

# HCVAAction

The voice of the hepatitis C professional community

## Taking the initiative:

how England is eliminating hepatitis C



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## 1. Foreword

The current NHS England Elimination Programme for hepatitis C has been an unprecedented arrangement and has yielded many great successes in the fight against the virus. Moreover, it is serving both as an example for other countries to learn from in their own efforts to eliminate hepatitis C before the World Health Organization 2030 goal and for how the NHS itself can tackle other public health challenges, as evidenced by NHS England stating that their new national agreement for HIV treatment and preventative drugs will build on the approach taken with hepatitis C.<sup>1</sup> This report is a first of its kind attempt to pull together the stories of the various initiatives that have made up the Elimination Programme and to learn key lessons from them, drawing upon in-depth interviews with voices involved from NHS England, The Hepatitis C Trust and pharmaceutical company partners.

Moreover, with the present programme coming to an end in 2024, there is a need for healthcare leaders and senior politicians, in partnership with other key stakeholders, to develop alternative arrangements for the continuation of hepatitis C efforts. While these discussions are ongoing, we hope this report can inform them and help ensure that the momentum the Elimination Programme has built is suitably maintained, so that we can eliminate hepatitis C by NHS England's 2025 target and maintain elimination thereafter.

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**Chair of HCV Action and Consultant Hepatologist,**  
**Nottingham University Hospitals NHS Trust and**  
**Biomedical Research Unit**

<sup>1</sup> Heafield, S (2022) 'Making more of medicines in the drive to end new HIV infections', NHS England. Available at: <https://www.england.nhs.uk/blog/making-more-of-medicines-in-the-drive-to-end-new-hiv-infections/>

## 2. Executive Summary

### Background

In December 2022, NHS England reported that it was on track to eliminate hepatitis C by 2025 and attributed this to its pioneering elimination programme. In just three years, the programme has found and treated 60,000 people for hepatitis C.

The NHS England elimination programme was developed in response to the WHO goal to eliminate hepatitis C by 2030. It responded to two critical challenges in addressing hepatitis C in England: firstly, most people with hepatitis C are unaware they have the virus, and secondly, many of those who do live with the virus face significant barriers to accessing treatment.

NHS England met these challenges with a ground-breaking commissioning model, asking pharmaceutical companies not just to set a competitive price for their drugs, but to propose strategies to find, diagnose and treat people in need of them as well. The resulting 'elimination deal' fixed drug prices and catalysed a series of new hepatitis C education, testing and support programmes. It also fostered collaboration from the outset, with the NHS, prisons, social care, the voluntary sector and the pharmaceutical industry working in partnership across England and in local areas.

This report explores the development of the programme, how several of the key initiatives have worked and developed over time, and next steps in the programme. It draws together publicly available reports and data on the initiatives, and data from a series of interviews undertaken with representatives from partners working on the initiatives involved. The report focuses on twelve such initiatives, selected in consultation with NHS England as particularly significant elements of the programme.

### Initiatives

The initiatives developed under the elimination programme take a wide range of approaches to reach and test people who need hepatitis C testing, and to support people who are diagnosed to access and complete treatment. The work is targeted mainly through services – working in settings such as prisons, drug services and hostels which tend to engage with higher numbers of people with hepatitis C – though testing is also becoming a routine add-on in other services as well. While each is distinct, the initiatives work across local systems to provide a comprehensive response to increasing hepatitis C testing and treatment:

- **Community peer-to-peer support:** Staff and volunteers with lived experience of hepatitis C use their professional skills and personal experience to find, engage and test people and support them through treatment. They work across local health systems, forming partnerships and delivering staff training. Peer teams have tested more than 29,000 people in 3 years and supported at least 5,200 into treatment – around 10% of all patients since the elimination programme began.
- **Outreach vans:** Vans include a mobile clinical space, allowing hepatitis C testing and treatment teams to seek out new populations and reach people who might not be engaged through other services. Vans typically visit hostels, day centres or outdoor areas.
- **South Asian community awareness and peer outreach:** Higher rates of hepatitis C are found among some British Asian communities, due to unsafe procedures carried out in some countries where people may have familial ties, and those affected may also be subject to stigma. This led to the development and expansion of a specialist peer programme in relevant communities which has tested over 700 people, alongside a national awareness campaign.
- **Community Liaison Officers:** CLOs link the work of acute trusts with other secondary care and community services for hepatitis C, to ensure pathways work for people who need treatment.
- **Prison – High Intensity Test and Treat (HITTs) and reception testing:** 'HITT' events test every person in a prison over a few days and link anyone diagnosed into hepatitis C treatment. This complements work with prison staff and governors to ensure all prisoners are tested at reception. This has seen 27,118 people tested as a result of HITTs.

- **Probation and bail hostel HITTs:** In addition to prisons, other institutions such as probation facilities and approved premises (bail hostels) have also been targeted for HITTs, providing an opportunity for residents to learn about hepatitis C, overcome stigma, get tested and, where necessary, access treatment.
- **Prison peer programme:** As in community settings, paid and volunteer peers work in prisons to build awareness, combat stigma, encourage testing and support people to access and undertake treatment. 85 volunteer peers have been recruited across 90 prisons and provided with line management and training by local Hepatitis C Trust peer teams.
- **Pharmacy testing:** Testing in pharmacies enables clients accessing needle exchange or opioid substitution to get tested for hepatitis C. Although there has been difficulty with uptake, examples of good practice are emerging.
- **The Patient Search Identification Tool:** Using NHS General Practice health records, this electronic tool screens for common risk factors and provides practices with a list of patients who may need to be tested for hepatitis C.
- **Testing and treatment in drug services:** Many people accessing drug services should receive testing and treatment for hepatitis C. However, pathways between drug treatment services and the NHS were prone to fragmentation, leading to a new effort by Gilead, the NHS and third sector drug treatment providers to optimise pathways, develop common standards and improve data-sharing.
- **Emergency Department (ED) testing:** Blood taken for any reason in several emergency departments across England is now routinely tested for hepatitis C, hepatitis B and HIV unless the patient opts out. This has proven effective at finding new cases of hepatitis C and B and HIV, along with previous cases that were lost to follow-up.
- **Point of Care testing:** These efforts involved the provision of oral swab kits by AbbVie and Cepheid testing machines by MSD, in order to offer testing with ongoing care to people in a variety of settings where there is a higher than normal prevalence of hepatitis C.
- **New initiatives:** In 2022, the NHS outlined plans for wider Emergency Department-style testing in additional settings, such as antenatal units, and for provision of at-home testing kits for those unable to access other services.

### Lessons

The most recent data we have shows the impact the elimination programme is having: prevalence fell in England by 43% between 2015 and 2021, while deaths from hepatitis C-related liver disease fell by 31%.

These initiatives vary widely in their approaches, complimenting and reinforcing each other. However, a number of common lessons can be drawn which help to illuminate the successes of the programme overall and lessons for tackling hepatitis C and similar public health challenges.

- Relationship-building and innovative new collaborations - between NHS bodies, voluntary organisations, prisons, pharmaceutical companies, drug services and other health and care providers – have played a crucial role in the programme. These partnerships have facilitated ongoing innovation, which in turn has been disseminated throughout the country by NHS England to ensure equity.
- Employing people with lived experience to find, test and support people with hepatitis C has enabled NHS services to reach people who typical health services tend to exclude. With roles working right across local health systems, peer teams are able to bring hepatitis C services to people in an appealing and acceptable way. These partnerships have also driven innovation and new approaches to person-centred care.
- There are opportunities to make screening for hepatitis C testing and other blood-borne viruses a routine and expected part of standard healthcare, and embed hepatitis C awareness among professionals who are working with people more likely to contract it. Consistent prison reception testing, and regular testing in drug treatment settings, is critical to elimination and to maintaining elimination over the long-term.
- Combined HIV, hepatitis B and hepatitis C testing in Emergency Departments offers a hugely effective way to identify people with BBVs. Integrating the resources for combined testing increases impact and reduces costs, while making testing routine and reducing potential stigma for patients who might feel they have been targeted. There are likely to be more opportunities for routine, integrated testing as we move towards maintaining elimination.

- Working across criminal justice settings, and linking these to community settings, holds real benefits. Strong reception testing must be combined with ensuring through-the-gate support for people leaving prison before they have started or completed their hepatitis C treatment. This is especially important where people are serving short sentences, and in prisons with high turnover.

## Conclusions and recommendations

The approach taken by NHS England to initiate a series of connected initiatives to address hepatitis C has clearly seen considerable successes. This can be viewed not only as a successful programme for hepatitis C, but demonstrates how effectively the NHS can tackle health inequalities.

However, the current programme and 'elimination deal' with pharmaceutical companies will end in March 2024. Alongside the introduction of Integrated Commissioning Systems and local commissioning of hepatitis C treatment at some point, this will signal a huge change in how hepatitis C is diagnosed and treated.

Data also consistently shows that whilst there has been great improvement in terms of diagnosing and treating people with hepatitis C, this is undermined by a lack of progress in reducing new infections. Investment in effective harm reduction measures that we know can prevent new infections, such as needle and syringe exchange programmes, will be crucial for hepatitis C elimination and for maintaining this over the long-term.

Drawing these factors together, and integrating our long-term approach across prevention, diagnosis, treatment and care, will require a comprehensive national strategy. This must sit across the NHS, UK Health Security Agency and other partners to align priorities, foster collaboration and integrate the hepatitis C response with wider work to tackle health inequalities.

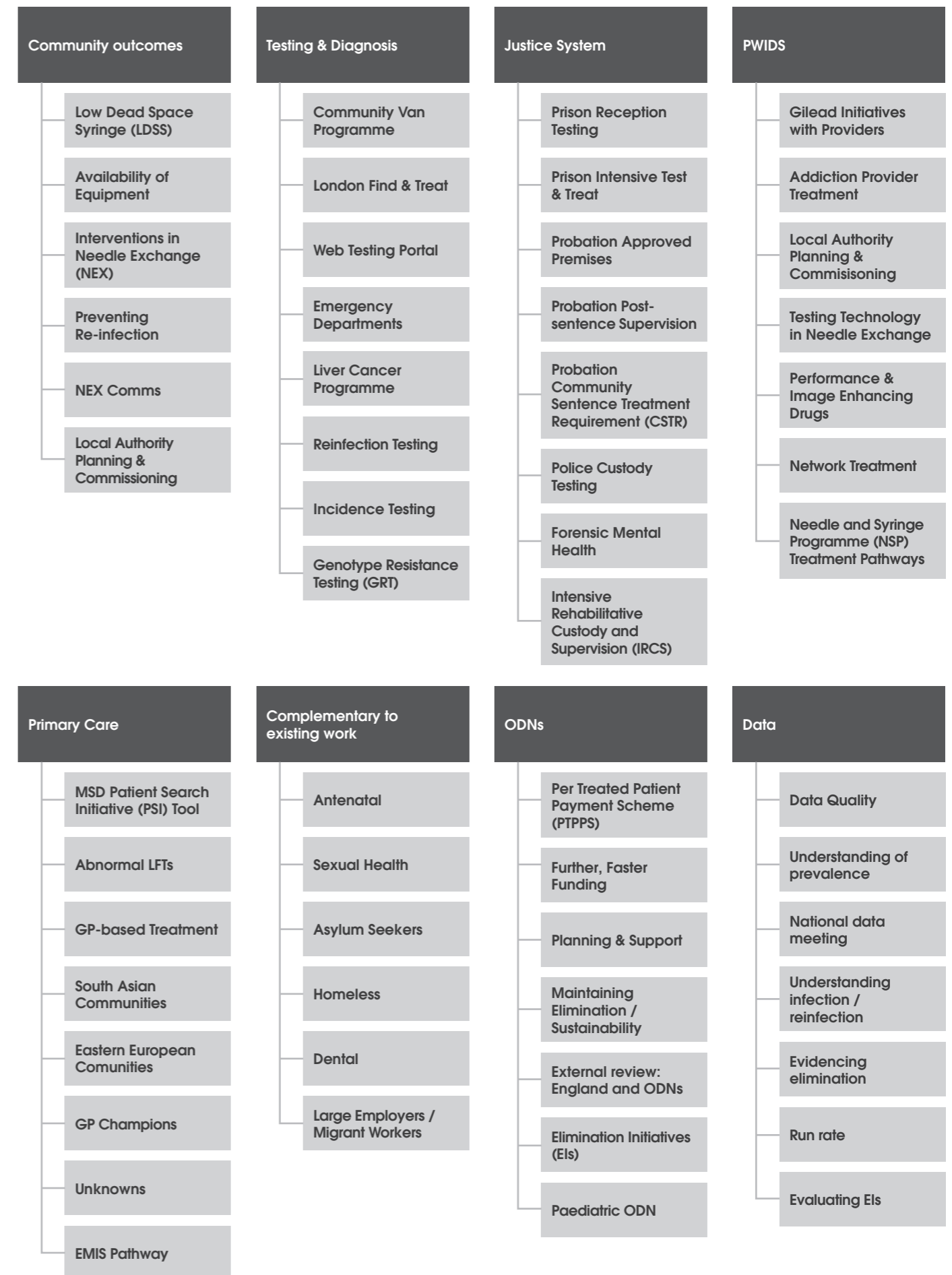


Figure: NHS England map of initiatives in the hepatitis C elimination programme

### 3. Introduction and methodology

England has developed a unique approach to elimination, driving collaborative working and innovation across the health system and partner services to combat hepatitis C. This has led to real learnings both for how we can eliminate hepatitis C across the UK and worldwide, and for how the UK can address other public health challenges. The aim of this report is to provide an overview of the NHS England elimination programme agreed in 2019. It profiles case-finding and treatment elimination initiatives that have been developed in different parts of the country and wider health and care system as a result.

Hepatitis C is a blood-borne virus (BBV) primarily affecting the liver. Without treatment, it can lead to an increased risk of mortality, liver disease, and many other health problems. There are a number of transmission routes, but the most common in the UK is through the sharing of drug-taking equipment, which accounts for around 90% of new infections. Hepatitis C is preventable and curable. In 2016, the UK Government signed up to the World Health Organization (WHO) global health sector strategy on viral hepatitis, which aims to eliminate hepatitis C as a public health threat by 2030. This strategy set goals for the prevention and cure of hepatitis C nationwide, as well as reductions in associated mortality. National viral hepatitis elimination programmes are now underway in all four UK nations, with NHS England specifically setting a target to eliminate the virus by 2025.

