*

these targets was to test all PWID for BBVs, similarly producing exceptionally high testing rates.

<b>Desired outcome supporting elimination</b>	<b>Suggested actions</b>	<b>Suggested organisational responsibility</b>
<p><b>Increased coverage and uptake of testing in substance misuse services</b></p>	<ul style="list-style-type: none"> <li>• Opt-out testing for hepatitis C to be commissioned by local authorities in substance misuse services</li> <li>• Re-offer of testing to all those engaged with substance misuse services every six months to be mandated and commissioned</li> </ul>	<p>Local authority commissioners</p>
<p><b>Increased coverage and uptake of testing in prisons</b></p>	<ul style="list-style-type: none"> <li>• Testing to be re-offered in prisons to those who did not receive a test at reception</li> <li>• Opportunities to be provided for those who previously tested to re-test in prison</li> <li>• Clear national protocol to be developed surrounding wording of opt-out test offer in prisons</li> <li>• Commissioners to support access for prisoners to second reception screening</li> <li>• Research to be conducted on transmission risk within prisons to determine impact of re-testing</li> </ul>	<p>NHS England Health and Justice</p> <p>National Institute for Health Research</p>
<p><b>Increased coverage and uptake of testing in sexual health services</b></p>	<ul style="list-style-type: none"> <li>• Funding for hepatitis C testing in sexual health services to be guaranteed protection</li> </ul>	<p>Local authorities</p>



### **Objective 3.2: Outreach and testing in the community is increased to find and diagnose people living with hepatitis C who are not in touch with services.**

There are clear missed opportunities for testing to be carried out in additional locations with high concentrations of at-risk groups. It was the view of every witness to the inquiry that delivery of testing in additional community settings outside of primary care or drug services - like pharmacies, hostels, daycentres, police custody, mosques and street outreach - would be crucial to ensuring all those living with hepatitis C are tested and treated.

Dry blood spot testing (DBS) - requiring only a very small amount of blood taken from a pinprick which is then blotted onto a test paper - is simple and can be delivered in any setting. Non-clinical workers can easily be trained to deliver this type of testing. As contrasted to blood samples taken by venepuncture, which must be taken by specialists, this approach has been shown to significantly increase testing coverage and increase the numbers of individuals coming forward for testing.

NSP in pharmacies or drug services present an opportunity to test PWID who are already attending to pick up injecting equipment or methadone prescriptions. Although most patients on a methadone prescription are likely to have already had a BBV test as part of their engagement with a drug service, those making use of NSP may not be engaged with a service, with NSP sites being a unique opportunity to offer a test to this cohort. Importantly, co-location of testing and treatment in pharmacies and other community settings creates seamless care pathways with significant positive benefits, discussed further in the 'Treatment' section below.

Targeted opt-out testing of routine blood samples in A&E departments was also mentioned as an innovative way to test large sections of the population. A ground-breaking 2015 campaign called 'Going Viral' offered routine testing in nine UK emergency departments for one week. Of 7,800 patients who had bloods taken across the emergency departments, 2,118 people were tested, an uptake of 27%. Of those tested, 3% were infected with hepatitis C, with 71 infections found over the course of the week<sup>36</sup>.

A portion of these would be people who previously tested positive, but this was still seen as an effective way to re-engage people who may have been lost to follow-up, in addition to finding new infections. The breakdown between these groups is demonstrated in a 2018 study of 5,383 samples from four busy A&E departments, which found a 1.69% overall prevalence of hepatitis C, and a 0.8% prevalence of previously undiagnosed hepatitis C cases<sup>37</sup>. These prevalence rates are substantially higher than general population estimates, and the study concluded that targeted A&E initiatives could provide a valuable contribution to increasing diagnosis rates.

Suggestions were made to co-locate testing for HIV and hepatitis C more frequently. HIV and hepatitis C have similar transmission routes, but HIV receives significantly more public attention. Hepatitis C testing should be offered routinely alongside HIV, and outreach services like mobile testing vans or street teams should offer testing for both. Targeted mail-outs of at-home testing kits was also proposed, and the take-up and cost-effectiveness of such a programme should be investigated. Incentives (including cash and vouchers) for at-risk individuals self-presenting for testing, and for bringing others from their networks to test, was cited as a desirable intervention with potential for significant impact. A 2014 literature review of studies investigating the impact of incentives on HIV/STI testing uptake found that incentives increased uptake of testing in all cases; this was particularly effective in non-clinical settings, where levels of uptake were between 18 and 43% greater for the incentivised group than the non-incentivised group<sup>38</sup>.

In order to ensure the best possible allocation of resources to new testing initiatives, Public Health England should conduct research to create a robust evidence base for targeted or universal testing in these settings. The relationship of cost-effectiveness of testing initiatives to prevalence rates should also be investigated. For example, a 2017 study determined that universal testing for HIV at GP surgeries was proven to be cost-effective in 'high-prevalence' areas with a prevalence of over 0.2%. Similar research could be undertaken for hepatitis C and used as a business case for new testing initiatives<sup>39</sup>.

<b>Desired outcome supporting elimination</b>	<b>Suggested actions</b>	<b>Suggested organisational responsibility</b>
<p><b>Increased numbers of people are tested in the community in non-traditional settings</b></p>	<ul style="list-style-type: none"> <li>• Opt-out testing in A&amp;E when bloods are taken to be introduced</li> <li>• Testing in police custody to be introduced</li> <li>• Every ODN to appoint a clinical staff member whose primary role is to work in the community rather than in a clinical setting</li> <li>• Testing to be introduced in as many community settings as possible, including pharmacies, homeless hostels, daycentres, and through street outreach teams, in addition to sexual health clinics and substance misuse services</li> <li>• Collaboration to be increased in community testing initiatives between BBVs, for instance mobile units testing for both HIV and HCV</li> </ul>	<p>ODNs, local authorities, local authority commissioners</p>
<p><b>Improved effectiveness of targeted testing initiatives in reaching greater proportions of those at risk</b></p>	<ul style="list-style-type: none"> <li>• Research and evidence synthesis to be conducted to determine effectiveness of testing initiatives in the settings suggested above, and to determine prevalence rate in a given population at which testing becomes cost-effective</li> </ul>	<p>Public Health England</p>

**Objective 3.3: Testing is widely available and supported in primary care.**

While primary care is considered a key setting for diagnosis and referral to specialised care, understanding of hepatitis C among GPs can often be low (as discussed in the ‘Awareness’ section). The inquiry heard multiple witnesses express that it was not unusual for patients who requested a hepatitis C test from a GP to be refused, based on the patient not having disclosed an obvious risk factor, or due to the GP being unaware of risk factors, symptoms or availability of treatment.

While universal screening of all blood samples taken in primary care was seen to be desirable, it was acknowledged as unlikely to be realistic in the current healthcare funding environment. Likewise, while awareness-raising and education initiatives for GPs were felt to be important interventions, severe time pressures and competing priorities faced by primary care workers were also acknowledged.

One suggested method of increasing testing through primary care and simultaneously improving awareness among GPs was an annual hepatitis C testing week in primary care, where all blood samples taken in a week are screened. This random screen would serve the purpose of data collection and prevalence monitoring, lead to diagnosis of a limited number of new infections, and increase knowledge of hepatitis C among GPs, supporting increased testing during the remainder of the year.

**“I’ve often heard GPs say ‘oh it doesn’t matter, you can’t have hep C’ or ‘it’s not treatable’.”**

**Dr Ahmed Elsharkawy**  
*(Consultant Hepatologist, University Hospitals Birmingham NHS Foundation Trust and Chair, British Viral Hepatitis Group)*

Previous pilots have shown that screening of new registrants is effective in some cases, particularly for new registrants who have recently moved to the UK from high-prevalence countries. This evidence should be put into practice, and further trials conducted to continue reviewing the effectiveness of targeted screening for new registrants at GP practices.

Data-based initiatives to improve targeted testing in primary care, such as automatic flagging of patient records with known risk factors, have previously been suggested and piloted. There is disagreement about whether these are effective, with some trials showing that pressures on GPs are so varied and numerous that these flags are not normally followed up. An academic and clinical consensus about an approach to flagging risk factors within primary care should be pursued.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased numbers of people are diagnosed through primary care</b></p>	<ul style="list-style-type: none"> <li>• An annual universal testing week to be introduced in GP practices</li> <li>• New registrants at GP practices who have recently moved from high prevalence countries to be automatically screened for hepatitis C, in line with the latest evidence</li> <li>• Evidence to be reviewed on automatic flagging of patients with risk factors in GP databases and a national approach to be standardised</li> </ul>	<p>NHS England</p>

**Objective 3.4: Increased numbers of people are tested due to standardisation of testing practices across the country.**

During our inquiry, witnesses described numerous examples of good practice where testing was being significantly scaled up in individual services or areas. However, these were often ad-hoc and reliant on champions in a certain service, with care pathways being disrupted and testing levels dropping again when this individual left their post. There is a clear need for standardisation and prioritisation of hepatitis C care across commissioning contracts for local authorities to reduce the level of variation and burden on individual staff members. Still, given that hepatitis C testing is currently not routinely included in commissioning contracts, and service-level targets are usually voluntary, inspiring enthusiasm in individual service workers and creating ‘champions’ for delivering testing and treatment were also seen as important.

Another barrier to testing resulting from lack of standardisation was discrepancy in the type of test conducted. In some cases, only an antibody test is conducted on an initial sample, which determines only if someone has been previously exposed to hepatitis C antibodies, requiring a further test to determine if they are chronically infected. This second test is not always followed through, and creates an unnecessary risk of disengagement from the care pathway.

Witnesses told us that this was often due to their tender process being guided overwhelmingly by cost, and the overall cost of laboratory testing being cheaper if the two tests are put to tender separately. This results in profound inefficiencies, as it does not take into account the cost of resource involved to take another sample, or the public health costs of patients potentially dropping out of the care pathway between the two tests.

Public Health England recommends that all hepatitis C tests should be reflex tested, meaning that an antibody positive result always triggers the appropriate follow-up test on the same sample. DBS testing allows for both these tests to be performed on a single sample, in addition to allowing for increased simplicity and testing in the community as discussed above. DBS testing should be the testing method encouraged in all services for maximum effectiveness and simplicity.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Opt-out dry-blood spot testing for hepatitis C is fully implemented in substance misuse services and prisons</b></p>	<ul style="list-style-type: none"> <li>• Commissioning contracts for substance misuse services and prisons to have clear mechanisms to hold services to account for failures to meet testing targets</li> <li>• Unnecessary tests and appointments to be reduced, and the use of reflex-tested dry blood spot samples, which necessitate only one sample and can be delivered in the community, to be mainstreamed</li> </ul>	<p>NHS England Health and Justice, Local authority commissioners</p>

# Linkage to care

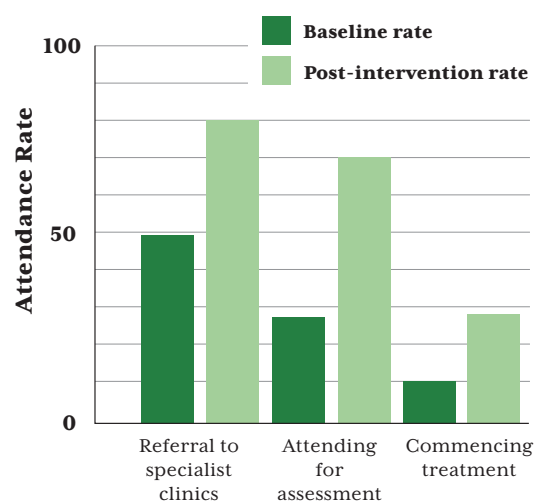
## Current situation

The time between diagnosis and beginning treatment poses the greatest risk of patients dropping out of the care pathway if they are not quickly referred and initiated onto treatment. Decreasing the time between diagnosis and treatment and ensuring patients are effectively supported through the referral process is key to translating every diagnosis into a cure, thus also preventing onward transmission.

Drop-out rates along the referral pathway are high. A 2005 study found that only 64.3% of patients diagnosed in primary care, 18.4% of those diagnosed in prison, 42.4% of those diagnosed in drug and alcohol services, and 62.6% of those diagnosed in secondary care were referred to appropriate specialist care. Overall, less than 50% of newly diagnosed patients were referred to an appropriate clinic<sup>40</sup>.

A similar study in 2015 found that the baseline study group had a rate of referral to specialist clinics of 49%, with only 27% attending for assessment and 10% commencing treatment. Following an evidence-based redesign of care pathways for the study population, these numbers were increased to 80% appropriately referred, 70% attending, and 28% commencing treatment, showing that a high drop-out rate is not inevitable and that linkage to care can be enhanced<sup>41</sup>.

Referral attrition rate



## Objective 4.1: Time between diagnosis and initiation of treatment is decreased.

Referral pathways remain overly complicated in some areas, with some specialist clinicians accepting referrals for hepatitis C exclusively from primary care, and not from community services, creating the necessity for an additional appointment and referral for those first tested in the community. It is crucial that referrals into secondary care are accepted from any service where someone might receive a test and diagnosis. One witness felt strongly that even in areas where staff in community services are told they cannot refer patients directly and must direct patients to a GP, this should be challenged on a case-by-case basis.

A witness from substance misuse service Addaction said that she felt a key strength of their service was its strong referral pathways, offering an immediate referral to anyone who is diagnosed, and ensuring patients are supported in arranging and attending clinical appointments. However, she was aware this was certainly not the case in all services, particularly where someone is first diagnosed in a non-traditional setting. Delays in referral to treatment cause a particular problem for PWID, who may have chaotic lives.

**“When you diagnose someone, if you don’t have the treatment with you – by the time you discuss at MDT, get your local treatment slot, and go back to the person, they won’t be where they were before. They might be in the next county or in prison.”**

Several witnesses expressed the view that in areas where patients cannot access treatment immediately, testing initiatives lose value due to the high likelihood of disengagement during the waiting period. Especially when patients are diagnosed in substance misuse services and may have chaotic lives, the risk of patients not returning for follow-up appointments increases significantly. This may also lead to a decreased likelihood of treatment in future if they move areas.

### Helen Hampton

(National Lead for Blood Borne Viruses, Addaction)

While in many ODN areas the waiting lists for treatment due to run rates have

been eliminated and people can now access treatment immediately, there remain some ODN areas, primarily in London, where those with less advanced liver damage are placed on waiting lists for treatment. This was highlighted as a situation damaging to effective care and leading to patients dropping out of contact with services.

Eliminating unnecessary appointments or bureaucracy to decrease the time between diagnosis and treatment to a minimum was considered crucial. Excess appointments often resulted from the perceived need to collect additional samples or conduct Fibroscan tests to determine a patient's current level of liver damage. The need for additional samples should be eliminated by ensuring all samples are reflex tested, with an automatic PCR analysis initiated for every antibody-positive sample. With the advent of DAA treatments which cure over 95% of people, particularly when access to treatment is universal, some argue that it is clinically unnecessary to conduct a Fibroscan prior to treatment, and that anyone who is chronically infected should be initiated onto treatment immediately. There is currently a lack of consensus on this point, and it would be beneficial to develop a clear clinical position to standardise practice and eliminate additional Fibroscan appointments where appropriate.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Simplified referral pathways lead to lower rates of drop-out from the care pathway</b></p>	<ul style="list-style-type: none"> <li>• Direct referrals into secondary care to be accepted from all services, not just from primary care</li> <li>• Simplified referral pathways to be agreed, eliminating unnecessary appointments prior to treatment</li> <li>• DBS and reflex tests to be carried out in the first instance, eliminating the need for additional samples</li> </ul>	<p>Operational Delivery Networks</p>

**Objective 4.2: Linkage to care is improved due to effective data-sharing.**

Lack of effective data-sharing between prisons and community care can lead to a breakdown in the care pathway. Historically, when interferon injections lasting 48 weeks were the primary treatment for hepatitis C, this posed a particular challenge to hepatitis C treatment in prisons. With the average length of stay in prison being much shorter than 48 weeks, many of those diagnosed in prison were not initiated onto treatment, and were subsequently lost to follow-up upon release.

The 8-12 week duration of new DAA treatments now allows most prisoners to begin and complete treatment within their sentence. However, length of stay in prison can be as short as 3-6 weeks in some cases, and lack of linkage between prison healthcare and community services can still cause a disengagement from care in these cases. Public Health England is currently investigating possibilities for a new informatics system which would ensure that primary care providers can receive information about prisoners' health histories.

Many GPs and services, as well as Public Health England, hold data about patients who have previously been diagnosed but refused treatment under the old treatment regime, or have fallen out of the care pathway. These patients should be re-contacted and offered treatment, an approach which is being piloted in some hospitals. A further step could be for GPs to survey their records for any patients with a known risk factor, and contact them to invite them for a test.