The programme in England has included an elimination deal between NHS England and three pharmaceutical companies, which supported some of the initiatives and partnerships with Hepatitis C Operational Delivery Networks (ODNs), NHS England Health and Justice, The Hepatitis C Trust, providers of healthcare in prisons, drug treatment service providers, local GPs and others. The report explores why an elimination programme and specific strands were considered necessary, how the initiatives were designed to work, how they have worked in practice and developed over time, and next steps in the final period of the current programme.

This report hopes to provide the overall context and narrative of the elimination programme and elimination initiatives, with the aim of documenting and celebrating the progress that has been made towards hepatitis C elimination in England and ensuring learnings are shared from this unique procurement exercise.

It focuses on twelve of the elimination initiatives developed in England, selected in consultation with NHS England.

#### Community-Based Initiatives

1. Community peer-to-peer support
2. Outreach vans
3. South Asian community awareness campaign and peer outreach work
4. Community Liaison Officers

#### Initiatives in the Criminal Justice System

5. Prison High Intensity Test and Treat (HITTs) and reception testing
6. Probation and bail hostel HITTs
7. Prison peer programme

#### Initiatives in Primary Care

8. Pharmacy testing
9. Patient Search Identification Tool

#### Initiatives in the Wider Health System

10. Testing and treatment in drug services
11. Emergency Department (ED) testing
12. Point of Care testing

### Methodology

An initial meeting to determine the scope and focus areas was held in April 2022 with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus Elimination, NHS England) and Georgia Threadgold (Senior Project Manager – Hepatitis C Virus Elimination, Specialised Commissioning, NHS England). We also used data from NHS Operational Delivery Networks (ODNs) provided in response to a 2021 survey and conversations with pharmaceutical industry providers about initiatives they have sponsored.

From the further interviews with NHS England, pharmaceutical companies and The Hepatitis C Trust; from publicly available reports and data; and past contributions to HCV Action events and publications from stakeholders in the elimination programme, we then developed a picture of what these initiatives involved; how they have developed; and, where possible, what they have achieved and their next steps, as well as overall conclusions and potential future directions for the elimination programme.

### 4. Background to the elimination programme and initiatives

Low rates of awareness and diagnosis are a central challenge to eliminating hepatitis C in England. In April 2019, NHS England announced a “first of its kind” deal to find and cure tens of thousands more people with hepatitis C, with the aim of England becoming the first country in the world to eliminate the virus.<sup>2</sup> As part of the focus of the NHS Long Term Plan on reducing health inequalities, the deal enabled NHS England, three pharmaceutical companies and other partners to work together to proactively identify and treat patients living with an undiagnosed infection of hepatitis C.<sup>3</sup>

The three pharmaceutical companies who provide direct-acting antivirals (DAAs) in the UK – Gilead Sciences, Merck Sharp and Dohme (MSD), and AbbVie – were asked to develop an offer to the NHS, setting out the price at which they could provide their DAA treatments. The companies were also asked to propose case-finding and treatment initiatives they would fund to identify the many thousands of as-yet undiagnosed people with hepatitis C in England. Following a review of these offers, NHS England awarded bids from the three companies ‘gold’ (Gilead Sciences), ‘silver’ (MSD) and ‘bronze’ (AbbVie), reflecting the size of each tender.<sup>4</sup> The programme was initially due to last three years, but was subsequently extended to five years, ending in April 2024. For the duration of the deal drug prices are fixed, creating a saving for the NHS against what the drugs would cost at market price without the deal.

This process both reduced drug prices – enabling more people to be treated – and built a framework to increase the numbers of people being tested and diagnosed. An initial aim was set to treat between 15,000 and 18,000 patients a year.

### How initiatives were developed

The elimination initiatives put forward by the pharmaceutical companies were developed in partnership with local health services, other healthcare providers, and voluntary sector providers, including The Hepatitis C Trust. Many of these initiatives, including both those originally conceived in 2019 and those which were integrated into the elimination programme later, have built on existing learning, experience or infrastructure from other pilots or services.<sup>5</sup> The deal with pharmaceutical companies enabled investment from them alongside that from the NHS itself, and was initially intended to focus on four main types of case-finding initiatives, concentrating on prisons, drug services, needle exchange in pharmacies and testing in GP practices.

NHS England was not prescriptive in setting the exact scope of the initiatives, instead setting out end outcomes and allowing the pharmaceutical industry providers and their partners to develop the specific initiatives. As part of its consideration of the offers made by each of the industry partners, NHS England assessed them to ensure the initiatives were comprehensive and could potentially cover the whole country with no geographical variation.<sup>6</sup> NHS England also provided some guidance on what would need to be covered, what would be practicable and feasible based on past experience, and introductions to relevant personnel in partners (e.g. governors and justice staff in the case of prisons).

The development and implementation of the elimination initiatives has been an iterative process, and they have evolved and expanded where appropriate. Practical implementation of initiatives sometimes proved more challenging than envisaged, necessitating a change of approach. As the roll-out of initiatives led to progress in some areas of the elimination programme, other gaps became apparent and new initiatives were devised to meet these needs. The first set of initiatives were launched in July 2019 and underwent a review in January 2020, in which ODNs were asked for their assessment of what was working. Reviewing the progress of initiatives has also been an opportunity for NHS England to review the geographies of different initiatives and

2 NHS England (2019) ‘NHS England strikes world leading deal to help eliminate hepatitis C’, 30 April 2019. Available at: <https://www.england.nhs.uk/2019/04/nhs-england-strikes-world-leading-deal-to-help-eliminate-hepatitis-c/>

3 NHS England (2019) ‘NHS Long Term Plan’. Available at: <https://www.longtermplan.nhs.uk/>

4 PMLive (2019) ‘Gilead Sciences gets ‘gold’ in England’s hepatitis C eradication drive’, 29 April 2019. Available at: [https://www.pmlive.com/pharma\\_news/Gilead\\_Sciences\\_gets\\_gold\\_in\\_englands\\_hepatitis\\_c\\_eradication\\_drive\\_1286159](https://www.pmlive.com/pharma_news/Gilead_Sciences_gets_gold_in_englands_hepatitis_c_eradication_drive_1286159)

5 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

6 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

how they were aligning, to ensure that the overall elimination programme wasn't too "piecemeal" and that encouraging results from certain initiatives could be replicated elsewhere if further ODNs expressed interest. For example, Gilead Sciences and The Hepatitis C Trust working closely with Practice Plus Group on High Intensity Test and Treat (HITT) events in prisons subject to PPG health provision produced results, leading NHS England to ensure that funding was provided to expand a version of this to the entire prison estate.<sup>7</sup>

As a result of these review processes and the availability of funds at certain points in the life of the programme, new initiatives have also been developed since 2019. Over time NHS England offered NHS Trusts opportunities to put forward business cases and bid for additional funds or pursued national-level efforts with other types of providers (for example, with community pharmacies). Pharmaceutical partners also identified funds in their budgets that could be used to explore further initiatives. And most recently in July 2022, NHS England announced new initiatives under the elimination programme as it enters its final years, such as a web portal offering self-testing for hepatitis C and the inclusion of hepatitis C in routine antenatal screening.

## 5. Elimination initiatives

### Community-based initiatives

#### Community peer-to-peer support

##### Background need

An estimated 74,600 people are living with hepatitis C in England. It is thought that more than half of those affected are unaware of their diagnosis. People living with or at risk of hepatitis C – in particular people who inject drugs (PWID), who make up more than 90% of those affected – are often poorly reached by health services and face stigma and intersecting layers of discrimination. They may also be unable to access health services for other practical or geographic reasons.

##### About the initiative

This background need is why The Hepatitis C Trust has run a peer-to-peer programme in the UK since 2010, in which people with lived experience of hepatitis C draw on that experience to support others at risk. This includes highlighting the importance of testing and attending clinic appointments, and providing practical one-on-one support. This approach is known to increase testing numbers and the likelihood of diagnosed patients going on to access specialist monitoring, and where appropriate, treatment. It enables the dissemination of key messages about hepatitis C prevention, diagnosis, treatment and care to people impacted by or at risk of hepatitis C infection wherever they are found, including drug services, hostels and homeless shelters.<sup>8,9</sup>

The Hepatitis C Trust was able to test the role of peers with lived experience in strengthening patient voice and helping patients to overcome stigma and lack of trust in services stemming from poor experiences in the past, for example by buddying them for hospital appointments. People with lived experience were able to deliver workshops and train workers in drug treatment and other allied services. The Hepatitis C Trust reported that peers were essential to ensuring that these perspectives stayed central to user experience, as staff training often was not enough to ensure that services continued to serve people from the client groups most affected by hepatitis C once peers leave.<sup>10</sup>

Under the deal with pharmaceutical providers, AbbVie and MSD supported the further development of peer-to-peer community support projects, alongside NHS England. AbbVie and MSD each asked The Hepatitis C Trust about existing experience with peers and how many patients could be reached, tested and supported each year if it were expanded, prompting The Hepatitis C Trust to develop a proposal for potential peer-led case-finding initiatives.

Following implementation of the MSD and AbbVie-funded Hepatitis C Trust Peer Elimination initiatives, NHS England subsequently confirmed that the track record of achievements by the peer programme created a business case for ensuring that every ODN initially had at least one peer.<sup>11</sup> Nine peer



Peers from The Hepatitis C Trust Midlands team at a testing event in Gainsborough, 2019

roles have been directly funded by AbbVie and 13 by MSD (not counting peers employed under the South Asian community initiative), with others funded directly by the NHS.

##### MSD

During the year leading up to the NHS elimination programme, MSD worked with the Hepatitis C Trust leadership to build on the peer experience and define the opportunity to provide a full-scale national peer programme. This was to be deployed as part of the NHS England elimination programme which was implemented in July 2019.

MSD funded initially 12 peer coordinators across 12 of the NHS ODNs. Each peer coordinator was to recruit a minimum of four peer volunteers in their respective ODN, in turn building a base of 48 volunteers for scalability and reach. For practical and resource reasons such as time needed to recruit, train and advertise for coordinators, the 12 new peer coordinators were recruited and trained in three tranches over 9 months, covering four ODNs at a time. Three project managers from MSD also undertook quarterly meetings with regional managers from The Hepatitis C Trust, with peer coordinators and often volunteers present, to monitor how recruitment of volunteers and levels

of community engagement were proceeding. MSD also undertook monthly or six-weekly meetings with ODN leads, to discuss progress, risks, issues and where MSD could provide support.<sup>12</sup>

##### AbbVie

AbbVie reported that early pilot work in 2017-2018 demonstrated to them the value of peer coordinators, prompting them to continue investing in hepatitis C peer initiatives as part of the national elimination programme.<sup>13</sup>

In 2019, AbbVie initially supported the development of peer-to-peer working in four ODNs (Cheshire and Merseyside, North East and North Cumbria, South Yorkshire and the North Central London Viral Hepatitis Network), working in partnership with The Hepatitis C Trust. In time, this also expanded to include the West Yorkshire ODN as well. Aiming to raise awareness of hepatitis C, identify and support hepatitis C positive clients to engage consistently with treatment services, they set performance indicators to measure success:

- Hepatitis C virus awareness, measured by number of clients attending workshops
- Number of clients referred to treatment
- Numbers of treatment starts

7 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

8 The Hepatitis C Trust, 'Community peer programme' and '#PeerSupportMeans'. Available at: <http://hepctrust.org.uk/services/community-peer-programme>; <http://hepctrust.org.uk/peersupportmeans>

9 Video from The Hepatitis C Trust about their peer-to-peer support work, where staff and volunteer peers with lived experience of hepatitis C have provided support to those at risk of and living with hepatitis C, raising awareness and supporting access to testing and treatment. <http://www.hcvaction.org.uk/resource/hepatitis-c-trust-peer-peer-programme>

10 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

11 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

12 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

13 From an interview with Natalie Wood (Business Unit Manager, AbbVie), November 2022

## Results so far

The inclusion of the peer-to-peer programme as an elimination initiative in the NHS England programme enabled The Hepatitis C Trust to substantially expand their recruitment of a staff network of Peer Support Leads across most of the ODNs. This helped with overcoming past difficulties with testing in services, and training was also given to partner services to raise awareness of the importance of testing. A peer support lead was employed by each of the four initial ODNs and a regional manager oversaw the programme; an early patient management system was developed based on the management software HubSpot; and peers were able to negotiate better pathways for patients that suited the client group, reducing patient drop-off from long waits and multiple appointments under the old system. This involved the development of a system in which peers could bring people directly to secondary care, bypassing GP referrals – the NHS accepted this approach on grounds that it aided equity of access for a patient group long excluded from services.

NHS England have reported that participants approached through outreach services were two-and-a-half times more likely to engage with healthcare systems if they were in a peer support group, and a 12% increase in those starting treatment if they had contact with a peer, suggesting that they are delivering good value.<sup>14</sup> The peer programme has also had good feedback from ODNs – at a meeting of ODNs in early 2020, NHS England asked which initiatives ODNs would like to see more of, and a majority of ODN representatives asked for an expansion of the peer programme. “It’s the thing that stood out as being one of the most successful at that point, particularly for the ODNs that hadn’t worked with peers before”, Rachel Halford of The Hepatitis C Trust commented. This expansion required the development of structures, with a larger pool of grassroots peers overseen by senior peer leads and regional managers.<sup>15</sup>

At time of writing, The Hepatitis C Trust employed 135 staff, mainly peer workers, as well as approximately 170 community volunteer peers and 85 based in prisons (see Prison Peers initiative below). Nine peers have been directly funded by AbbVie and 13 by MSD, with others funded within the NHS. NHS England did not directly

employ any peers, but it enabled NHS Trusts to bid to a central pot of money and contract with The Hepatitis C Trust, leading to 22 such agreements to employ peers in local areas. Since the expansion of community peer working under the elimination programme, more than 29,000 patients have been tested and 5,220 supported into treatment.<sup>16</sup>

Community outcomes	2019/20	2020/21	2021/22	2019-2022 Total
Total number of people tested	1,845	7,452	19,919	29,216
Total number of people found to be RNA+	1,342	2,164	3,267	6,773
Total number of treatment starts	1,117	1,543	2,560	5,220

**Table 1: Patient outcomes from the community peer programme, 2019-2022, internal data from The Hepatitis C Trust senior management (as of January 2023)**

Additionally, The Hepatitis C Trust has reported that peer working has seen 15,401 staff trained in hepatitis C awareness in health, care and prison settings and that on average, just under 1 in every 7 tests (15.7%) undertaken in the community has identified markers for current or previous hepatitis C infection.<sup>17</sup>

As was the case for many of the elimination initiatives, it should be noted that from early 2020, the COVID-19 pandemic had a significant impact on delivery and it is likely that more patients may have been engaged, tested and supported with treatment if it were not for the impact of the pandemic.