It was reported that in some areas, primary care providers have encountered difficulty in using historical patient data for this purpose due to concerns about patient consent from Caldicott Guardians responsible for oversight of service-user information. A standardised approach allowing for the use of patient data in hepatitis C look-back initiatives should be developed. It should be considered that the use of patient data for this purpose would constitute a potentially life-saving intervention with significant public health benefits.

The inquiry also heard that approaches to notification of positive test results varied, with only the service that conducted the test receiving notification of results in some areas, while in others the ODN also received notification. Notification of test results at ODN level should be standardised, to allow ODNs to contact patients directly in the event of an appropriate referral not being made at the point of diagnosis.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Data about an individual's hepatitis C status and testing history is accessible to all health services</b></p>	<ul style="list-style-type: none"> <li>NHSE national treatment database to be further developed to include all patients diagnosed</li> <li>Better informatics systems to be developed to ensure primary care providers can receive information about former prisoners' hepatitis C status</li> <li>ODNs to be notified of all positive results, allowing them to centrally contact and refer patients if a referral is not made at point of diagnosis is not made at point of diagnosis</li> </ul>	<p>NHS Digital and Public Health England</p> <p>ODNs, laboratories</p>
<p><b>Those previously diagnosed but lost to follow-up are re-engaged into treatment</b></p>	<ul style="list-style-type: none"> <li>Public Health England to provide data to support the NHS in re-contacting people who were previously diagnosed but lost to follow-up</li> <li>Where appropriate, GPs and local services to conduct additional lookback exercises of patient records to re-engage those lost to follow-up</li> <li>National guidance to be developed regarding the use of patient data for this purpose</li> </ul>	<p>NHS England, NHS Digital</p>

**Objective 4.3: Innovative peer programmes encouraging attendance at clinical appointments are supported and expanded.**

The numerous benefits of peer programmes to hepatitis C care have already been discussed, but peer “buddying” programmes are a particularly key resource to combat exceptionally high DNA (did not attend) rates for PWID at clinical appointments. An innovative peer programme delivered by The Hepatitis C Trust arranges for a standing open slot at clinics for peers to attend with new patients – meaning no admissions, letters, or referrals. When tests are carried out immediately after a peer talk or peers meet someone who is aware of their positive status, the peer accompanies the new patient to the clinic slot as early as the following week. A peer initiative with this approach called Follow Me, currently running in Camden, has initiated multiple patients onto treatment as early as 10 days after their initial test.

While the lives of those living with hepatitis C can be chaotic, witnesses noted that homeless hostels or substance misuse services can be one of few sources of stability for these populations, providing an opportunity for intervention. The importance of homelessness and health workers aligning their interventions and ensuring that healthcare for the homeless is delivered alongside efforts to stabilise their circumstances was emphasised. The potential of hepatitis C treatment to lead to other positive behavioural change due to increased overall health, confidence, and a sense of social investment was repeatedly mentioned, though the need for additional research to establish these causal links will be discussed later.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
More PWID linked into care through peer support of more chaotic patients to attend appointments and complete treatment	Peer programmes to be commissioned as an integral part of hepatitis C care in commissioning contracts for substance misuse services and homelessness services	Local authorities



# Treatment

## Current situation

In 2016/17, 9,440 patients were treated in England, slightly below the NHS England target of 10,000 new treatment initiations<sup>42</sup>. This target has been increased to 12,500 for 2017/18<sup>43</sup>. This target is currently effectively enforced as a maximum cap on treatment through the CQUIN system, which has penalised ODNs financially if they exceed their 'run rate'.

The unprecedented introduction of run rates linked to CQUIN payments, despite the availability of curative treatments approved as cost-effective, was characterised by witnesses at our evidence sessions as a “crude way to manage spend on hepatitis C because of fears about the budget impact of new medicines”. This system has been widely criticised for creating waiting lists for treatment, disincentivising new diagnoses, and being poorly aligned to regional prevalence and existing services (the run rates were allocated based on estimated prevalence from 2011 or earlier, and with no correlation to existing resources within the area).

Since the establishment of ODNs in 2015, many have worked through their waiting lists, and most outside of London will soon be approaching universal access to treatment, with the need to find the undiagnosed quickly becoming the greatest challenge. With NHS England's recent announcement of upcoming negotiations with industry towards a long-term strategic care and funding agreement, most experts expect the run rate system to become obsolete.

The current juncture provides an opportunity to boldly define new treatment targets and seize the opportunity to deliver care in the community provided by the simplicity of new DAA treatments.

## Objective 5.1: A minimum of 20,000 people begin treatment every year until hepatitis C is eliminated.

An estimated 160,000 people are chronically infected with hepatitis C in England. The government often references its firm commitment to the WHO goal of eliminating hepatitis C as a public health concern by 2030, defined as 90% of those living with hepatitis C having been diagnosed, and 80% of those diagnosed having been treated.

Based on the current prevalence estimate, to achieve or exceed its commitment to this WHO target, England would have to treat over 115,000 currently infected patients, before accounting for new infections. Currently, hepatitis C incidence (new infection) is considered challenging to measure, and data is imprecise, but rough estimates indicate approximately 5,000 new infections per year<sup>44</sup>.

At least  
**20,000**  
people must begin  
treatment every year to  
achieve NHS England's  
ambition of  
elimination by 2025

To achieve NHS England's recently expressed commitment to eliminate hepatitis C by 2025 - five years earlier than the WHO target - it will be necessary to diagnose and treat over 16,000 people yearly from within the currently infected population, as well as additional numbers to maintain a decline in prevalence when accounting for new infections.

Based on these estimates, at least 20,000 people must begin treatment every year in order to achieve the commitment to elimination by 2025 expressed by NHS England. In fact, it may be more pragmatic to adopt an even greater target initially, tailing off to lower targets in future years. This would reflect the assumption that as overall prevalence falls and approaches very low numbers, those still living with hepatitis C will be harder to reach and more resources will have to be expended for every additional treatment initiation.

Higher treatment target numbers in the earlier years of the strategy would also contribute to fewer transmissions of the virus, further accelerating a decline in prevalence.

We recommend that a minimum target of 20,000 new treatment initiations per year be adopted immediately and reviewed yearly based on up-to-date prevalence and incidence data. Within the current treatment environment, this target is eminently achievable.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
A target of 20,000 people per year treated is set, incentivised, and monitored	<ul style="list-style-type: none"> <li>Run rate cap to be removed and replaced by ambitious minimum targets determined at ODN level</li> <li>Proportional prison treatment targets to be set for prisons specifically in every ODN depending on prison population</li> </ul>	NHS England

**Objective 5.2: Treatment is available directly in the community and accessible to all.**

The new DAA treatments present an extraordinary opportunity to deliver care outside of a hospital setting. However, the current structure of the hepatitis C care pathway remains centred around hospitals and referrals to specialised care, a holdover from the previous treatment regime. Experts from across the care pathway told us that the best way to treat increasing numbers of people is to ensure treatment is co-located with testing in community services and easily accessible to patients in settings they are comfortable in and are often already accessing. Witnesses told us that “treatment at the point of diagnosis has to be the way forward” for non-cirrhotic patients, with only those likely to be cirrhotic referred to specialist care. With ever-improving testing and diagnosis technologies, it is already possible for patients to receive their diagnosis within hours in some cases, and the ambition should be to dispense treatment immediately after first diagnosis.

With the ease of delivery of DAA treatments and reduced need for patient monitoring during treatment, all staff in settings where hepatitis C testing takes place could be accredited to deliver treatment directly, eliminating the need for referrals and trips to hospital for patients. GPs should also be prescribing and delivering treatment directly, with little need for referral into secondary care after diagnosis. Experts overwhelmingly expressed the conviction that patients with chaotic lives will feel more comfortable considering treatment in services they are used to accessing, and where they often have personal connections with the staff.

Home care also presents a novel care pathway for hard to reach groups, simultaneously relieving pressure on hepatitis services and allowing specialist teams to focus on clinically challenging patients. A home care pathway pilot in Nottingham found that there was an average cost saving of £523 per patient when delivering treatment through the home care pathway as compared to secondary care. A high rate of patient satisfaction was recorded, and the service was particularly valued by patients living further away from services or living with disabilities.