## Reflections and future plans

Staff from The Hepatitis C Trust reflected that peers could sometimes become overstretched with their functions or lose autonomy as more management layers were added to oversee the expanding scheme and ensure that people with complex needs are getting enough support. They also expressed concern about ensuring that peer programmes receive enough time and funding in the closing years of the elimination programme to find and support through treatment as many people as possible in target communities before areas announce that they believe micro-elimination has been achieved. This will ensure that no potential patients are “left behind”.<sup>18</sup>

MSD has aimed to use the monitoring meetings it has held with The Hepatitis C Trust and peers to document and share best practice, including with ODNs and peers not funded by MSD. MSD believes that the initiative has shown that investing in peer networks is resulting in greater patient engagement, in terms of people being tested, found to be positive, treated or otherwise provided with information at workshops. It has built on the existing work of The Hepatitis C Trust, suggesting “People with lived experience - peers - have been a wise investment for us”.<sup>19</sup>

The immediate value of peers was the importance of lived experience, as peer volunteers know where people at risk of hepatitis C can be found and can engage with them at a different level. AbbVie also suggested that the expanded role of peers in being able to find and support people has been valuable, as it enables immediate testing. Feedback from ODNs had been strongly positive, though in some areas it took longer than in others for clinical or service staff to understand the peer programme and grant them vital access.<sup>20</sup>

The popularity of peers funded by MSD and AbbVie has also led to demand from ODNs and therefore to decisions by NHS England to directly fund additional peers. Peer roles have varied according to need and local ODN pathways, with some being involved in testing and others prioritising engagement and leaving testing to clinical staff, for example. Professor Graham Foster has commented that “peers are always one of the success stories... We’ve had a federal system where people do their own thing because we think that gets the best out of people, we’ve left (ODNs) to use the peers in whatever way they see as appropriate, but we know they’re very highly regarded.”<sup>21</sup>

“People with lived experience – peers – have been a wise investment”

Kuldip Sembhi, Hepatitis C Elimination Programme Lead, MSD

MSD did suggest that there is a case for strengthening coordination and information-sharing between peers and services to obtain more accurate data.

## Outreach vans

### Background need

Services offering hepatitis C testing are often far away from those who need to be tested, and people may be wary of having blood taken or be unaware that they are at risk. This is a likely contributing factor to many of the estimated 74,600 people in England with hepatitis C remaining undiagnosed.<sup>22</sup>

### About the initiative

Outreach vans have a long-established role in getting health services to people who tend to be excluded from the mainstream healthcare system, including in reaching and diagnosing people with hepatitis C. Since 2011, mobile outreach vans run by The Hepatitis C Trust have targeted at-risk populations, offering rapid antibody testing, information and advice from trained staff. This work involves partnering with local services to publicise a visit, maximising use of available time and establishing referral pathways. Vans will typically visit hostels, day centres or other sites where people may need hepatitis C testing, but where testing is not available as part of the existing on-site service, or provide a mobile site to conduct street outreach away from services.<sup>23</sup> However, prior to the elimination programme, the use of vans in hepatitis C care at scale was rare. NHS England and The Hepatitis C Trust have worked to increase the usage of outreach vans in several ODNs. Vans are operated by peers and/or clinical staff, and may be equipped with Cepheid point of care RNA testing machines and Fibroscan machines as well as BBV testing options.

<sup>14</sup> Fenton, K and Gillyon-Powell, M (2022) ‘Emergency department opt out testing for HIV, hepatitis B and hepatitis C: The first 100 days’. NHS England, 29 November 2022. Available at: <https://www.england.nhs.uk/long-read/emergency-department-opt-out-testing-for-hiv-hepatitis-b-and-hepatitis-c-the-first-100-days/>

<sup>15</sup> From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

<sup>16</sup> From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

<sup>17</sup> Reid, L et al (2022) ‘Peer-led HCV services reach poorly serviced populations at scale: a model for tackling health inequalities’, The Hepatitis C Trust. Available at: [https://www.postersessiononline.eu/173580348\\_eu/congresos/ILC2022/aula/THU\\_256\\_ILC2022.pdf](https://www.postersessiononline.eu/173580348_eu/congresos/ILC2022/aula/THU_256_ILC2022.pdf)

<sup>18</sup> From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

<sup>19</sup> From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

<sup>20</sup> From an interview with Natalie Wood (Business Unit Manager, AbbVie), November 2022

<sup>21</sup> From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

<sup>22</sup> UK Health Security Agency (2023) ‘Hepatitis C in the UK 2023: Working to eliminate hepatitis C as a public health threat. Data to end of 2021’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1133731/hepatitis-c-in-the-uk-2023.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1133731/hepatitis-c-in-the-uk-2023.pdf)

<sup>23</sup> The Hepatitis C Trust, ‘Outreach and testing van.’ Available at: <http://hepctrust.org.uk/services/outreach-and-testing-van>



Mayor of London Sadiq Khan with representatives from The Hepatitis C Trust and London Joint Working Group on Substance Use and Hepatitis C (LJWG) with the Trust's testing van, 2019

In a HepCare study on the work of Find & Treat, Surey *et al* concluded that “highly trained peer support workers working as part of a specialist outreach clinical team help to identify a high proportion of individuals exposed to hepatitis C, achieve high rates of engagement with treatment services and maintain high rates of treatment success amongst a population with complex needs”. In 2019, over a third of people tested by UCLH Find & Treat for hepatitis C required treatment for the virus.<sup>24</sup>

Vans were not part of the original elimination programme in 2019, but in the autumn of 2020, NHS England offered local ODNs funding to provide clinical outreach vans to reach patients not currently engaged with services.<sup>25</sup> ODNs were then able to put forward business cases for funding to secure vans locally. In 2021 NHS England commissioned 10 new community outreach vans as an investment under the hepatitis C elimination programme, in order to find and treat people where they live rather than “expecting patients to travel long distances to hospital-based services”.<sup>26</sup> The 10 community vans support safe community working across ODNs in England, and alongside other independently funded vans they focus on areas of high health inequality and offer testing (and treatment) to

patients from various backgrounds such as those who sleep rough, asylum seekers, sex workers and people who inject drugs.<sup>27</sup> In 2021, it was hoped an additional Find & Treat van based with UCLH would enable the testing of “tens of thousands” of people England-wide, particularly people from homeless populations who are impacted by hepatitis C and other conditions.<sup>28</sup>

#### Results so far

NHS England report new data about the impact of community van work is due to be published in 2023, but at the time of writing we do have some examples of data for vans in specific areas. For example, an NHS England-funded Community Van operated by Birmingham ODN has been in use across the West Midlands since May 2021. Prior to this, the Birmingham team were already using a mobile unit, which was funded by the University Hospital Birmingham Charities and paid for only for the days that it went out. As of March 2022, the new NHS England-funded van had been used for 87 days and enabled 184 people to be reached and tested. Some teams delivering with the van used it as a clinic in a set venue each week, and other teams used it on a more ad hoc basis at different sites or for testing events at sites across the West Midlands.<sup>29</sup>

#### Reflections and future plans

NHS England and NHS Cancer Alliances also developed an initiative that enabled NHS organisations to put forward a business case for a second van focused on the early detection and treatment of liver disease. Starting in March 2022, this included an outreach partnership pilot with hepatitis C ODNs in 12 areas, with the NHS England Cancer Directorate to deliver fibroscans and ultrasound scans, alongside hepatitis C testing, to high-risk populations using community vans. Those who have advanced cirrhosis (or other liver disease) can be referred into a liver surveillance pathway and provided with peer support to help them stay on that pathway.<sup>30</sup> Several ODNs now have these second vans, which represents a potentially significant crossover with work to tackle hepatitis C.<sup>31</sup>

#### South Asian community initiatives: peers and awareness campaigns

##### Background need

Higher rates of hepatitis C are found among some Asian or Asian British populations than in the UK population as a whole. This may be linked to higher rates of hepatitis C in parts of South Asia and to “sub-optimal sterilisation procedures” for medical and dental care in some facilities in South Asian countries, which can lead to people contracting hepatitis C before moving to the UK or when returning to visit.<sup>32</sup> The incidence of hepatitis C can be up to five times higher among British South Asian people than the UK population, with an estimated 7,500 people living with undiagnosed hepatitis C and at risk of serious illness.<sup>33</sup>

One challenge in increasing testing and treatment among South Asian communities is the issue of social stigma, which can prevent people from accessing testing. The often-asymptomatic nature of hepatitis C can also delay people who think they may have the virus seeking treatment if they feel well, despite the risk of liver damage increasing with time.<sup>34</sup> It is therefore essential that information about hepatitis C is provided in

a way that is accessible and meaningful to the target populations, in order to reduce stigma and increase both awareness of the virus and access to testing.

##### About the initiative

To face this challenge, since 2009 The Hepatitis C Trust has run projects which aim to support South Asian populations, including the use of peer workers and testing events at religious sites and events such as Melas. The elimination programme built on this work with two distinct strands supported by different pharmaceutical companies. Initially Gilead Sciences developed social media campaigns and awareness events to raise overall knowledge of the virus among South Asian communities, and in a later addition to the elimination initiatives, MSD supported outreach work in these communities, working closely with and building on existing programmes initiated by The Hepatitis C Trust.

##### Awareness work

Building upon HepFREE research<sup>35</sup> into how to deliver primary care to ethnic minority and/or immigrant populations, in 2019/20 Gilead Sciences included five ODNs in a first-year pilot (Leicester, Manchester, Barts, St George's and Lancashire). Gilead Sciences also suggest that they brought experience with “developing and measuring disease awareness campaigns at pace” to this particular initiative. An existing Facebook campaign around ‘Be Free of Hep C’ was updated in August 2019 to target South Asian populations specifically. In 2020, the South Asian work was deepened to include benchmarking, influencer mapping and sourcing of campaign champions, and an ‘Expert Council’ was established to support the development of the campaign approach and materials.<sup>36</sup>

The initiative also involved the development of a dedicated website, engaging comedians and developing comedy video content under the name ‘Hep C, Ki?’, a programme which encourages at-risk individuals within British South Asian communities to seek advice from their healthcare provider, get tested and get treated.<sup>37,38</sup>

24 Surey, J *et al* (2019) ‘From peer-based to peer-led: redefining the role of peers across the hepatitis C care pathway: HepCare Europe’, *Journal of Antimicrobial Chemotherapy*, Volume 74, Issue Supplement\_5, November 2019, Pages v17–v23. Available at: <https://doi.org/10.1093/jac/dkz452> & HSJ Solutions (2019) ‘Hospital designs an outreach service to facilitate early diagnosis and interventions for preventing risk of tuberculosis and hepatitis C, delivering screening and healthcare to over 100,000 people’. Available at: [bit.ly/3VQ2Wj9](http://bit.ly/3VQ2Wj9)

25 Midlands Partnership NHS Foundation Trust (2020) ‘Pioneering outreach service extended’. Available at: <https://www.mpft.nhs.uk/about-us/latest-news/pioneering-outreach-service-extended>

26 UCLH Foundation Trust (2021) ‘World Hepatitis Day marks arrival of a new van to find & treat homeless patients’, 28th July 2021. Available at: <https://www.uclh.nhs.uk/news/world-hepatitis-day-marks-arrival-new-van-find-treat-homeless-patients>

27 UK Health Security Agency (2022) ‘Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full report. Data to end of December 2020’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

28 UCLH Foundation Trust (2021) ‘World Hepatitis Day marks arrival of a new van to find & treat homeless patients’, 28th July 2021. Available at: <https://www.uclh.nhs.uk/news/world-hepatitis-day-marks-arrival-new-van-find-treat-homeless-patients>

29 Data supplied by Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), December 2022

30 UK Health Security Agency (2022) ‘Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full report. Data to end of December 2020’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

31 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

32 Bristol-Myers Squibb Pharmaceuticals Ltd, The Hepatitis C Trust & the British Liver Trust (2015) ‘Hepatitis C in the South Asian Community: A Best Practice Casebook’. Available at: <http://hcvaction.org.uk/sites/default/files/resources/CASE%20BOOK%20FINAL%20%283%29.pdf>

33 Interview and data from Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Jamina Gibson (Marketing Specialist, Gilead Sciences), November 2022

34 The Hepatitis C Trust – South Asian Outreach. Available at: <http://hepctrust.org.uk/services/south-asian-outreach>

35 NHS Health Research Authority (2016) ‘HepFree sub-study version 1’. Available at: <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/hepfree-sub-study-version-1/>

36 HCV Action (2019) ‘National Hepatitis C ODN Stakeholder Event, Thursday 4th July 2019’. Available at: <http://www.hcvaction.org.uk/sites/default/files/resources/National%20Hepatitis%20C%20ODN%20Stakeholder%20Event%20slides%20-%20website.pdf>

37 Hep C Ki?. Available at: <https://hepc.co.uk/>

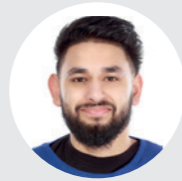
38 Hep C, Ki? (2021) Available at: <https://www.youtube.com/playlist?list=PLzJyFqhb0Uo2bZkYDuKYA6O4mjhZVbZi>





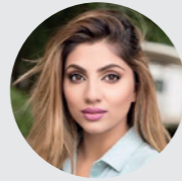
“ Before getting involved with Hep C, Ki? I didn't know what hepatitis C was, how you get it, what the symptoms are, or how it can impact your long-term health – it was a mystery to me. I was particularly surprised to learn that half of people living with hepatitis C don't know they have it. I would urge everyone who thinks they might be at risk to ask their GP for a test and to encourage their family to do the same. ”

Sukh Ojla



“ Those of us who take family visits to the “motherland” can often miss or overlook the areas of risk associated with hepatitis C – be it unsanitised needles at a hospital, or razors at a barber. As a creator from a minority background, I felt compelled to lend my voice to something that could help my community. Humour can have such a powerful way of making you see things in a different light and I'd like to think this campaign has delivered a message in a unique way that hasn't been explored before and encourages people to get tested. ”

Ali Official



“ I am so proud to be supporting Hep C, Ki? - a campaign that is breaking down barriers and helping to protect the health of our community. ”

Mehreen Baig

Quotes from comedians supporting 'Hep C, Ki?' on the campaign's website: <https://hepc.co.uk/>

'Hep C, Ki?' was chosen as the South Asian HCV awareness campaign name when it launched in May 2021. Translating across many South Asian languages as “Hep C, what?”, the phrase is intended to reflect lower awareness of hepatitis C amongst South Asian communities in England and promote family-led discussions about risk factors.