Dispensing treatment in the community (outside of hospital) also means that VAT is not levied on the treatments, resulting in a 20% cost saving which could be reinvested in case-finding and service development. Delivering treatment in the community is truly the simplest, most affordable, and most effective approach, requiring only that the enabling structures of accreditation for primary care and community workers are put in place.

**“We need to expand the pool of hep C ‘treaters’ – I like to use that phrase because it doesn’t have to be people like me [clinicians] treating people with hep C, we should incentivise primary care to deliver DAA therapy.”**

**Dr Ahmed Elsharkawy**  
*(Consultant Hepatologist, University Hospitals Birmingham NHS Foundation Trust and Chair, British Viral Hepatitis Group)*

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Delivery of treatment in the community facilitates access to treatment for patients</b></p>	<ul style="list-style-type: none"> <li>• Testing and treatment in the community to be prioritised, the patient pathway to be reviewed and flexible services located where patients are most likely to access them to be designed</li> </ul>	<p>ODNs</p>
	<ul style="list-style-type: none"> <li>• Funding mechanisms to be developed to ensure treatment cost savings are reinvested into developing services and treating additional people</li> </ul>	<p>NHS England</p>
	<ul style="list-style-type: none"> <li>• Increased in-reach and treatment delivery in prisons by primary care teams to be facilitated</li> </ul>	<p>ODNs</p>
	<ul style="list-style-type: none"> <li>• Treatment to be distributed directly to community settings, and as many people as possible to be trained and accredited to deliver treatment in diverse settings including substance misuse services, sexual health clinics, hostels, pharmacies and home care</li> </ul>	<p>ODNs</p>
	<ul style="list-style-type: none"> <li>• The most effective funding and organisational responsibility set-up to be determined to widen delivery of treatment through home care</li> </ul>	<p>ODNs</p>
	<ul style="list-style-type: none"> <li>• A clear protocol to be developed for when a patient can be treated without referral to specialist care, for example based on APRI or FIB4 scores</li> </ul>	<p>British Association for the Study of Liver, British Viral Hepatitis Group</p>

**Objective 5.3: Treatment is flexible and presents minimal disruption to patients, minimising the risk of patients dropping out of the care pathway.**

DAA treatments are now all-oral (tablet-based) and have cure rates of approximately 95% for all genotypes. There is little need for a patient to attend appointments while on treatment, outside of treatment collection and post-treatment tests to confirm a cure result. However, appointments where blood samples are taken to measure viraemia levels are still often required at two, four, and eight weeks into treatment. This is a holdover from a previous treatment regime, creating additional barriers to patients and unnecessary pressure on clinical resources. These requirements should be eliminated universally, with only pre- and post- treatment appointments being required.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Reduced need for clinical engagement during treatment leads to increased treatment completion	<ul style="list-style-type: none"> <li>• Patient monitoring during treatment to be minimised, removing the requirements for clinical appointments at two, four, and eight weeks into treatment</li> </ul>	NHS England, British Association for the Study of Liver, British Viral Hepatitis Group/BVHG

**Objective 5.4: Access to treatment is universal, including for those who are reinfected.**

NHS England’s current position allows for re-treatment only for those with severe liver damage whose first course of treatment has failed. There is no provision for re-treatment for those who are reinfected with less severe liver damage. This position is incompatible with a ‘treatment as prevention’ approach and with a commitment to elimination, and any commitment to universal access to treatment must include provision for re-treatment, regardless of level of liver damage or infection route.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Universal access to treatment, including for those reinfected, leads to a steadily falling prevalence and incidence rate	<ul style="list-style-type: none"> <li>• NHSE guidance to be developed to support and enable treatment of patients who are reinfected</li> <li>• All diagnoses to be initiated onto treatment regardless of whether it is a first infection or reinfection</li> </ul>	NHS England

# Funding

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## Current situation

NHS England currently undertakes procurement for hepatitis C treatments every six months. When new DAA treatments were first approved for use on the NHS, the treatments were priced in the order of £35,000 per course of treatment. Despite being perceived as expensive, the treatments were approved as cost-effective by NICE due to the significant overall savings resulting from fewer cases progressing to severe liver damage and liver cancer. While the £35,000 figure is often still cited informally, it is now considerably outdated, and significant reductions in treatment costs have been secured due to market competition.

NHS England reports that it spent approximately £200 million on direct-acting antiviral treatments for hepatitis C in 2016-17<sup>45</sup>. Though the costs of hepatitis C medicines are subject to commercially confidential pricing agreements, we know that 9,440 patients were treated in 2016-17. By this measure, assuming the full spend on treatments was also distributed in the same year, a course of treatment would cost approximately £21,000, a reduction in cost of over 40%. Even this number is significantly higher than the accepted figure within clinical circles, where it is widely understood that a course of treatment can now be well below £10,000.

As a further confirmation of reduction in treatment costs, in Scotland, the expert advisory Treatment and Therapies Group recently issued advice to the Scottish Government which stated: “For 2016/17, just over 1,700 people were treated at a cost of £32 million. If 3,000 people were to be treated in 2018/19, the drug cost would be considerably lower (by several million pounds) than that incurred in 2016/17”. While the procurement environment in Scotland is not directly comparable to that in England, this statement confirms that, broadly, there has been a reduction of around 50% in treatment costs in the last year alone.

Despite these cost reductions, the resulting savings have not been reinvested into services to encourage additional case-finding and diagnoses. Since treatment is funded directly by NHS England Specialised Commissioning, the budget is ring-fenced exclusively for direct spend on treatments and, as discussed previously, the number of treatments delivered every year is capped. One witness said of the resulting situation: “When you speak to specialist commissioners in NHS England, they say ‘our job is not to commission services, our job is to fund drugs’. But if you can’t deliver the drugs adequately then it’s pointless funding the drugs.” A clear barrier to efforts to eliminate hepatitis C is caused by the limitations of the commissioning system, despite conditions like treatment costs and ease of treatment now being better than ever before.

Longer-term strategic approaches to funding hepatitis C care have long been proposed. In Australia, often held up as an international model, the government has secured a national funding agreement with pharmaceutical companies. Under this agreement, any treatments above an agreed threshold come at no additional cost. This creates a pressurised system where treating maximum amounts of people as soon as possible is incentivised. An estimated 81% of the infected population in Australia has been diagnosed. Italy and parts of Canada (particularly British Columbia) have also struck block funding deals for treatment and committed to providing treatment for all, regardless of severity of liver damage.

A similar strategic approach appears closer than ever in England, with NHS England announcing in January 2018 that it would be entering negotiations with the pharmaceutical industry to reach a new funding arrangement for hepatitis C treatments. The proposed new funding arrangement is intended to support the elimination of hepatitis C in England by 2025 at the latest, five years earlier than the WHO goal of eliminating the virus by 2030. If this commitment is to be achieved, significant advances on current treatment numbers must be made, and this must be the primary goal of the funding agreement.

**“I’ve spoken to clinicians in the spoke hospitals, and what they want from us as the hub, is to give them money to employ admin support, or nurses, or to free up clinician time to negotiate with local services or set up local services. That just is not enabled in the current system.”**

**Dr Ahmed Elsharkawy**  
*(Consultant Hepatologist, University Hospitals Birmingham NHS Foundation Trust and Chair, British Viral Hepatitis Group)*

**Objective 6.1: A long-term, strategic approach to funding for hepatitis C care and treatment is supported by a national elimination strategy.**

There was overwhelming support in our inquiry for a long-term strategic funding agreement allowing for financial certainty for industry, government, and service providers. The current six-month procurement cycle for treatments, while providing maximum opportunity for treatment cost reductions due to competition between industry providers, also creates significant challenges. Due to the lack of financial certainty, industry is reluctant to commit long-term funding to case-finding and additional services, and there is a risk that providers might withdraw from the procurement process altogether if the market shifts.

A senior manager at a global pharmaceutical company with experience in the international treatment market acknowledged that in the global market the UK was falling behind in delivery of hepatitis C treatments. Industry representatives giving oral and written evidence all expressed a willingness to explore alternative funding models going beyond treatment to encompass risk-sharing joint funding approaches to non-treatment related aspects of care like outreach and diagnosis, linkage to care programmes, or investment in research, if longer-term financial certainty could be guaranteed.

NHS England stated in its announcement of negotiations with industry that an element of the new funding deal will be establishing a role for the pharmaceutical industry in finding currently undiagnosed patients and enrolling them into treatment. This reflects the shifting priorities of the hepatitis C treatment landscape towards finding the undiagnosed, as those with the most advanced liver damage who were previously in touch with services have overwhelmingly been treated.

However, adding a significant role for industry in funding case-finding further complicates the commissioning environment, and increases the need for an overarching national strategy. Under such an approach, the pharmaceutical industry would begin serving what would in effect be a commissioning function, in addition to the fragmented commissioning already taking place between NHS England, local authorities, and Clinical Commissioning Groups (CCGs). It is conceivable that private companies will be delivering regional and local case-finding services, while remaining in competition with one another, creating a pressing need for centralised strategic coordination and regulation.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>An effective long-term funding deal between NHS England and industry is reached and supported by a national elimination plan</b></p>	<ul style="list-style-type: none"> <li>The deal to be accompanied by additional funding to find the undiagnosed and initiate greater numbers of patients into treatment</li> <li>The elimination strategy to include mechanisms to determine who is responsible for delivering each aspect of the strategy</li> </ul>	<p>NHS England, industry, Department of Health and Social Care</p>

**Objective 6.2: The new strategic funding model effectively supports the greatest possible number of diagnoses and treatment initiations each year.**

Many witnesses further criticised the fragmented commissioning landscape surrounding hepatitis C care for its negative effects on delivery of care in the community. Currently, treatment for hepatitis C is commissioned centrally by NHS England as a specialised service. Testing in drug services and sexual health clinics, needle exchange programmes in pharmacies, and local awareness-raising is commissioned by local authorities from their public health grant, while testing in hospitals and specialised hepatitis C care are commissioned by CCGs. Prescribing decisions and oversight of treatment delivery are conducted by ODNs.

This results in a complex funding environment for community care, with one clinician stating: “As a clinician interested in treating hepatitis C outside of hospital settings, currently my funding streams are multiple and I have to get agreement across the organisations to enable me to deliver it. That takes a lot of effort, perseverance, and resource”. Another said: “There is a lot of cost in the complex allocation and modelling, and it never seems to satisfy anyone. Either you don’t have enough patients to fill the slots, or you run out too fast. That’s not satisfactory.”

Several witnesses expressed the conviction that the current hepatitis C treatment budget was more than sufficient to move towards elimination, but inefficiently allocated, with one witness saying: “The medicines aren’t in the right places and aren’t close to the patients. We could have the same budget, but ensure treatments are allocated to patients at the point where they engage”.

As discussed in previous sections, the national environment of funding cuts to local authorities and community health services have created an environment where many settings crucial to hepatitis C elimination are finding it difficult to deliver quality care. Community care settings will be crucial to increasing numbers of people tested and delivering treatment in the community, and ensuring funding for these services is sustained or increased should be seen as a cost-effective investment creating an enabling environment for elimination.

Witnesses stated that for a funding agreement with industry to have the greatest possible effect, it would need to be accompanied by a strategy ensuring that funds are effectively distributed to all necessary areas and services, with clarity about who is responsible for delivery of every aspect of the plan. The upcoming deal also provides an opportunity for industry to fund new initiatives like direct cash incentives for testing or a mass awareness campaign, which would have previously been difficult to align with the NHS commissioning structure.

<b>Desired outcome supporting elimination</b>	<b>Suggested actions</b>	<b>Suggested organisational responsibility</b>
<b>Substance misuse services, sexual health clinics, and prisons have sufficient funding to effectively deliver case-finding and testing initiatives</b>	<ul style="list-style-type: none"> <li>The deal to include effective mechanisms to ensure funds are effectively distributed to all necessary areas</li> </ul>	NHS England, industry
<b>New case-finding initiatives are supported by the upcoming funding agreement</b>	<ul style="list-style-type: none"> <li>Consideration to be given to the introduction of monetary incentives for testing and treatment initiations</li> </ul>	NHS England, industry

## Monitoring progress

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### Current situation

The key national reporting documents for hepatitis C are Public Health England's annual 'Hepatitis C in the UK'<sup>46</sup> and 'Hepatitis C in England' reports<sup>47</sup> which collate available data on deaths from hepatitis C, incidence of new infections, and service provision. The UK report has been published yearly since 2004 and is mandated by the Department of Health and Social Care; since 2017 an England only report has also been produced with more comprehensive metrics to help inform public health action to support elimination in England. A similar report for the London region contains more detailed data on hospital admissions and testing rates within services broken down by local authority<sup>48</sup>. However, the latest data available is from 2015, since when the treatment landscape has changed significantly.

Although modelling is ongoing to update national prevalence estimates, estimates of prevalence for hepatitis C are uncertain. The current national prevalence estimate is based on modelling that has not been significantly updated since the establishment of run rates, developed using data from 2011 or before. There are limited reliable prevalence estimates for any specific risk group except for PWID, although PHE's sentinel surveillance does give us an indication of the proportion of risk groups tested that have positive results. Similarly, measuring incident (new) infections is highly challenging, and no firm estimate of total incident infections exists. Public Health England states that "in order to plan services effectively, it is important to estimate the number of people likely to need treatment", but acknowledges limitations to its own modelling approach<sup>49</sup>. There is also no national data on reinfection rates or reinfection risk within different risk groups.

### **Objective 7.1: Ambitious local, regional and national targets are used to incentivise and drive increases in testing and treatment.**

A national elimination strategy for England should aspire to be an international example of good practice to which other nations can look for guidance and inspiration in progressing their own hepatitis C strategies. The strategy should set out clearly what elimination means for England, guided by an ambition to relegate hepatitis C to the status of a rare and unusual disease, with any occasional outbreaks resulting in immediate treatment and containment.

Going beyond the global baseline set out in the World Health Organization's Global Health Sector Strategy on Viral Hepatitis, the strategy should include ambitious targets to decrease national prevalence, incidence and mortality, as well as absolute numbers for overall prevalence, prevalence in people who inject drugs, incidence of new infections, incidence of end-stage liver disease and mortality.

To inspire action to tackle hepatitis C and benchmark progress, regional or sector-based commitments to elimination play a useful role. In Greater Manchester, a regional elimination plan is in the final stages of development, and will be launched as part of the roll-out of the Greater Manchester Health and Social Care Partnership. A regional elimination strategy for other major cities could be developed, and would be particularly useful in London, which faces the highest hepatitis C prevalence rates in the country and where waiting lists for treatment are still common. Experts also mentioned the potential positive impact of a commitment to elimination and corresponding strategy within prisons.

Targets should also be set at ODN level to incentivise and monitor equitable and effective delivery of testing and treatment in every area. Mechanisms should be put in place to ensure ODNs that are not performing to target are supported to improve rather than penalised.



Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>A national elimination strategy with ambitious targets is developed to support the upcoming strategic funding agreement</b></p>	<ul style="list-style-type: none"> <li>• A national elimination strategy to contain targets for incidence, prevalence, and mortality going beyond the global baseline set out in the World Health Organization's Global Health Sector Strategy on Viral Hepatitis</li> <li>• Micro-elimination strategies (at city or sector level) to be used as a tool to monitor early progress and inspire good practice</li> </ul>	<p>Department of Health and Social Care</p>

**Objective 7.2: Improved accuracy of incidence and prevalence data enables more efficient allocation of resources and monitoring of progress towards elimination.**

Improving the quality and type of data collected on hepatitis C prevalence and incidence would allow for better allocation of testing and treatment resources, as well as provide a more accurate barometer of progress. A reliable estimate of yearly hepatitis C incidence is crucial to developing relevant treatment targets to achieve elimination.

Establishing monitoring systems to track prevalence and incidence separately within PWID, prisoners, South Asian communities, and MSM communities would allow for more efficient resource allocation toward case-finding and linkage to care in these communities.

Public Health England should be clear about the data it requires and intends to include in its annual monitoring report. The data included in the report and the patient registry should be kept under regular review, to ensure sufficient data is being collected and reported on to understand the effectiveness of strategies towards elimination.