Gilead conducted a series of qualitative interviews with hepatitis C patient group representatives, representatives from South Asian communities, and healthcare professionals working in high-prevalence areas in the UK. A quantitative survey was undertaken in partnership with Opinium, with over 300 respondents from a wide variety of ages, backgrounds, and locations across the three communities. All research was validated by a diverse multidisciplinary expert council consisting of representatives from key patient groups (including The Hepatitis C Trust), NHS England, South Asian communities and public health experts. Market research indicated that humour could be an effective way to reach and engage the target audience, helping to broach a taboo topic, reframe myths and reduce stigma.

At the heart of the Hep C, Ki? campaign is a series of shareable comedy videos, developed in collaboration with prominent South Asian comedians Ali Official, Eshaan Akbar and Sukh

Ojla. Dr Amir Khan was also included in the most recent videos to provide an expert voice. The videos focus on common, shared experiences of South Asian communities in the UK that intersect with the risk factors for contracting hepatitis C (e.g. travel and attitudes to health and community) whilst delivering clear and relatable messages on prevalence, risk factors, testing and treatment. As a multi-channel campaign, the launch also included a month-long radio advertisement programme, advertorials in key Asian media outlets, and targeted media activity. Based on learnings from the launch, the campaign also came to encompass a social media campaign across Facebook, TikTok, Instagram and WhatsApp based on nudge theory, reaching younger people and asking them to speak to older people.

Finally, an ODN toolkit was created, including a suite of materials that can be used in clinics to raise awareness of hepatitis C and testing services. The materials include a poster, screen saver and leaflet with a tailored call to action for each of the key five ODNs, and up to two versions in South Asian languages. These materials have also been provided to The Hepatitis C Trust for wider community events.<sup>39</sup>

### South Asian peer work

In 2021, MSD worked with The Hepatitis C Trust to further strengthen the South Asian peer work programme by funding and enabling the recruitment of two staff from December 2021. MSD began to support the South Asian peer project toward the end of the third year of the elimination initiative, in order to ensure that at-risk communities from different cultures were being reached. MSD worked with The Hepatitis C Trust to develop a proposal focused on South Asian communities, initially in twelve cities. Those cities were chosen by current footprint and relationships, anticipating that an impact could be made quickly in areas with South Asian communities and high prevalence.<sup>40</sup>

### Results so far

#### Awareness work

As of November 2022, Gilead estimate the reach of the 'Hep C, Ki?' campaign included:

- 5,000 engagements and over 85,000 views of campaign content on comedians' and influencers' social media
- A radio advert with a potential reach of 590,000
- 20 radio interviews with a potential reach of 2.8 million, including with BBC Asian Network, BBC Leicester, and BBC Leeds
- 11 original articles in print/online media, with greatest success in South Asian-specific and comedy trade outlets, such as the Asian Express
- 66% of print/online articles contained key campaign messaging and 50% of articles included one or more campaign video

Furthermore, following the success of the original launch of the campaign, on World Hepatitis Day 2022 Gilead teamed up with influencer Parle Patel to urge his followers and their families who think they might be at risk to get tested. The video received over 14,000 views across his social media channels. Follow up media outreach with existing media contacts on World Hepatitis Day led to traction in comedy and British South Asian news outlets. The KPIs set for the campaign by NHS England did not include a specific focus on testing.<sup>41</sup>

### South Asian peer work

The South Asian Peer project is still relatively new and work to assess the full impact of the programme is ongoing. However, since it started in December 2021, peer working in South Asian communities has seen 754 people tested.

### Reflections and future plans

Though largely predating these elimination initiatives, UK Health Security Agency data has suggested hepatitis testing increased by 66% in South Asian populations between 2015 and 2019. However, although testing fell 30% in 2020 due to COVID-19 (when 26,860 people were tested, down from a high of 38,175 in 2019), the proportion of those tested who tested positive for hepatitis C had also begun to fall even before the pandemic (from 1.5% in 2015 to 1.1% in 2019 and 1% in 2020).<sup>42</sup>

Rachel Halford of The Hepatitis C Trust suggested that outcomes data from the South Asian peer work so far, albeit from a short period, suggested that there is value to investing in peer programmes in specific ethnic minority and migrant communities: “If you're going to eliminate a disease, you need to be able to access every single community and one of the gaps were the South Asian communities”. She also suggested that there may be a case for Eastern European communities, also known to have higher hepatitis C prevalence, to receive similar support.<sup>43</sup> UKHSA data has suggested that HCV testing increased by 103.4% in Eastern European populations between 2015 and 2019, but again this testing activity was subject to a sharp fall in 2020 due to the COVID-19 pandemic, and the proportion testing positive fell to 3.1% in 2020.<sup>44</sup>

The MSD peer project team and The Hepatitis C Trust worked together to extend the original 12-month fixed term role for 2022, to instead last up to the end of March 2024. A consistent finding has been that alongside recruiting peer workers with lived experience, securing support from South Asian community and religious leaders who can encourage testing and minimise stigma has been important.

40 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

41 From an interview Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Jamina Gibson (Marketing Specialist, Gilead Sciences), November 2022

42 UK Health Security Agency (2022) 'Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full Report'. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

43 All-Party Parliamentary Group on Liver Health Inquiry Report (2018) 'Eliminating Hepatitis C in England, March 2018'. Available at: <http://www.hepc.org.uk/sites/default/files/Eliminating%20Hep%20C%20APPG.pdf>

44 UK Health Security Agency (2022) 'Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full Report'. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

39 From an interview Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Jamina Gibson (Marketing Specialist, Gilead Sciences), November 2022

One problem that has been reported with the South Asian peer initiative has been ensuring the project is targeted at the right areas. Initial targeting has often begun from the premise of identifying areas with both high hepatitis C prevalence and large South Asian populations, but further investigation in some areas matching this description, such as Southend, found no clear link. This led MSD to invest further in data analysis, to identify or rule out potential hotspots of need more effectively.<sup>45</sup>

Gilead suggest that early involvement and buy-in of key community stakeholders in their campaign meant that strong communication channels were opened for feedback, and that amplifying the voices and platforms of influential community figures meant that the campaign could be trustworthy and authentic. The next steps of the campaign in 2023 will focus on the legacy of the campaign and ensure key community stakeholders are equipped to continue to drive this message.

Gilead is also now working with NHS England to ensure future 'Hep C, Ki?' campaign assets drive people towards the upcoming hepatitis C home testing portal (see [New Initiatives](#) below).

This will involve gearing the campaign website and ODN toolkit towards driving people to the postal testing portal, for example via QR codes.<sup>46</sup>

## Community Liaison Officers

### Background need

Community Liaison Officers (CLOs) are NHS staff whose role is designed to link acute trusts with other secondary care and community services, ensuring that the work of acute care services is aligned with community-based treatment provision. Although similar to a degree to the Hepatitis C Trust peer team roles, these CLO roles lie within the management and governance structure of the ODN NHS host trust.

### About the initiative

In 2019, MSD began working with ODNs to recruit CLOs to provide practical, educational and emotional support through workshops and one-to-one contact via drug services. In addition, they planned to proactively target homeless populations and other high-risk marginalised groups, working in homeless hostels, night shelters and drug treatment centres. CLOs work with the ODN clinical teams to align and coordinate hepatitis C services.

By 2020, the scheme was supporting ODNs with direct resources to improve coordination and alignment between services, and to intensify activity in areas of greatest need by increasing the number of CLOs. By 2021, CLOs had been funded in three ODNs as part of the initiative: Leicester, Manchester, and Humberside and North Yorkshire.

CLOs were first recruited in the Leicester ODN, followed later by Manchester and Humberside and North Yorkshire, though establishing the roles took time due to NHS recruitment and workforce protocols and the impact of COVID-19. Although MSD provided funding for the posts, the job descriptions for CLOs were determined by the ODNs and varied based on need. In Leicester they focused heavily on outreach work, including pharmacy and drug and alcohol service testing. In Humberside, the CLOs have been trained to carry out Fibroscans in order to identify cases of liver cirrhosis.<sup>47</sup>

### Results so far

At the end of the third year of the project, MSD reported to NHS England that CLOs have resulted in:

- Almost 4,000 people being engaged
- Over 1,600 people tested
- Almost 250 people treated

As the first ODN to use the roles, Leicester has provided perhaps the deepest account of CLOs. Leicester employed two CLOs on 18-month contracts and was able to use these roles as additional peer support. It has been reported that the roles brought significant benefit to the network, with their backgrounds being particularly helpful. One of the officers had been a recovery worker with Turning Point and so had relationships with the vast majority of the local hepatitis C patients already, while the other had lived experience of hepatitis C. Manchester and Humberside & North Yorkshire have been using the roles in a similar manner, to provide flexibility and supplement peer work. The Leicester CLOs have supported over 90 patients into treatment and engaged with over 400 potential patients and staff.

### Reflections and future plans

As NHS employees, it has been reported that although this yields other potential benefits in terms of access and coordination, there have been different restrictions as to what the CLOs could do, including concern over patient escorts, medication deliveries and training of external staff. This has made a close working relationship with peers from The Hepatitis C Trust in Leicester important, with the CLOs attending training days and conferences delivered by The Hepatitis C Trust as a result. A CLO was offered to the Birmingham ODN, but MSD ultimately reallocated this money to helping Birmingham recruit a peer through The Hepatitis C Trust peer programme.

However, being employed directly by the ODN host trust means that CLOs operate under an NHS badge, which in turn can grant them access to different services and information sharing. In some instances, it has been suggested this has enabled them to coordinate and align services to a greater degree than if they were not employed directly by the host NHS trust.<sup>48</sup> However, it should be noted the staff peers from The Hepatitis C Trust do often have honorary contracts and even NHS badges as well where ODNs have been able to establish this level of inclusion into their local teams.

## Initiatives in the criminal justice system

Hepatitis C prevalence is 2.4% across the prison estate and linked to risk factors such as higher rates of injection drug use among those sentenced to prison.<sup>49</sup> This has led to a number of efforts focused within the criminal justice system, which have over time expanded beyond the prison estate itself to include probation services and bail hostels.

### Prison High Intensity Test and Treat (HITT) and Reception Testing

#### Background need

While prison blood-borne virus opt-out testing was introduced by Public Health England and NHS England in 2013 and fully implemented by 2018, data showed that only 19.4% of new receptions were tested for hepatitis C in English prisons in 2017/18.<sup>50</sup> This meant additional complementary approaches to increase testing in prisons were needed.

#### About the initiative

Against this backdrop, NHS England Health and Justice piloted and subsequently rolled out a national hepatitis C prison peer programme to support the increase in take-up of reception testing. Delivered by The Hepatitis C Trust, the main aims of the prison peer programme were to raise awareness with both staff and people in prison, reduce stigma and support those affected.

In 2018, when the deal for the elimination programme was being developed, The Hepatitis C Trust suggested a partnership programme between Gilead, Practice Plus Group (PPG, formerly Care UK, who at the time delivered around 40% of the prison health care contracts) and The Hepatitis C Trust to develop a whole prison testing programme.

The High Intensity Test and Treat (HITT) programme began in July 2019 with NHS England and Gilead signing a contract to support wing-based testing of all people in prison. Hepatitis C Trust national staff have been able to focus on stakeholder engagement with prison health teams and ODNs, while working in partnership with PPG regional coordinators who were recruited to focus on the HITTs. Peers played a crucial role in HITTs by raising awareness in advance of them taking place,

<sup>48</sup> From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

<sup>49</sup> Presentation by Georgia Threadgold (Senior Project Manager, Hepatitis C Elimination, NHS England and NHS Improvement) and Sean Cox (Director of Prison Services, The Hepatitis C Trust) – HCV Action (2022) 'HCV ACTION WEBINAR: THREE YEARS TO GO – WHERE ARE WE IN THE JOURNEY TO HEPATITIS C ELIMINATION? 6 MAY 2022 SUMMARY REPORT'. Available at: <http://www.hcvaction.org.uk/sites/default/files/resources/Data%20with%20three%20years%20to%20go%20to%20elimination%20-%20summary%20report.pdf>

<sup>50</sup> From an interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Andy Jones (Associate Director, Medical Sciences, Gilead Sciences), November 2022

<sup>45</sup> From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

<sup>46</sup> Interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Jamina Gibson (Marketing Specialist, Gilead Sciences), November 2022

<sup>47</sup> From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

helping people get tested, and then following up to test any people who were not reached during the event and to support those who tested positive into rapid treatment. Gilead investment funded regional blood-borne virus leads, and enabled training and implementation of new localised test and treat pathways.<sup>51</sup> Gilead Medical Scientists have been involved in the development and implementation of the prison HITT elimination initiatives.

Ten prisons were identified for the first wave of testing and “roadshows” were carried out by The Hepatitis C Trust HITT coordinators to explain to stakeholders in PPG provision prisons about hepatitis C elimination and the goals of the HITTs. The Trust HITT team also presented at ODN network meetings when local ODN support was also needed to supplement prison health teams – ODN involvement initially varied by area and early HITTs tended to be conducted by Hepatitis C Trust and prison health team staff, but now in most areas ODNs are also part of the collaborations.<sup>52</sup>

As a matter of process, prisons are identified and asked if a HITT can be carried out, or in some cases governors or the health provider will come forward with a request. The Criminal Justice Programme Oversight Group in NHS England, which manages HITTs, must then approve the request, and staff within the prison are brought on board with the aims of the HITT. To do this they consider many factors, including the offer and take up rate of reception testing. For the HITT to be viable, over 60% of new people in the prison must already be receiving tests on reception to ensure a good baseline count. Other factors include staffing, the availability of ODN support and factors affecting capacity at the prison, such as whether it is subject to an ongoing audit. In addition, a quick turnaround on tests, followed by support and clear pathways to treatment, has been found to be key to providing reassurance and rapid treatment to residents who test positive.

To be considered a successful HITT, 95% of prison residents must be tested. It can be beneficial for prison peers to talk to people on the prison wings, where health and addiction service staff are not always able to establish trust or gain access. Peers can attempt to lower stigma, provide education, and break down barriers. A manager of one of the regional prisons teams in The Hepatitis C Trust, suggested that “when we go into the prison and share our lived experience of the criminal justice system, the walls just drop – there is no longer that ‘us and them’ mentality”. He also cited an example of a testing event where peers were unable to be present and only 60% of prison residents were tested, which he attributed to a lack of peer involvement.<sup>53</sup>

The rollout of the HITTs in PPG prisons subsequently led to interest in extending the project to prisons where the contract for healthcare provision was held by a provider other than PPG. NHS England in particular were wary of avoiding an inequitable approach if not all prisons were covered, which led to work to ensure all prisons and their specific healthcare providers (such as NHS Oxleas and Spectrum Community Health CIC) would be able to benefit from HITTs.<sup>54,55</sup>

“When we go into the prison and share our lived experience of the criminal justice system, the walls just drop – there is no longer that ‘us and them’ mentality”

Lee Devereux, Manager of the South Region Prisons team at The Hepatitis C Trust, on the work of prison peers

People in prison tested, confirmed for hepatitis C and referred to/starting treatment, related to prison HITTs

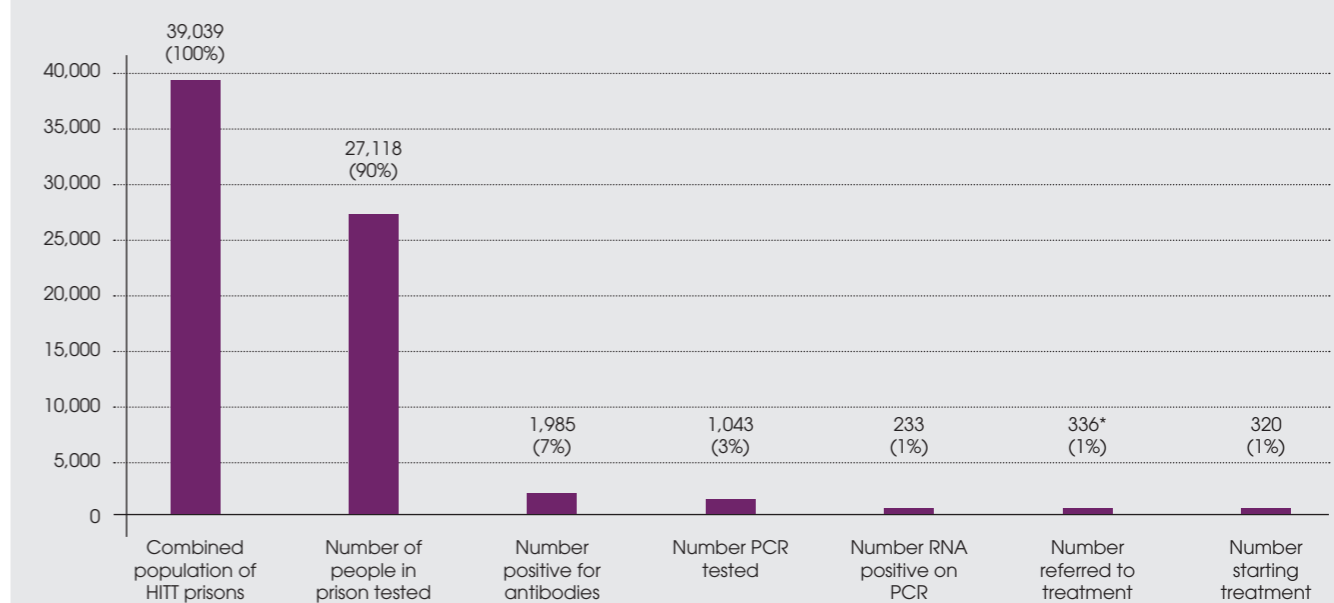


Figure 2: Cascade of care from prison HITTs. \*Note that treatment referrals outnumbering positive PCRs is due to partial data or patients having had a positive PCR from another source

Results so far

This initiative from Gilead, The Hepatitis C Trust and the Practice Plus Group has incorporated regional Blood Borne Virus testing leads, a national HITT manager and 47 prison services, with a combined inmate population of 30,039. 16 of these 47 prisons achieved micro-elimination. As of May 2022, 43 HITTs had been carried out, in both PPG and non-PPG prisons. Uptake of testing by people in prison stood at 90%, with 27,118 people tested. This resulted in just under 2,000 antibody positives, of whom just over 1,000 were successfully referred for PCR testing (antibody positives not referred for further PCR confirmation were mainly due to due to cross-referencing with health records that will have revealed people were already in or had received treatment, had had a PCR on reception, had previous blood results, or had simply self-cleared of the virus).<sup>56</sup>

Uptake of screening and reception testing has risen to around 65%. While those leading the HITT initiative eventually hope to access all prisons, the target is to ensure 75% of the prison estate has been subject to a HITT by the end of 2024.<sup>57</sup>

The development of end-to-end pathways in prisons from reception testing, streamlined pathways to treatment, peer support and

follow-up for people leaving prison have also all been key, alongside HITT events. 113,312 reception tests have been carried out on people entering a prison with a participating prison health provider. The first COVID-19 lockdown significantly impacted test offer and uptake rates, which led staff and ODNs to modify the pathways, and testing and treatment rates have since recovered. Working closely with ODNs, streamlined pathways mean that 90% of patients diagnosed with hepatitis C are initiated into treatment whilst in prison. The Follow Me programme – a programme from The Hepatitis C Trust – has been particularly effective in linking people leaving prison who are still undergoing treatment into the community peers programme to ensure that ‘through the gate’ support is in place.<sup>58</sup>

As of April 2022, 26 of the 48 PPG prisons had achieved a 90% testing rate in the preceding 12 months and 33 prisons had reached an RNA+ treatment target of 90%. Gilead suggest that if the partners involved in HITT and reception testing work continue to maintain these testing and treatment rates, they could be on track for the whole prison network to achieve the hepatitis C micro-elimination target of 95% testing and 90% of diagnosed patients commenced on treatment by March 2024.<sup>59</sup>

51 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

52 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

53 The Hepatitis C Trust (2021) “When we go into the prison and share our lived experience of the criminal justice system, the walls just drop.” #PeerSupportMeans: Lee Devereux’. Available at: <http://www.hepctrust.org.uk/blog/sep-2021/%E2%80%9Cwhen-we-go-prison-and-share-our-lived-experience-criminal-justice-system-walls-just-drop-%E2%80%9C-lee-devereux/>

54 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

55 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

56 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

57 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

58 From an interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Andy Jones (Associate Director, Medical Sciences, Gilead Sciences), November 2022

59 From an interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Andy Jones (Associate Director, Medical Sciences, Gilead Sciences), November 2022



A HITT event at HMP Wayland in October 2022, with peers from The Hepatitis C Trust and staff from Practice Plus Group and Norfolk and Norwich University Hospitals NHS Foundation Trust

### Reflections and future plans

The partnership has evolved as reception testing pathways have become embedded across the PPG prison estate and micro-elimination has been achieved in a number of prisons. Efforts have focused more on ensuring reception testing is maintained and testing-to-treatment pathways are streamlined, with follow up for clients on treatment as they leave prison.

There were practical limitations on the HITT model in some prisons. HITTs were not possible during the COVID-19 lockdowns. After they were lifted, continued restrictions made it more difficult for prison HITTs to make use of open spaces and create a comforting environment using incentives (such as refreshments) to encourage residents to come and get tested, alongside which teams would be able to provide harm reduction information and hepatitis C awareness training. Instead, a mobile cell-to-cell approach had to be adopted. Testing by prison-based drug treatment service providers during lockdown dropped to 8% of the testing rate they would normally expect to see, but improved to 25% by August 2020.<sup>60</sup>

Prison staffing levels and related security concerns also made the cell-to-cell approach easier to manage safely than a full-scale HITT. Furthermore, some prisons were also sceptical of comprehensive HITTs, citing resources or other factors, which led to the development of targeted testing events

where Hepatitis C Trust staff would go in with a peer, a nurse, and the ODN to reach a specific list of people (compiled based on health records and focused on those who had not been tested in the last 12 months or have a history of higher-risk behaviour). Category D prisons ('open prisons') also required an emphasis on home visits in order for higher testing rates to be secured.<sup>61</sup>

Those involved report that the prison HITT model has proven successful, despite challenges. The decision by NHS England to invest in expansion to non-PPG prisons in particular was a reflection of these successes. The programme has also yielded a number of lessons:

- Successful HITTs have been found to depend on good joint working between The Hepatitis C Trust and prison health teams; healthcare providers having dedicated blood-borne virus leads in the prisons; good recordkeeping following HITTs; and ongoing training to make sure nurses and healthcare teams have good information on hepatitis C.<sup>62</sup>
- Drug treatment services were useful as an initial gateway at the start of the initiative and were helpful in enabling people in prison to access testing and treatment while avoiding stigma associated with hepatitis C, as it would appear to other prison residents that they were accessing drug services rather than a hepatitis C clinic.
- Effective strategic cooperation between

HITT teams and prison officers, health teams and governors is key to making sure that HITTs are effective, with groundwork laid weeks in advance and buy-in secured from prison staff and leadership. Mop-up sessions after HITTs have also been key to ensure all residents are found and tested, enabling testing rates as high as 98%. Gilead noted the critical role of staff from The Hepatitis C Trust in bringing governors on board.

- Another key learning has been the importance of effective opt-out reception testing. Reception testing has been mandated by HM Prison and Probation Service (HMPPS) in prisons since 2018, following initial rollouts in 2013.<sup>63</sup> However, prisons vary in how thoroughly they implement it and to what degree they exceed the 90% target of residents agreeing to testing set by HMPPS.
- Encouraging strong reception testing is vital as without a high degree of reception testing, counts are continually disrupted and getting an accurate and consistent sense of hepatitis C prevalence is difficult.<sup>64</sup>
- Both HITT and prison reception pathway improvement activities have relied on collaboration at a regional and local team level. These teams are cross functional and include expertise from peers from The Hepatitis C Trust, Regional BBV Leads, ODNs and Gilead Medical Scientists. As the prison estate is varied, these regional teams are able to identify particular issues and develop individual plans for individual prisons.
- Reception testing and HITTs work side-by-side. Reception testing is vital for when someone enters prison, making sure that people are tested within the first week, while HITTs focus on finding those already in prison and on reducing stigma, educating prison officers, and ensure that a "whole prison process" is developed for testing.<sup>65</sup>

In terms of achieving the goal to complete a HITT in at least 75% of the prison estate by the end of 2024, next steps include expanding the scope of prisons targeted. HITTs so far have prioritised women's and reception prisons, for example, where higher prevalence and drug use are factors.<sup>66</sup> The next

stage will focus on Category A prisons where people in prison are on longer sentences and have often not been tested, Category C prisons (training and resettlement), and Home Office immigration removal centres. Some prisons that have hosted a HITT already will also be revisited, to assess levels of prevalence and reinfection.<sup>67</sup>

There is a general need to ensure elimination is achieved and maintained in prisons, and ensure there is continued measurement of progress across the prison estate. Across the 49 PPG prisons, hepatitis C testing uptake is over 85% with >90% of diagnosed patients being treated. Therefore there is a focus on pathways in the highest turnover prisons such as female and remand sites and on achieving or maintaining micro-elimination status across all sites. Oxleas and Spectrum prisons have made significant improvements in regard to testing new admissions and ensuring patients access treatment, but there is still more to be achieved across all prisons types. Gilead is supporting HITTs in non-PPG, Spectrum and Oxleas prisons through the partnership with The Hepatitis C Trust, as well as continuing to support pathway optimisation and training for prisons that are having a HITT.<sup>68</sup>

### Probation & bail hostel HITTs

#### Background need

In addition to prisons, wider criminal justice system institutions such as probation facilities and approved premises (sometimes known as bail hostels) house a cohort of people at higher risk of hepatitis C. These were therefore identified as good locations for prison-style HITTs, to provide an opportunity for residents to learn about hepatitis C, overcome stigma, get tested and potentially access treatment if they are found to be in need of it.

60 Presentation on Gilead Sciences Sciences' elimination initiatives by Dr Phil Troke – HCV Action (2020) 'HCV ACTION WEBINAR: NATIONAL HEPATITIS C ODN STAKEHOLDER EVENT, 6TH OCTOBER 2020 – SUMMARY REPORT'. Available at: [http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report\\_0.pdf](http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report_0.pdf)

61 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

62 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

63 National Offender Management Service (NOMS), NHS England and Public Health England (PHE) (2015) 'National Partnership Agreement between: The National Offender Management Service, NHS England and Public Health England for the Co-Commissioning and Delivery of Healthcare Services in Prisons in England 2015-2016'. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/460445/national\\_partnership\\_agreement\\_commissioning-delivery-healthcare-prisons\\_2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460445/national_partnership_agreement_commissioning-delivery-healthcare-prisons_2015.pdf). Public Health England (2017) 'Summary report: National engagement event for bloodborne virus (BBV) opt-out testing in prisons in England, 2017'. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/707591/Event\\_Report\\_FINAL.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/707591/Event_Report_FINAL.pdf)

64 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

65 From an interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Andy Jones (Associate Director, Medical Sciences, Gilead Sciences), November 2022

66 The Hepatitis C Coalition (2019) 'HEPATITIS C COALITION ROUNDTABLE ON HCV AND BLOOD BORNE VIRUSES IN PRISON', JANUARY 2019. Available at: <http://www.hepc-coalition.uk/wp-content/uploads/2019/02/HCV-and-blood-borne-viruses-in-prisons-v2-Jan-2019.pdf>

67 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

68 From an interview with Peter Shand (Associate Director, Government Affairs, Gilead Sciences) and Andy Jones (Associate Director, Medical Sciences, Gilead Sciences), November 2022

## About the initiative

Collaboration has been taking place between NHS England and HMPPS to plan and conduct testing and treatment services within probation services and approved premises for bail. Daniel Stretton, Programme Manager from the National Approved Premises Team at the National Probation Service, noted that approved premises offer a great opportunity to build upon the High Intensity Test & Treat (HITT) programme and reception testing programmes in custody. In particular, HITTs can offer those who either may not have taken up the offer of a test or have been missed while in prison a chance to access testing and treatment.<sup>69</sup>

Working with the national lead for approved premises in the probation service, staff from The Hepatitis C Trust established a steering group alongside NHS England to explore the best way to roll out HITTs in approved premises. There are 107 of these premises across England and Wales, housing around 8 to 20 residents each, creating a need for perhaps even greater coordination than prison HITTs required. ODNs do not align with National Probation Service geography and numbers of approved premises by ODN also vary, with some ODNs having as many as eight approved premises in their area. NHS England confirmed that HITT teams from The Hepatitis C Trust do not need data sharing agreements for probation and approved premises HITTs, provided no client data is accessed, which somewhat eased the process of organising them.<sup>70</sup>

## Results so far

The rollout of the project began in April 2021. As of September 2022, around 40% of the 107 approved premises in England had seen at least one HITT event carried out. The original ambition was to test at every approved premises by the end of 2022, but the impact of COVID-19 on service capacity has continued to have an impact.