In order for this monitoring to be conducted effectively and kept under regular review, it is important that sufficient resources are available to Public Health England to undertake this work. To this end Public Health England should appoint a hepatitis C elimination lead of sufficient rank to allocate resources when and where needed. Accurate, up-to-date national data should also be used to celebrate progress and ensure England is recognised as an international leader in tackling hepatitis C.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Improved data collection and reporting enables more efficient allocation of resources and monitoring of progress towards elimination</b></p>	<ul style="list-style-type: none"> <li>• Surveillance systems for prevalence and incidence among PWID and MSM to be improved, and surveillance for the homeless population to be established, so effectiveness of strategies aimed at different groups can be better analysed</li> <li>• A hepatitis C elimination lead in PHE to be appointed</li> <li>• Indicators included in annual hepatitis C reporting to be kept under review</li> </ul>	<p>Public Health England</p>

**Objective 7.3: Additional research and pilot projects allow for bold, innovative approaches to improvement in hepatitis C care.**

There is much innovative work being tried across England, especially in finding and linking patients into care. It is vital that this is monitored in real time so that effective pilots or high-implication research findings can be identified and adopted nationally more quickly and efficiently, but also so resources can be diverted away from initiatives that prove ineffective.

The ‘Prevention’ section discussed a ‘treatment as prevention’ approach, which would seek to target and treat as many people who are actively injecting drug users as possible, seeking to minimise onward transmission and decrease prevalence among PWID. As this approach is trialled, a robust analysis of its effectiveness should be conducted.

Multiple experts expressed their conviction that hepatitis C treatment could contribute to resolving other behavioural issues, lifestyle change and reduced reoffending rates. There is a lack of empirical evidence for this hypothesis but given similar anecdotal testimony from across various services and the potentially vast positive implications of such a correlation, a large-scale study on the topic should be commissioned.

There is currently little data about reinfection rates, and as discussed in the ‘Treatment’ section, ensuring services collect data about reinfection within different risk groups would assist in appropriately targeting resources and behavioural interventions to minimise reinfection.

These are only several examples of areas where improved monitoring and additional research could contribute to bold new approaches to hepatitis C care and others should be developed in collaboration with researchers and service providers.

Witnesses expressed the view that clearer channels to share examples of best practice should be created, to encourage other areas to adopt good practice and avoid duplication of research and pilots. Good practice case studies are currently shared nationally by several organisations, but witnesses expressed a desire for strong leadership from Public Health England on this front.

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Improved monitoring of innovative initiatives and approaches to hepatitis C care allows successful models to be easily identified and up-scaled</b></p>	<ul style="list-style-type: none"> <li>• Improved surveillance of reinfection rates to be implemented in order to better target resources for re-testing and retreatment</li> <li>• Additional research to be conducted into the potential for hepatitis C treatment to reduce reoffending rates or contribute to recovery journey</li> <li>• Ground-breaking research on hepatitis C care to continue to be conducted and commissioned</li> <li>• Results of local pilot projects to be distributed nationally and scale-up of effective initiatives encouraged</li> </ul>	<p>Public Health England, HCV Action</p>

# Conclusion

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The findings of this inquiry give us much cause for optimism. It is our firm belief that elimination of hepatitis C in the very near future is an achievable national ambition.

Expert witnesses to our inquiry have illustrated areas where significant challenges still exist, and it is clear that improvements will be needed in order to achieve elimination. Lack of awareness, sub-optimal testing levels, complex care pathways, funding pressures, a fragmented commissioning environment and short-term treatment funding models all present significant barriers to testing and treatment.

We welcome NHS England's ongoing negotiations with industry towards a long-term, strategic funding agreement for hepatitis C. The resulting funding deal has the potential to kick-start innovative strategies to improve prevention, increase diagnosis and permit unlimited access to treatment around the country. To that end, this report has recommended a series of interventions in all aspects of the hepatitis C care pathway.

It is essential that the recommendations contained in this report are implemented as part of a cohesive national plan for elimination. We must recognise the pressures of England's expressed ambition to eliminate hepatitis C by 2025, and act now to deliver immediate improvements, especially in areas where recommended interventions have already been proven and widely recognised as effective.

One key element of any plan must be a strategic timeline that ensures co-ordination and prevents waste. We must build capacity along with demand. If we are to build a model that we can showcase to the world, we must also be bold and not shy away from trying truly transformative ideas, rapidly embracing those that work and jettisoning those that do not. This will require much improved real-time monitoring to assess the effectiveness of our interventions, as well as progress towards our goal.

Given the broad buy-in required to co-ordinate the necessary actions across devolved administrative and commissioning structures such as HMPPS, CCGs, ODNs and local authorities, we believe the formation of a cross-ministerial group providing oversight of hepatitis C elimination efforts would be appropriate. Ministers with responsibility over public health, prison health and local government should be engaged, as should senior representatives of NHS England and Public Health England.

We hope that this report provides a blueprint for strategic and deliberate national action leading to an England where hepatitis C is no longer a public health concern. We have a once-in-a-generation opportunity. We must not waste it.

# Acknowledgements

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- **Charles Gore**, *Chief Executive*
- **Urte Macikene**, *Policy and Parliamentary Adviser*
- **Aidan Rylatt**, *Policy and Parliamentary Adviser*

**The following people gave oral evidence to the inquiry:**

- **Alex Bax** (*Chief Executive, Pathway*)
- **Dr Iain Brew** (*Speciality Doctor, Viral Hepatitis, Leeds Teaching Hospitals NHS Trust*)
- **Mike Elliott** (*Vice President, Medical Affairs, Gilead [on behalf of AbbVie and Gilead]*)
- **Dr Ahmed Elsharkawy** (*Consultant Hepatologist, University Hospitals Birmingham NHS Foundation Trust; Chair, British Viral Hepatitis Group*)
- **Professor David Goldberg** (*Consultant in Public Health Medicine/Clinical Epidemiology, Health Protection Scotland*)
- **Helen Hampton** (*National Lead for Blood Borne Viruses, Addaction*)
- **Dr Brendan Healy** (*Consultant in Microbiology and Infectious Diseases, University Hospital of Wales; Chair, Welsh Viral Hepatitis Subgroup*)
- **Andy King** (*Patient representative*)
- **Arshad Mahmood** (*Chairman, Jamatia Islamic Centre, Birmingham*)
- **Dr Éamonn O'Moore** (*National Lead, Health and Justice Team, Public Health England*)
- **David Rowlands** (*Director, DR-web.co.uk and patient representative*)
- **Rachael Sadegh** (*Service Manager – Substance Misuse, London Borough of Tower Hamlets*)
- **Stuart Smith** (*Head of Drug Services, The Hepatitis C Trust*)
- **David Stuart** (*Substance Use Lead, 56 Dean Street*)

**The following people and organisations submitted written evidence:**

- **AbbVie**
- **Professor Graham Foster** (*Professor of Hepatology, Queen Mary University of London*)
- **Gilead**
- **Professor Will Irving** (*Chair - National Strategy Group for Viral Hepatitis, Professor and Honorary Consultant in Virology - University of Nottingham and Nottingham University Hospitals*)
- **The London Joint Working Group on Substance Use and Hepatitis C**
- **MSD**
- **National AIDS Trust**
- **NHS England**
- **David Rowlands** (*Director, DR-web.co.uk and patient representative*)

Additional input was provided by **Helen Harris** (*Clinical Scientist and Research Associate, Public Health England*).

## Appendix

**Objective 1.1: Awareness of hepatitis C within the public is increased, leading to fewer risky behaviours, increased self-presentation for testing, re-engagement of those previously diagnosed into treatment and decreased stigma.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Increased awareness within the general public leads to decreased stigma and greater numbers of people getting tested and treated	<ul style="list-style-type: none"> <li>Department of Health and Social Care to commission a pilot investigating the effectiveness of awareness-raising messaging, with the aim of building a business case for a national awareness campaign</li> <li>A high profile, Government-backed national awareness campaign to be implemented</li> <li>A media ‘champions’ campaign, encouraging high-profile figures with experience of hepatitis C to talk about their experience publicly, to be implemented</li> <li>Industry to be incentivised via a long-term strategic funding agreement to invest in national awareness-raising programmes</li> <li>All awareness-raising publicity to include key messaging conveying the short duration and ease of treatment, as well as the urgency of getting tested and treated as soon as possible</li> </ul>	Department of Health and Social Care, Public Health England, NHS England, industry
Increased awareness among people living with hepatitis C who would not consider themselves to be ‘at risk’	<ul style="list-style-type: none"> <li>Awareness-raising publicity to be distributed in schools, airports (specifically on flights to South Asia), in dentists, magazines and on billboards</li> </ul>	NHS England, Department of Health and Social Care, industry
Increased awareness within at-risk groups who may be out of touch with services through technology and social media	<ul style="list-style-type: none"> <li>Use of big data for improved profiling of those at risk and targeted advertising on social media and/or apps to be investigated</li> </ul>	NHS England, Department of Health and Social Care, industry