In some cases, HITTs have focused solely on testing by an ODN nurse and accompanying peers, but in some ODNs deeper peer engagement and awareness sessions have been incorporated as well. In approved premises, prevalence has been found to be very low and HITTs so far have led to two recorded cases of residents beginning treatment. However, this may reflect problems with data

quality. To address this, work is being undertaken to begin mirroring HITT data in approved premises and probation settings against NHS England Health and Justice data, so that all secure settings can collect the same data and ensure consistent reporting.

## Reflections and future plans

Work is now being expanded to probation service facilities more broadly, with agreement recently secured from the National Probation Service for this purpose. This will involve establishing a steering group and conducting Q&A sessions and training with probation staff to help them understand hepatitis C elimination and explore current referral pathways. It is hoped that training will help staff to identify clients who are engaging in higher risk behaviours and refer them to The Hepatitis C Trust for testing and harm reduction advice where appropriate. Some ODNs are already going into Probation Delivery Units, developing relationships with staff and beginning to carry out testing. ODNs will send data on testing to NHS England, which in turn will share data with The Hepatitis C Trust to collate.<sup>71</sup>

Staff and peer teams from The Hepatitis C Trust plan HITTs with probation service settings and approved premises in the same fashion as the prison HITTs, with this initiative having grown out of that model. However, the variance among probation and bail settings and disruption due to the reorganisation of HMPPS service provision in 2019-2021 during the life of the initiative means there is less uniform evidence about the best way to approach probation and bail HITTs.

Furthermore, in contrast to prisons, probation and bail services are not required to organise opt-out reception testing for BBVs, meaning the baseline prevalence rates in these secure settings are less clear. This could make building strategic relationships with these settings to establish consistent opt-out testing beneficial, in order for HITT work to be as effective as it has been in prisons.<sup>72</sup> In one ODN probation services have been persuaded to carry out swab tests for hepatitis C in tandem with their routine drug testing, but not all probation services carry out drug testing as part of their licence.<sup>73</sup>

## Prison peer programme

### Background need

As in other services and areas, peers with lived experience of hepatitis C can play a role in finding and supporting people affected. 2019 research on health and wellbeing in prisons noted that access to well-trained and supervised peer workers is regarded by Her Majesty's Inspectorate of Prisons for England and Wales (HMIP) as a key constituent of efforts to promote health and well-being in prison. However, despite this, less than half of prisons (41%) actually had established peer support interventions to support people in prison for any kind of general health and wellbeing. There was no consistent deployment of peer workers, with individuals in these roles working on a range of health topics and initiatives, but "educational roles concerning Hepatitis C" was noted as one of these, due to the higher prevalence of hepatitis C in the prison population.<sup>74</sup>

### About the initiative

Prison peers are employed by The Hepatitis C Trust to work specifically with people in prison to support them in to testing and treatment, and NHS England Health and Justice has supported this programme as part of the elimination drive. Within The Hepatitis C Trust, the peer programme includes coordinators who oversee regions of prisons, organised to align to HMPPS's own regions, with peer support leads below, organising work on the ground.<sup>75</sup> Staff peer support leads also work to identify people in prison who might want to be a peer and provide training, with an aim to recruit two volunteer peers per prison – these volunteers have lived experience of hepatitis C itself, injecting or other relevant life experience, and so aim to connect with people in prison in a way that service staff without lived experience sometimes cannot.<sup>76</sup>

Initial NHS England funding was for a pilot in London prisons. This led to an increase in uptake for BBV testing and improved pathways into treatment, leading to the programme being expanded to women's prisons and prisons in the Thames Valley. From there, the peer programme was then rolled out nationally based on The Hepatitis C Trust's operational regions (North, Midlands, South East, South West, London and Eastern), though women's and reception prisons have been prioritised based on estimated prevalence and available resource.

As with the testing-focused HITTs, peers are able to use their role and lived experience to engage with people who may mistrust or not feel understood by prison, healthcare or drug service staff. Peers work to lower the stigma, provide education, and break down barriers. It is hoped that by dispelling myths and overcoming mistrust, peers can then encourage people to get tested and treated.<sup>77</sup>

Though separate from the prison HITTs initiative, prison peers can also play a part in making the HITTs work. This includes raising awareness among residents of upcoming HITT events; finding and accompanying residents to testing during HITTs; following up with them to "mop-up" any people missed by the HITT; and ensuring that those who are found to be positive can rapidly get onto a treatment pathway.<sup>78</sup> Peers have also played a key role in laying groundwork for HITTs with prison officers and prison health staff, educating them about hepatitis C and the importance of elimination. Further, peers also support people identified through HITTs to get onto treatment pathways, and also link hepatitis C-positive residents of short-term and remand facilities to ensure they get 'through the gate' support from community peers to continue treatment when they are released as part of The Hepatitis C Trust's 'Follow Me' programme.<sup>79</sup>

### Results so far

As of September 2022, peers had accessed 90 prisons and had successfully recruited and trained peer volunteers in a majority of these. Approximately 85 peer volunteers have been recruited, and while some prisons have the target minimum of two peer volunteers, some prisons have as many as five. Reception prisons are subject to high levels of turnover, which has made recruiting peers in these places particularly difficult and made outside support for residents vital. Prison security protocols have at times also blocked certain peers from becoming volunteers. No data is yet available on testing and treatment that prison peers have directly enabled, but in some prisons, prison peers carrying out testing is now being explored.

The work of peers can also be measured in part by their involvement in the HITT events as well. For example at HMP Leyhill in Gloucester in May 2021, three peers from The Hepatitis C Trust and one substance misuse peer worked alongside the staff team for the whole of a HITT event. This enabled

69 HCV Action (2021) 'HCV ACTION NATIONAL HEPATITIS C ODN STAKEHOLDER WEBINAR SERIES, NOVEMBER 2021 – SUMMARY REPORT'. Available at: <http://www.hcvaction.org.uk/sites/default/files/resources/National%20Hepatitis%20C%20ODN%20Stakeholder%20Webinar%20Series%202021%20summary%20report.pdf>

70 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

71 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

72 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

73 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

74 James Woodall & Charlotte Freeman (2020) 'Promoting health and well-being in prisons: an analysis of one year's prison inspection reports', *Critical Public Health*, 30:5, 555-566. Available at: <https://www.tandfonline.com/doi/pdf/10.1080/09581596.2019.1612516>

75 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

76 The Hepatitis C Trust (2021) "'When we go into the prison and share our lived experience of the criminal justice system, the walls just drop.'" #PeerSupportMeans: Lee Devereux'. Available at: <http://www.hepctrust.org.uk/blog/sep-2021/%E2%80%9Cwhen-we-go-prison-and-share-our-lived-experience-criminal-justice-system-walls-just>

77 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

78 From an interview with Stuart Smith (Director of Community Services, The Hepatitis C Trust) and Rachel Halford (Chief Executive, The Hepatitis C Trust), September 2022

79 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

them to provide crucial support to the testing team and promote hepatitis C awareness to the prison residents. Post-HITT feedback was requested from all team members at Leyhill and found that “The Hepatitis C Trust Prison Peers were exceptionally knowledgeable about hepatitis C. They worked tirelessly each day of the HITT.”<sup>80</sup>

### Reflections and future plans

No data is yet available on testing and treatment that peers have directly enabled, but in two prisons, volunteer prison peers are now being trained to carry out testing directly. However, the number of prisons that peers have worked in and been able to recruit volunteers in, train staff in or both represents a substantial footprint in and of itself.

Early on in the roll-out of the prison peer project, getting peer coordinators security-cleared and navigating informal stigma was difficult, as by necessity these staff have lived experience of prison. However, coordinators have since reported that much of this has since been overcome through relationship-building and communication. Securing continued buy-in from prison governors and officers, beyond initial permission, will also be key in order to underline the continued importance of reception testing as a priority for prison staff and leadership as part of hepatitis C elimination.

The success of the peers has in turn enabled increased recruitment, which is key to sustainability. As of late 2022, recruitment was focused on efforts where there has been less of a breakthrough until now, with peer team members overseeing two to three prisons as opposed to 10-15 prisons each. For example, HMP Leicester and HMP Nottingham together will be served by one dedicated peer coordinator.

In some instances, effective working has also come from The Hepatitis C Trust’s peer coordinators working with existing substance misuse peers or Health and Wellbeing Champions, training them in providing support around hepatitis C where prison staff suggested this as an alternate to separate peer volunteers.<sup>81</sup>

“Prison Peers were exceptionally knowledgeable about hepatitis C. They worked tirelessly each day of the HITT.”

Hanham Secure Health on the value of peers.

## Initiatives in primary care

### Pharmacy testing

#### Background need

People who inject drugs, or who have injected them in the past, may use community pharmacies to access Opioid Substitution Therapy (OST) and Needle and Syringe Programmes (NSP). This means there is an opportunity in these settings to provide readily-available testing for hepatitis C, and the possibility from there of access to referral to hepatitis C treatment.



Peers from The Hepatitis C Trust’s team in Leicester supporting pharmacy testing, 2021

#### About the initiative

In June 2011, The Hepatitis C Trust coordinated a national roll out of hepatitis C and hepatitis B testing in community pharmacies following a very successful pilot project in 2009, working across 20 Primary Care Trusts. The pilot diagnosed 1 in 6 of the people tested with either hepatitis C or B, representing a significantly higher proportion of positive tests compared to those undertaken in GP surgeries. The Hepatitis C Trust also offered free training and supporting materials to areas wanting to offer testing and information on where funding for the tests and the pharmacists’ time to deliver them could be identified locally. Between May and August 2009, 19 pharmacies undertook a total of 234 tests, which found 35 people who had hepatitis C antibodies and 4 people with hepatitis B surface antigens.<sup>82</sup>

Later in 2018, the London Joint Working Group on Substance Use and Hepatitis C and MSD published findings from a pilot of point of care hepatitis C testing to people accessing NSP based at community pharmacies in London. The pilot aimed to address a lack of access to hepatitis C testing and treatment referral pathways for those not currently engaging in community drug treatment services but actively injecting drugs, by exploring whether provision in community pharmacies could provide a potential point of contact to offer hepatitis C testing, education and referral into treatment.

A total of 216 tests were completed from October 2017 and March 2018 – these found that 53% of patients tested positive for hepatitis C antibodies. 47% of these were told for the first time that they were antibody positive, and 78% of those engaging with further assessment in secondary care had chronic hepatitis C. Further, 57% of those tested did not know that newer interferon-free DAA treatment was available – 15 patients commenced antiviral therapy as a result of the pilot.<sup>83</sup>

Building on these previous examples of work, the Pharmaceutical Services Negotiating Committee (PSNC) and NHS England developed an initiative as part of the elimination programme. It aimed to increase testing levels for hepatitis C amongst people who inject drugs who are not currently engaged in community drug and alcohol treatment services, in order to increase diagnosis of hepatitis C and decrease the burden of illness and onward transmission. The pharmacy testing scheme was set up nationally to provide testing for people who could not be accessed via other services, but were in touch with pharmacies. Pharmacists were to be financially incentivised to spend time assessing risk factors and testing patients who might be at risk of hepatitis C, in part to get over reluctance to test people where there was disagreement about which service should be testing them.<sup>84</sup>

The Hepatitis C Antibody Testing Service commenced in community pharmacies in

September 2020. Where individuals test positive for hepatitis C antibodies, they can be referred for appropriate further testing and treatment via the relevant ODN. If an individual has previously been tested and the result was negative, it is recommended that they are retested six months on from when the test took place.<sup>85</sup> However, the service was time-limited in the first instance, running until 31 March 2022, subject to a review “to ascertain whether the service is effective in testing this difficult-to-reach patient cohort and successfully directing people who test positive towards further PCR testing and treatment.”<sup>86</sup> In April 2022, the service was extended to run until at least 31st March 2023.<sup>87</sup>

Providers receive £36 per test performed, which must also cover other costs incurred by providing the service, such as training staff and disposal of clinical waste.<sup>88</sup> Any community pharmacy that met the prerequisites for service provision detailed in the service specification could register to provide this service. If contractors met these, they could then notify NHS England and register electronically; ensure they were ready to register patients on the Hepatitis C IT Registry; and ensure any staff providing the service watched an NHS England training video.<sup>89</sup>

#### Results so far

In September 2021, the Pharmaceutical Journal reported that only 662 community pharmacies out of more than 11,800 in England had registered to deliver the service since it was launched in September 2020. In total, 679 community pharmacies had initially registered to deliver the service between its launch and August 2021, but 17 later de-registered. Moreover, data suggested community pharmacies had carried out just 119 hepatitis C antibody tests since the service’s launch.<sup>90</sup> Data as to whether any patients had initiated treatment as a result of pharmacy testing is currently unavailable.<sup>91</sup>

83 London Joint Working Group on Substance Use and Hepatitis C (2018) ‘HCV testing in NSP (Needle and Syringe Provision) Community Pharmacies Pilot (Phase 1) – Report and Findings’. Available at: <http://ljwg.org.uk/wp-content/uploads/2018/05/LJWG-Pharmacy-Testing-Phase-1-final-report-.pdf>

84 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

85 Pharmaceutical Services Negotiating Committee (2020) ‘Hepatitis C testing service Published on: 24th February 2020 | Updated on: 23rd August 2022’. Available at: <https://psnc.org.uk/national-pharmacy-services/advanced-services/hep-c/>

86 NHS (2020) ‘Service specification. Community pharmacy Hepatitis C Antibody Testing Service – Advanced Service.’ Available at: <https://www.england.nhs.uk/wp-content/uploads/2020/08/par0097-hep-c-service-specification.pdf>

87 NHS Business Services Authority, ‘Community Pharmacy Hepatitis C Antibody Testing Service’. Available at: <https://www.nhsbsa.nhs.uk/community-pharmacy-hepatitis-c-antibody-testing-service>

88 Pharmacy Magazine (2020) ‘Pharmacies to get £36 for providing NHS Hep C tests’. Available at: <https://www.pharmacymagazine.co.uk/latest/pharmacies-to-get-36-for-providing-hep-c-tests>

89 NHS England (2020) ‘Community Pharmacy Hepatitis C Antibody Testing Service’. Available at: <https://www.england.nhs.uk/primary-care/pharmacy/community-pharmacy-contractual-framework/hep-c-antibody-testing-service/>

90 Robinson, J (2021) ‘Fewer than 700 community pharmacies sign up to provide hepatitis C testing’, The Pharmaceutical Journal. Available at: <https://pharmaceutical-journal.com/article/news/fewer-than-700-community-pharmacies-sign-up-to-provide-hepatitis-c-testing>

91 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

80 Wolf, K (2021) ‘High Intensity Testing & Treatment (HITT) HMP Leyhill’, Hanham Secure Health. Available at: <https://www.hanhamsecurehealth.co.uk/wp-content/uploads/2021/06/HSH-HITT-Leyhill.pdf>

81 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

82 Reid, L (2011) ‘Pharmacy-based testing for hepatitis B and hepatitis C’, The Hepatitis C Trust. Available at: <http://www.hcvaction.org.uk/sites/default/files/resources/Pharmacy-based%20testing%20for%20hepatitis%20B%20and%20hepatitis%20C%20%28hep%20c%20trust%29.pdf>

In 2021 work by researchers from the University of Southampton, in collaboration with The Hepatitis C Trust and Community Pharmacy South Central (Hampshire and Isle of Wight LPC), suggested that fourteen (70%) ODNs had met with a representative from the local pharmaceutical committee and 95% of ODNs had pharmacies that had registered interest in the advanced service, with more than ten pharmacies registering interest in the majority of ODNs (63%).<sup>92</sup>

Four ODNs (20%) had arranged additional training for pharmacies. Fourteen (70%) respondents were aware of their referral pathway. Two (10%) ODNs reported that the pharmacist would perform a dry blood spot test to check if a client was antibody positive. However, only three (15%) ODNs reported that testing had started in their region, despite eight ODNs (40%) reporting a prior pilot of pharmacy-based HCV testing.