**Objective 1.2: Awareness of hepatitis C among primary care professionals is increased, leading to increased testing in primary care.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Increased awareness of hepatitis C among GPs leads to increased testing of at-risk groups and more efficient care pathways	<ul style="list-style-type: none"> <li>Targeted testing initiatives to be increased in primary care (e.g. a hepatitis C ‘testing week’ where all bloods taken are also tested for hepatitis C)</li> </ul>	NHS England
	<ul style="list-style-type: none"> <li>Resources on hepatitis C best practice to be produced for primary care workers, for example through health circulars</li> </ul>	Chief Medical Officer, Public Health England
	<ul style="list-style-type: none"> <li>All positive test results to be accompanied by information about where to refer a patient, and contact details for The Hepatitis C Trust for support</li> </ul>	Public Health England

**Objective 1.3: Awareness is increased and stigma is decreased within particular risk groups through targeted initiatives.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Increased awareness of hepatitis C within the South Asian community	<ul style="list-style-type: none"> <li>Awareness-raising messaging aimed at the South Asian community to be developed, including talks and materials delivered in Urdu and other south Asian languages, outreach in mosques, and messaging through South Asian media channels</li> </ul>	Public Health England, Islamic community organisations
Increased awareness of hepatitis C among men who have sex with men	<ul style="list-style-type: none"> <li>Awareness-raising messaging aimed at MSM communities to be developed, with a focus on innovative, previously untried methods such as publicity via commonly used apps</li> </ul>	Sexual health clinics
Increased awareness of hepatitis C among PWID and people in prison	<ul style="list-style-type: none"> <li>Awareness-raising talks delivered by peers to be commissioned as an integral part of contracts for substance misuse services and in prisons</li> </ul>	NHS and local authority commissioners, NHS England Health and Justice, substance misuse services

**Objective 1.4: Awareness of the short duration and ease of new DAA treatments is increased, dispelling reticence to test and get treated among PWID and people in prison.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Increased awareness of the ease and short duration of new DAA treatments among prisoners	<ul style="list-style-type: none"> <li>Nationally-approved NHS England Health and Justice publicity highlighting the ease of new treatments to be rolled out across HM prison estate</li> <li>Peer programmes to be commissioned as an integral part of hepatitis C treatment services in commissioning contracts in prisons</li> </ul>	NHS England Health and Justice
Increased awareness of the ease and short duration of new DAA treatments among PWID	<ul style="list-style-type: none"> <li>Nationally-approved publicity highlighting the ease of new treatments to be rolled out across substance misuse services</li> <li>Hepatitis C peer programmes to be commissioned as an integral part of commissioning contracts for substance misuse services</li> </ul>	Local authority commissioners

**Objective 2.1: Sufficient injecting equipment and opioid substitution therapy is available to all PWID to support prevention and harm reduction efforts.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Fewer transmissions of hepatitis C among PWID due to adequate NSP provision and access to OST	<ul style="list-style-type: none"> <li>Public Health England to establish a target for an increase of PWID reporting adequate provision, in line with the WHO 2020 target for NSP</li> <li>Public Health England to monitor and report on this target in its annual 'Shooting Up' report</li> <li>Needles, syringes, and other injecting equipment to be widely available in drug services and sexual health services, particularly in areas identified as having growing infection incidence</li> <li>Funding for NSP and OST in substance misuse services to be protected</li> </ul>	Public Health England, local authorities

**Objective 2.2: Knowledge about prevention is increased in prisons, substance misuse services, and sexual health clinics.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Prison staff are an effective source of information for prisoners on harm reduction and prevention	<ul style="list-style-type: none"> <li>• BBV training to be made compulsory for prison staff</li> </ul>	NHS England Health & Justice, Her Majesty's Prison and Probation Service
Fewer new infections as a result of improved knowledge of transmission risks	<ul style="list-style-type: none"> <li>• Peer programmes to be commissioned as an integral part of hepatitis C treatment services in commissioning contracts for substance misuse services and in prisons</li> </ul>	NHS England Health and Justice

**Objective 2.3: All those diagnosed are educated about transmission risks, leading to reduced reinfection rates.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Fewer reinfections due to improved knowledge of transmission risks	<ul style="list-style-type: none"> <li>• Peer programmes delivering messaging about prevention to be expanded and included as an integral part of hepatitis C care in commissioning contracts for drug and alcohol and sexual health services</li> <li>• Drug and alcohol and sexual health service workers to be trained to deliver behavioural intervention messages to prevent reinfection</li> <li>• Commissioning guidance to be developed to ensure local authority commissioners understand the importance of hepatitis C prevention</li> </ul>	Local authority commissioners  Local Government Association, Public Health England

**Objective 2.4: New, innovative approaches to prevention lead to a decline in hepatitis C transmissions.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Lower transmission rates among PWID due to increased targeting of testing and treatment at actively injecting PWID	<ul style="list-style-type: none"> <li>• A 'treatment as prevention' approach to be upscaled, targeting actively injecting drug users for treatment to prevent onward transmission</li> <li>• NSP providers to be commissioned to engage, test, and treat PWID</li> </ul>	NHS England, Operational Delivery Networks, local authority commissioners
Safer injecting practices due to harm reduction initiatives in the community	<ul style="list-style-type: none"> <li>• More radical methods of prevention like drug consumption rooms to be explored</li> </ul>	Department of Health and Social Care



**Objective 3.1: All those at risk who engage with local services are offered a hepatitis C test.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased coverage and uptake of testing in substance misuse services</b></p>	<ul style="list-style-type: none"> <li>• Opt-out testing for hepatitis C to be commissioned by local authorities in substance misuse services</li> <li>• Re-offer of testing to all those engaged with substance misuse services every six months to be mandated and commissioned</li> </ul>	<p>Local authority commissioners</p>
<p><b>Increased coverage and uptake of testing in prisons</b></p>	<ul style="list-style-type: none"> <li>• Testing to be re-offered in prisons to those who did not receive a test at reception</li> <li>• Opportunities to be provided for those who previously tested to re-test in prison</li> <li>• Clear national protocol to be developed surrounding wording of opt-out test offer in prisons</li> <li>• Commissioners to support access for prisoners to second reception screening</li> <li>• Research to be conducted on transmission risk within prisons to determine impact of re-testing</li> </ul>	<p>NHS England Health and Justice</p> <p>National Institute for Health Research</p>
<p><b>Increased coverage and uptake of testing in sexual health services</b></p>	<ul style="list-style-type: none"> <li>• Funding for hepatitis C testing in sexual health services to be guaranteed protection</li> </ul>	<p>Local authorities</p>

**Objective 3.2: Outreach and testing in the community is increased to find and diagnose people living with hepatitis C who are not in touch with services.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased numbers of people are tested in the community in non-traditional settings</b></p>	<ul style="list-style-type: none"> <li>• Opt-out testing in A&amp;E when bloods are taken to be introduced</li> <li>• Testing in police custody to be introduced</li> <li>• Every ODN to appoint a clinical staff member whose primary role is to work in the community rather than in a clinical setting</li> <li>• Testing to be introduced in as many community settings as possible, including pharmacies, homeless hostels, daycentres, and through street outreach teams, in addition to sexual health clinics and substance misuse services</li> <li>• Collaboration to be increased in community testing initiatives between BBVs, for instance mobile units testing for both HIV and HCV</li> </ul>	<p>ODNs, local authorities, local authority commissioners</p>
<p><b>Improved effectiveness of targeted testing initiatives in reaching greater proportions of those at risk</b></p>	<ul style="list-style-type: none"> <li>• Research and evidence synthesis to be conducted to determine effectiveness of testing initiatives in the settings suggested above, and to determine prevalence rate in a given population at which testing becomes cost-effective</li> </ul>	<p>Public Health England</p>

**Objective 3.3: Testing is widely available and supported in primary care.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p><b>Increased numbers of people are diagnosed through primary care</b></p>	<ul style="list-style-type: none"> <li>• An annual universal testing week to be introduced in GP practices</li> <li>• New registrants at GP practices who have recently moved from high prevalence countries to be automatically screened for hepatitis C, in line with the latest evidence</li> <li>• Evidence to be reviewed on automatic flagging of patients with risk factors in GP databases and a national approach to be standardised</li> </ul>	<p>NHS England</p>