73% of respondents wanted further guidance on the implementation of the service, including guidance with the initial set up and how to effectively communicate between clinicians and pharmacists. Qualitative feedback about the service was varied, but a consistent theme was the need to expand the eligible population for the service. It was suggested that as many ODNs have had prior successful pilot testing programmes, these learnings needed to be drawn on to scale-up the service.

### Reflections and future plans

Representatives for community pharmacies have acknowledged that disruption caused by the COVID-19 pandemic has been an issue, but The Hepatitis C Trust raised questions about why community pharmacies are not allowed to test people who inject drugs and are engaged with OST services at another care provider under the terms of the scheme. Ryan Buchanan, Associate Professor of Hepatology at the University of Southampton, suggested that "It's that cohort [of opiate substitution patients] that community pharmacists have a fantastic relationship with because they are sometimes picking up their methadone every day and they're often waiting there for the pharmacist to dispense their methadone, so there's an opportunity to do the test".<sup>93</sup>

Professor Graham Foster from NHS England suggested that pharmacists have not yet seen the financial incentive as enough to cover the work involved proportional to their existing workloads, leading to low uptake of testing. The PSNC has organised a review of the programme, which would include a qualitative study engaging pharmacists about their thoughts on how the initiative had been organised – this review will help to determine the future of the initiative and what further lessons can be learned. Professor Graham Foster from NHS England suggested this may include exploring the Leicester model, which involves using a room in a pharmacy and posting a nurse or a peer worker with a Cepheid machine to test people attending the pharmacy, rather than relying on pharmacy staff to do it as part of their core business.<sup>94</sup>

A study protocol by Cook *et al* has also begun exploring what works in pharmacy-based testing, noting for example that the UK programme does not include on-site RNA testing and that training for pharmacists includes a video rather than delivery by local clinicians.<sup>95</sup>

## Patient Search Identification Tool

### Background need

People who have hepatitis C may be unaware of their infection, but in touch with primary care about other health needs. This represents an opportunity to use health records for identification, testing, and then referral to treatment if a person is found to be positive. Indicators for testing may include a history of injection drug use, blood transfusions before the introduction of proper screening of NHS blood products in September 1991, or existing liver disease, among other things.<sup>96</sup>

### About the initiative

A randomised control trial was run in 45 primary care practices in south west England called the Hepatitis C Assessment Through to Treatment (HepCATT) project, with an intention of increasing case-finding, testing, and treatment of hepatitis C through various initiatives in primary care, such as learning resources for staff, leaflets and information for patients, and software identifying patients with risk factors for hepatitis C infection.



The HepCATT trial found that primary care settings could play a crucial role in identifying and treating people with hepatitis C.<sup>97</sup>

Building on these findings, in primary care services in 2019 MSD began rolling out the use of a healthcare record data analytics tool, the Patient Search Identification (PSI). This identifies at-risk populations in primary care health records to identify patients for further review and potential testing and treatment. It does this by searching for coded hepatitis C risk factors in patient records in primary care settings to identify potentially at-risk patients that should be reviewed and, if appropriate, tested. The initiative also began exploring a working group to develop a pathway from identification to testing and treatment. By 2020, this case-finding tool was available in >95% GP practices in England.

MSD developed the PSI tool and tested it in Birmingham, finding it worked as well as HepCATT, and this came to be selected as an initiative by NHS England. MSD was then able to outsource codes to allow all GP practices in England to use it, and work was undertaken by a working group to strengthen the pathway for identified cases.

### Results so far

UKHSA's April 2022 report on hepatitis C in England, featuring data up to the end of 2020, noted the role of the PSI tool and stated that the tool is "available within all 3 of the main GP clinical systems", and that case studies have been developed to support uptake and usage. UKHSA further suggested that increased uptake will boost targeted and opportunistic testing of high-risk groups, including those infected by historical NHS administered contaminated blood products, alongside a national programme of communications and workforce development activity to enable primary care practitioners to support HCV elimination.<sup>98</sup> It should be noted that the COVID-19 pandemic saw a 36% decline in hepatitis screening rates in primary care, impacting somewhat on the success of the PSI initiative in this time.<sup>99</sup>

### Reflections and future plans

MSD have suggested the challenge in getting practices to use the tool so far is related to getting primary care to prioritise hepatitis C, when it is not commissioned or incentivised by Quality and Outcomes Framework (QOF) funding, and at a time when GPs are already facing heavy workloads.

<sup>92</sup> Cook, C et al (2021) 'The implementation of the national health service England service for hepatitis C antibody testing in community pharmacies: a national survey of hepatitis C operational delivery networks', *Gut*; 70:A25-A26. Available at: [https://gut.bmj.com/content/70/Suppl\\_3/A25.2](https://gut.bmj.com/content/70/Suppl_3/A25.2)

<sup>93</sup> Robinson, J (2021) 'Fewer than 700 community pharmacies sign up to provide hepatitis C testing'. Available at: <https://pharmaceutical-journal.com/article/news/fewer-than-700-community-pharmacies-sign-up-to-provide-hepatitis-c-testing>

<sup>94</sup> From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

<sup>95</sup> Cook, C et al (2022) 'The I-COPTIC Collaboration, I-COPTIC: Implementation of community pharmacy-based testing for hepatitis C: Delphi consensus protocol', *International Journal of Pharmacy Practice*, Volume 30, Issue 6, December 2022, Pages 541–547, <https://doi.org/10.1093/ijpp/riac064>

<sup>96</sup> Drainoni, Mari-Lynn et al (2012) 'Effectiveness of a Risk Screener in Identifying Hepatitis C Virus in a Primary Care Setting', *American Journal Public Health*, 102(11): e115–e121. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3477946/>

<sup>97</sup> Horwood, J et al (2020) 'Increasing uptake of hepatitis C virus infection case-finding, testing, and treatment in primary care: evaluation of the HepCATT (Hepatitis C Assessment Through to Treatment) trial', *British Journal of General Practice*; 70 (697): e581–e588. Available at: <http://www.hcvaction.org.uk/sites/default/files/resources/HepCATT%20study.pdf>

<sup>98</sup> UK Health Security Agency (2022) 'Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full Report'. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

<sup>99</sup> EMIS (2022) 'Primary care data set to accelerate early identification of the 1000s of 'hard to reach' patients unknowingly living with Hepatitis C'. Available at: <https://www.emishealth.com/news-insights/primary-care-data-set-to-accelerate-early-identification-of-the-1000s-of-hard-to-reach-patients-unknowingly-living-with-hepatitis-c>

Where practices have chosen to actively adopt the tool, MSD suggested this tended to be linked to one of a few factors. In some areas ODNs or MSD had good relationships with primary care and were able to leverage these relationships to encourage use of the tool. In other practices, the presence of a GP with Special Interest (GPSI) in hepatitis C or infectious disease generally, or alternatively a GP involved in health provision in prisons or drug and alcohol services, had served as a valuable link to establishing the importance of hepatitis C screening in GP practices.

The PSI tool can be used to produce a list of positive diagnoses who were previously lost to follow-up, which will be a relatively small list and can potentially then be shared with the ODN to take forward the work of contacting those people, reducing the workload for GPs. However, getting GPs to run risk factor lists and invite these patients for testing has thus far proven more difficult, for several reasons. Firstly, GPs vary widely in how they code for all relevant risk factors, such as abnormal liver function, HIV, hepatitis B, TB, drug use or involvement with drug services, prison time, homelessness, travel to regions of hepatitis C prevalence, or exposure to blood transfusions or blood products pre-1991. This may be due to training or time constraints in some cases, or due to concern on the part of GPs about recording sensitive data around stigmatised risk factors.

Secondly, risk factor lists would include all patients with one high risk factor or a combination of the above criteria, which can quickly generate “unmanageable” lists. MSD have encouraged a shift in the explanation of the process away from a framing of “primary care case-finding”, instead describing the process as an “integrated approach to case-finding in primary care”. This emphasises that there will not be a burden on GPs and that ODNs will be able to take on the practical work of testing those with risk factors.

As of September 2022, there is limited data on how many people have been called in for tests and put onto treatment pathways, though ascertaining this is the next step in the development of the PSI tool initiative. MSD anticipated a renewed push in 2023, with practices and ODNs beginning to call in patients. There has been some progress with “pockets” of practices that have used the PSI tool to run hepatitis C risk lists and cross-reference these with lists of patients being called in for other tests, but even this has placed somewhat of an administrative burden on primary care.<sup>100</sup>

NHS England and MSD partnered with medical technology firm EMIS to further develop the PSI.<sup>101</sup> In July 2022, it was announced that a further pilot programme led by NHS England and MSD will use PSI software alongside EMIS. Starting in late 2022, this three-month programme aimed to search an estimated 300,000 primary care records for patients who have a coded hepatitis C virus positive test, but no treatment record, and those with at-risk factors, such as intravenous drug use, blood transfusions or organ transplantation before 1992. Once an at-risk patient has been identified, the local ODN (if they have signed up to participate in the programme) will invite the patient for a review, screening and if appropriate, treatment.<sup>102</sup>

The EMIS Pathway for Hepatitis C pilot work will now involve seven ODNs (Greater Manchester & Eastern Cheshire, Cheshire & Merseyside, Lancashire and South Cumbria, and the four London ODNs). It was intended to go live in Liverpool in October 2022 and aims to ensure ODNs are working together with primary care to find patients through a portal that “surfaces” patients at risk or with a positive diagnosis, and creating a dashboard of them. Through greater collaboration and by building on existing systems that GPs are using alongside the PSI tools, it is hoped that ODNs will be able to access GP data.<sup>103</sup>

At the time of publication, with only 15 months left of the initiative towards March 2024, MSD and NHS England are supporting communications work to educate GPs about the elimination drive and the GP-to-ODN localised pathways. This includes referral and signposting to the Web Testing Portal via the GP clinical systems, for example. A push in 2023 could include work at conferences attended by GPs to raise awareness of the toolkit, MSD suggest. A roundtable in September 2022 was also held with GPs to understand their concerns about using the PSI tool, particularly their concerns about categorisation of stigmatised risk factors and the work involved in referring on those from ‘at-risk’ lists for further testing. Furthermore, the Addiction Professionals Network have run webinars to educate GPs about their role, but the Network reported that engagement tended to be from GPs already involved in hepatitis C. MSD plan to work with the National Association of Primary Care (NAPC) and medical education providers on communications to GPs, providing them with content outlining the importance of primary care for elimination.<sup>104</sup>

## Initiatives in other services

### Testing and treatment in drug treatment services

#### Background need

Injecting drug use (previous or current) continues to be the most important risk factor for hepatitis C infection in all nations of the UK. While data on risk factors for hepatitis C infections are missing from the majority of laboratory reports, data we do have from 2020 reinforces that injecting drug use is the most important documented risk factor in England, cited directly as the risk in around 76.8% of all cases where risk factors were disclosed. Moreover, “prison” accounted for a further 22.5%, reflecting higher levels of injecting drug use in the prison population.<sup>105</sup> This makes strengthening testing and treatment in drug services a key part of reaching at-risk populations.

However, despite the clear prevalence of hepatitis C in drug treatment services (DTS), pathways between DTS and the NHS became fragmented as provision of addiction services were moved into public health from the NHS, following the 2012 Health and Social Care Act, with the system reliant on staff to work around barriers to care. Difficulties with service pathways might involve treatment pathways being too complex for patients to easily follow, appointments not being scheduled appropriately for patients or hospitals simply being too far away, leading to patients falling out of treatment and needing to be re-referred.<sup>106</sup>

#### About the initiative

In 2018, this need led to an initial collaboration between Gilead, Change Grow Live (CGL) – a third sector provider of addiction services – and the NHS to improve hepatitis C patient outcomes by enabling people accessing CGL services to have a simpler, shorter and more effective path from testing to access to care. Across 65 CGL sites between May and October 2018 in the initial stages of the project, the partnership achieved:

- A 36% increase in hepatitis C testing
- A 45% increase in referrals
- 1,200 staff being trained in Dry Blood Spot Tests (DBST)
- Treatment completions for over 70 patients

- A reduction in phlebotomy waiting times from 5 months to 8 weeks by training more than 60 nurses
- 85% of services having onsite clinics to micro-eliminate hepatitis C

These earlier partnerships then helped shape a later initiative tendered by NHS England as part of the elimination programme. This involved funding the creation of 25 regional coordinator roles within CGL that drove testing and referral levels across all services. Additionally, Gilead deployed a team of seven Patient Access to Care (PAC) managers to support the effectiveness of the CGL coordinators and improve coordination with the NHS, as well as providing direct investment for regional coordinators and data analysts. The team worked in partnership with ODNs to review data, optimise pathways, support clinical services within CGL and move towards a test and treat model, relieving pressure on NHS referral times and patient non-attendances.