**Objective 3.4: Increased numbers of people are tested due to standardisation of testing practices across the country.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p>Opt-out dry-blood spot testing for hepatitis C is fully implemented in substance misuse services and prisons</p>	<ul style="list-style-type: none"> <li>Commissioning contracts for substance misuse services and prisons to have clear mechanisms to hold services to account for failures to meet testing targets</li> <li>Unnecessary tests and appointments to be reduced, and the use of reflex-tested dry blood spot samples, which necessitate only one sample and can be delivered in the community, to be mainstreamed</li> </ul>	<p>NHS England Health and Justice, Local authority commissioners</p>

**Objective 4.1: Time between diagnosis and initiation of treatment is decreased.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p>Simplified referral pathways lead to lower rates of drop-out from the care pathway</p>	<ul style="list-style-type: none"> <li>Direct referrals into secondary care to be accepted from all services, not just from primary care</li> <li>Simplified referral pathways to be agreed, eliminating unnecessary appointments prior to treatment</li> <li>DBS and reflex tests to be carried out in the first instance, eliminating the need for additional samples</li> </ul>	<p>Operational Delivery Networks</p>

**Objective 4.2: Linkage to care is improved due to effective data-sharing.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p>Data about an individual's hepatitis C status and testing history is accessible to all health services</p>	<ul style="list-style-type: none"> <li>NHSE national treatment database to be further developed to include all patients diagnosed</li> <li>Better informatics systems to be developed to ensure primary care providers can receive information about former prisoners' hepatitis C status</li> <li>ODNs to be notified of all positive results, allowing them to centrally contact and refer patients if a referral is not made at point of diagnosis is not made at point of diagnosis</li> </ul>	<p>NHS Digital and Public Health England</p> <p>ODNs, laboratories</p>
<p>Those previously diagnosed but lost to follow-up are re-engaged into treatment</p>	<ul style="list-style-type: none"> <li>Public Health England to provide data to support the NHS in re-contacting people who were previously diagnosed but lost to follow-up</li> <li>Where appropriate, GPs and local services to conduct additional lookback exercises of patient records to re-engage those lost to follow-up</li> <li>National guidance to be developed regarding the use of patient data for this purpose</li> </ul>	<p>NHS England, NHS Digital</p>

**Objective 4.3: Innovative peer programmes encouraging attendance at clinical appointments are supported and expanded.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
<p>More PWID linked into care through peer support of more chaotic patients to attend appointments and complete treatment</p>	<p>Peer programmes to be commissioned as an integral part of hepatitis C treatment services in commissioning contracts in substance misuse services and homelessness services</p>	<p>Local authorities</p>

**Objective 5.1: A minimum of 20,000 people begin treatment every year until hepatitis C is eliminated.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
A target of 20,000 people per year treated is set, incentivised, and monitored	<ul style="list-style-type: none"> <li>Run rate cap to be removed and replaced by ambitious minimum targets determined at ODN level</li> <li>Proportional prison treatment targets to be set for prisons specifically in every ODN depending on prison population</li> </ul>	NHS England

**Objective 5.2: Treatment is available directly in the community and accessible to all.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Delivery of treatment in the community facilitates access to treatment for patients	<ul style="list-style-type: none"> <li>Testing and treatment in the community to be prioritised, the patient pathway to be reviewed and flexible services located where patients are most likely to access them to be designed</li> </ul>	ODNs
	<ul style="list-style-type: none"> <li>Funding mechanisms to be developed to ensure treatment cost savings are reinvested into developing services and treating additional people</li> </ul>	NHS England
	<ul style="list-style-type: none"> <li>Increased in-reach and treatment delivery in prisons by primary care teams to be facilitated</li> </ul>	ODNs
	<ul style="list-style-type: none"> <li>Treatment to be distributed directly to community settings, and as many people as possible to be trained and accredited to deliver treatment in diverse settings including substance misuse services, sexual health clinics, hostels, pharmacies and home care</li> </ul>	ODNs
	<ul style="list-style-type: none"> <li>The most effective funding and organisational responsibility set-up to be determined to widen delivery of treatment through home care</li> </ul>	ODNs
	<ul style="list-style-type: none"> <li>A clear protocol to be developed for when a patient can be treated without referral to specialist care, for example based on APRI or FIB4 scores</li> </ul>	British Association for the Study of Liver, British Viral Hepatitis Group

**Objective 5.3: Treatment is flexible and presents minimal disruption to patients, minimising the risk of patients dropping out of the care pathway.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Substance misuse services, sexual health clinics, and prisons have sufficient funding to effectively deliver case-finding and testing initiatives	<ul style="list-style-type: none"> <li>The deal to include effective mechanisms to ensure funds are effectively distributed to all necessary areas</li> </ul>	NHS England, industry
New case-finding initiatives are supported by the upcoming funding agreement	<ul style="list-style-type: none"> <li>Consideration to be given to the introduction of monetary incentives for testing and treatment initiations</li> </ul>	NHS England, industry

**Objective 5.4: Access to treatment is universal, including for those who are reinfected.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Universal access to treatment, including for those reinfected, leads to a steadily falling prevalence and incidence rate	<ul style="list-style-type: none"> <li>NHSE guidance to be developed to support and enable treatment of patients who are reinfected</li> <li>All diagnoses to be initiated onto treatment regardless of whether it is a first infection or reinfection</li> </ul>	NHS England

**Objective 6.1: A long-term, strategic approach to funding for hepatitis C care and treatment is supported by a national elimination strategy.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
An effective long-term funding deal between NHS England and industry is reached and supported by a national elimination plan	<ul style="list-style-type: none"> <li>The deal to be accompanied by additional funding to find the undiagnosed and initiate greater numbers of patients into treatment</li> <li>The elimination strategy to include mechanisms to determine who is responsible for delivering each aspect of the strategy</li> </ul>	NHS England, industry, Department of Health and Social Care

**Objective 6.2: The new strategic funding model effectively supports the greatest possible number of diagnoses and treatment initiations each year.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Substance misuse services, sexual health clinics, and prisons have sufficient funding to effectively deliver case-finding and testing initiatives	<ul style="list-style-type: none"> <li>The deal to include effective mechanisms to ensure funds are effectively distributed to all necessary areas</li> </ul>	NHS England, industry
New case-finding initiatives are supported by the upcoming funding agreement	<ul style="list-style-type: none"> <li>Consideration to be given to the introduction of monetary incentives for testing and treatment initiations</li> </ul>	NHS England, industry

**Objective 7.1: Ambitious local, regional and national targets are used to incentivise and drive increases in testing and treatment.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
A national elimination strategy with ambitious targets is developed to support the upcoming strategic funding agreement	<ul style="list-style-type: none"> <li>A national elimination strategy to contain targets for incidence, prevalence, and mortality going beyond the global baseline set out in the World Health Organization's Global Health Sector Strategy on Viral Hepatitis</li> <li>Micro-elimination strategies (at city or sector level) to be used as a tool to monitor early progress and inspire good practice</li> </ul>	Department of Health and Social Care

**Objective 7.2: Improved accuracy of incidence and prevalence data enables more efficient allocation of resources and monitoring of progress towards elimination.**

Desired outcome supporting elimination	Suggested actions	Suggested organisational responsibility
Improved data collection and reporting enables more efficient allocation of resources and monitoring of progress towards elimination	<ul style="list-style-type: none"> <li>Surveillance systems for prevalence and incidence among PWID and MSM to be improved, and surveillance for the homeless population to be established, so effectiveness of strategies aimed at different groups can be better analysed</li> <li>A hepatitis C elimination lead in PHE to be appointed</li> <li>Indicators included in annual hepatitis C reporting to be kept under review</li> </ul>	Public Health England

**Objective 7.3: Additional research and pilot projects allow for bold, innovative approaches to improvement in hepatitis C care.**

<b>Desired outcome supporting elimination</b>	<b>Suggested actions</b>	<b>Suggested organisational responsibility</b>
<p><b>Improved monitoring of innovative initiatives and approaches to hepatitis C care allows successful models to be easily identified and up-scaled</b></p>	<ul style="list-style-type: none"> <li>• Improved surveillance of reinfection rates to be implemented in order to better target resources for re-testing and retreatment</li> <li>• Additional research to be conducted into the potential for hepatitis C treatment to reduce reoffending rates or contribute to recovery journey</li> <li>• Ground-breaking research on hepatitis C care to continue to be conducted and commissioned</li> <li>• Results of local pilot projects to be distributed nationally and scale-up of effective initiatives encouraged</li> </ul>	<p>Public Health England, HCV Action</p>



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