Over time, Gilead also expanded the number of drug treatment services they engaged with to include the NHS Addictions Provider Alliance in 2019 and later Humankind, We Are With You, Turning Point, and WDP, supporting these providers to improve care pathways and focus services on hepatitis C. To further enable this, the Hepatitis C Drug Treatment Services (DTS) Provider Forum was established, with an aim to drive towards consistent commissioning standards, consistency in data reporting, and aligned priorities and services under a joint mission statement.

#### Results so far

These previous successes led to the elimination programme focus on working in partnership to improve patient finding, testing and access to care in DTS. From May 2019 to September 2022, 98,322 tests were completed and 6,475 patients were linked to care, across approximately 159 services covering 134,690 clients in structured treatment. Gilead hope that the initiative will soon hit the milestone of 100,000 tests being performed since the start of the tender.<sup>107</sup>

Gilead and DTS partners have committed to eliminating hepatitis C in these services by the end of 2023, two years ahead of the national elimination target of 2025. In April 2022, the CGL services at West Kent, Reading and Bromley announced that they had achieved micro-elimination.

100 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

101 EMIS Partners (2021) ‘EMIS partners with NHS England and MSD’. Available at: <https://www.emishealth.com/news-insights/emis-partners-with-nhs-england-and-msd>

102 EMIS (2022) ‘Primary care data set to accelerate early identification of the 1000s of ‘hard to reach’ patients unknowingly living with Hepatitis C’. Available at: <https://www.emishealth.com/news-insights/primary-care-data-set-to-accelerate-early-identification-of-the-1000s-of-hard-to-reach-patients-unknowingly-living-with-hepatitis-c>

103 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

104 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

105 UUK Health Security Agency (2023) ‘Hepatitis C in the UK 2023: Working to eliminate hepatitis C as a public health threat. Data to end of 2021’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1133731/hepatitis-c-in-the-uk-2023.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1133731/hepatitis-c-in-the-uk-2023.pdf) & UK Health Security Agency (2022) ‘Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem – Full report, Data to end of December 2020’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

106 Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022

107 Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022



This meant 100% of people using these services with a history of injection drug use had been tested for hepatitis C, 90% of people with a history of injecting and identified as being at risk since their last test had been tested within the last 12 months, and 75% of people who were diagnosed with hepatitis C had started treatment. CGL stated that “hitting these targets is a major achievement for each of these services, and for our role in supporting the NHS in its aim to eliminate hepatitis C as a major health concern”.<sup>108</sup> Further, micro-elimination has been achieved in Andover, Aylesbury, Chichester, Gainsborough, Halton and Knowsley, Richmond, St Helens and Warrington.<sup>109</sup>

Alignment across DTS providers has also been an important outcome of the initiative. For example, the new partnerships helped to overcome previous scepticism about remote testing, involving posting Dry Blood Spot Tests out to service users, with one effort securing a 33% response rate from DBST kits that were sent out after previously lower uptake.<sup>110</sup>

### Reflections and future plans

NHS England elimination programme lead Mark Gillyon-Powell praised the elimination initiatives in drug services for cutting across complex commissioning boundaries and working directly with service providers. The former medical director at Gilead Sciences, Dr Phil Troke, outlined how Gilead had also worked with drug treatment services to strengthen data capture and analysis.<sup>111</sup> Partnership working enabled services to be adapted during the pandemic to home testing, remote monitoring, and targeted testing on homeless populations.<sup>112</sup>

The Hepatitis C DTS Provider Forum established as part of the initiative was also the first of its kind across the sector. The forum brings together leadership across six DTS partners, Gilead, the Hepatitis C Trust and NHS England to share elimination best practice and ensure different bodies can support each other to overcome barriers to testing and treatment. The forum has also reportedly enabled more sharing of timely access to data for all stakeholders, which has historically been difficult with no single view of patient pathways.

DTS coordinators and the PAC team from Gilead have also been able to drive focused testing across services and simplify care pathways by bringing together a range of stakeholders from local authority commissioners, ODN clinical leads, ODN Managers, DTS leadership and local spoke hospital representatives. However, in some places treatment pathways are reportedly still somewhat fragmented, with people that have tested positive in the past 12 months still awaiting the start of treatment. Gilead suggest that a future update of the NHS England Service Specification for HCV treatment could incorporate the suggested four-week target between a positive test and treatment, to ensure all individuals testing positive start treatment as soon as possible and are not lost to follow up.

There is also still the potential to explore best practice in commissioning standards for DTS, incorporating testing, regular retesting and integrated treatment pathways with NHS services. However, the cost of testing and retesting is likely to be challenging for smaller DTS providers and this may remain a consideration for commissioners.

Gilead are also working with services to understand which other roles in the DTS could manage testing and treatment, to alleviate pressures in services, and with The Hepatitis C Trust on evolving the focus of peers from testing to treatment.

Bringing more services into drug treatment services was also suggested as a means to further strengthen integration and ease of access for clients – rules have already been changed to allow clients to collect opioid substitutes, for example. The presence of nurses or other key clinical staff in drug treatment services could mean that patients receive hepatitis C treatment while on-site, in order to further reduce the number of separate points on the pathway. Hull has already provided an initial model for this, with NHS England commissioning the service to treat patients.<sup>113</sup>



## Emergency Department testing

### Background need

Research in 2020 by a team from the London School of Hygiene & Tropical Medicine, National Institute for Health Research Health Protection Research Unit (NIHR HPRU) at University College London, Guy's and St Thomas' NHS Trust and Gilead Sciences suggested that Emergency Departments (ED) could be a cost-effective testing location, noting that rates of hepatitis are higher among ED patients than in the general population.<sup>114</sup> This was linked to ED presentations by people from marginalised communities, including people who are homeless or who inject drugs. Further, almost two in five patients in ED have a blood test as a routine part of their care, providing a valuable opportunity to test for hepatitis C and other BBVs. NICE guidelines currently recommend opt-out HIV testing in EDs in areas where prevalence is higher than 0.2%, but there was no equivalent UK guidance for hepatitis testing in ED, partly due to a lack of cost-effectiveness evidence.<sup>115</sup>

### About the initiative

ED testing for hepatitis had been piloted previously in East London and by Gilead Sciences in Leeds, which had provided a baseline of evidence that it could work in combination with other blood testing. In early 2021, NHS England asked ODNs if they

would like to express interest, in which case ODNs would be invited to draw up business cases and work with their Emergency Department consultants on proposals appropriate to their areas. Seven ODNs came forward, wanting to run testing across twelve emergency departments in total, with a variety of different models. One model involved opt-out testing for hepatitis C on every blood test that is already being taken in the ED – any patient who undergoes a blood test, which is about 80% of patients, gets an opt-out test.

The proposal from Manchester ODN covered three of their Emergency Departments and included opt-out testing. Bristol and Severn ODN has opted to employ a peer to sit in the Emergency Department at peak times and encourage people to be tested. The aim of this approach was to find out which models work best for patient finding and engagement through experimentation in different areas.

In March 2021, the HIV Action Plan for England also led to NHS England funding ED testing in areas with high HIV prevalence, creating an opportunity to implement coordinated BBV testing that incorporated hepatitis C as well. In addition to their involvement as a hepatitis C ED pilot area, Manchester ODN are being funded as a National Action Plan site as well, along with parts of London, Blackpool, Brighton and Salford. However, the HIV Action Plan funding remains separate from the

<sup>108</sup> Change Grow Live (2022) 'Tackling hepatitis C – three of our services have reached a major milestone'. Available at: <https://www.changegrowlive.org/about-us/news-views/three-services-micro-elimination>

<sup>109</sup> Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022

<sup>110</sup> Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022

<sup>111</sup> HCV Action (2020) HCV Action Webinar: National Hepatitis C ODN Stakeholder Event, 6th October 2020 – Summary Report. Available at: [http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report\\_0.pdf](http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report_0.pdf)

<sup>112</sup> Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022

<sup>113</sup> Interview with Lois Bryant (Associate, Government Affairs, Gilead Sciences), Will McCully (Director, Patient Access to Care, Gilead Sciences) and Peter Smethurst (Senior Business Unit Director, Hepatitis and Emerging Viruses, Gilead Sciences), November 2022

<sup>114</sup> Williams, J et al. (2020). 'An Economic Evaluation of the Cost-Effectiveness of Opt-Out Hepatitis B and Hepatitis C Testing in an Emergency Department Setting in the United Kingdom', Value in Health, Volume 23, Issue 8, 1003 – 1011. Available at: [https://www.valueinhealthjournal.com/article/S1098-3015\(20\)32063-5/fulltext](https://www.valueinhealthjournal.com/article/S1098-3015(20)32063-5/fulltext)

<sup>115</sup> NIHR (2020) 'Testing for hepatitis in ED departments is likely to be cost-effective in many areas of the UK'. Available at: <https://evidence.nihr.ac.uk/alert/testing-for-hepatitis-in-ae-departments-is-likely-to-be-cost-effective-in-many-areas-of-the-uk/>

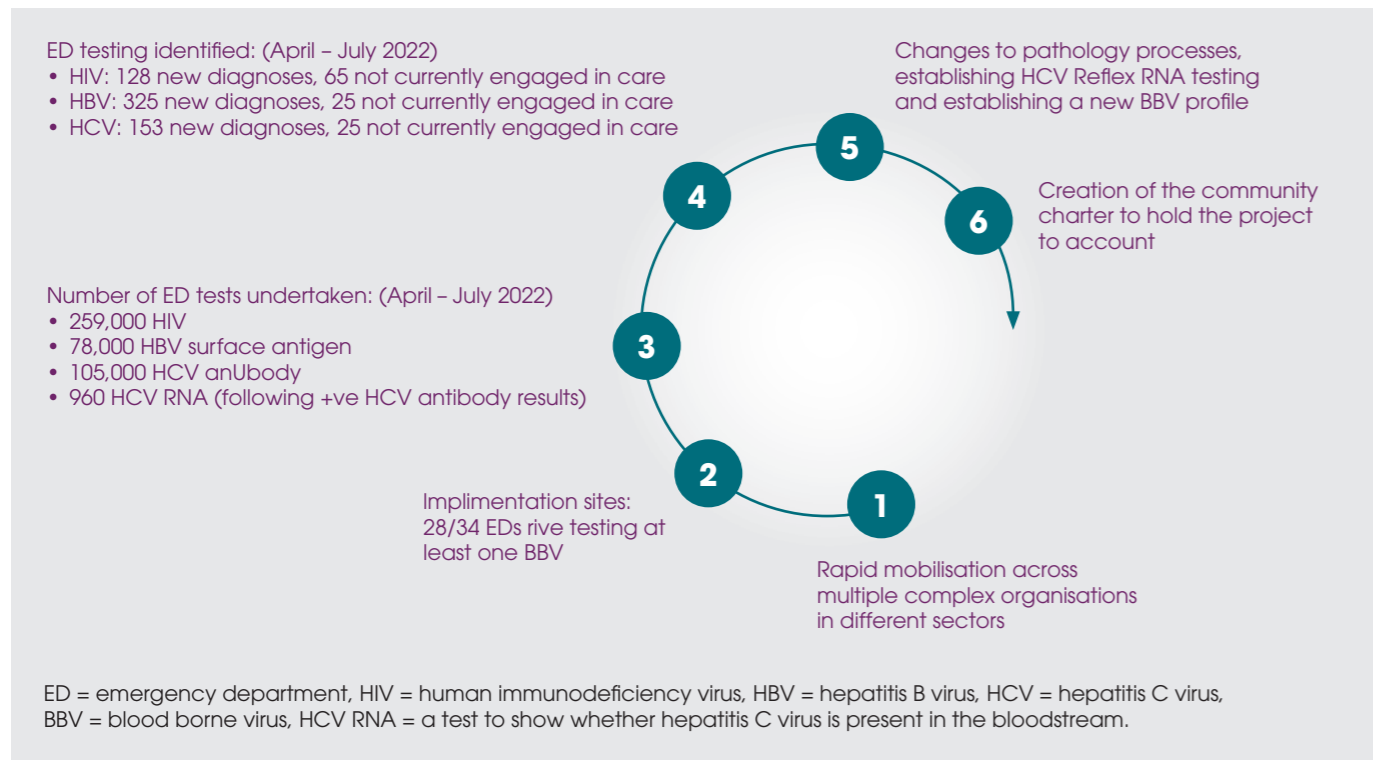


Figure 3: NHS England results from the first 100 days of Emergency Department opt-out testing

approved funding for hepatitis C testing from NHS England for the seven ODNs.<sup>116</sup>

NHS England further provided creative posters and leaflets to display in EDs to inform patients about the need for hepatitis C testing. NHS England has also been engaging testing laboratories to ensure they are able to process hepatitis C results as part of the results pathway – for viral hepatitis, laboratories send the results through to ODNs, for the ODNs to then get in contact with those patients. This means EDs only have to take bloods and send them to the lab, minimising the impact of their workload.

### Results so far

The initiative went live in London in April 2022, with an aim for hepatitis C and B testing to become available in every Emergency Department in the city – this was already the case for opt-out HIV testing. One of the provisions NHS England has asked for is to ensure that EDs carry out reflex RNA tests after initial antibody tests, which is a new process in many of these departments and has required the provision of staff training and information for patients.

NHS England has released interim findings from the first three months of the London ED opt-out programme (1 April 2022 to 31 July 2022), reporting that:<sup>117</sup>

- 153 people had been newly identified with hepatitis C.
- A further 25 people were found who had disengaged from care and 7 people were identified who had previously cleared the virus.
- Of those identified to be living with HCV and not in care, 119 were linked to care by 31 July (of whom 96 were newly diagnosed, 20 had previously disengaged from care, and 3 had previously cleared the virus).

### See figure above

Some ODNs have reported that they are awaiting the findings of the London rollout, but in the meantime NHS England is advising them on where to secure HIV funding for potential combinations. Experience so far in areas where hepatitis and HIV testing are combined is that it is easier to encourage both staff to perform tests and patients to undergo it in combination. Mark Gillyon-Powell reported that “we are finding more hepatitis C than HIV and we’re finding more hepatitis B than both of

those put together” through this approach.<sup>118</sup> 350 people were either newly diagnosed with hepatitis B or had previously disengaged from care, along with 193 newly diagnosed or previously disengaged from care for HIV.<sup>119</sup>

### Reflections and future plans

Key NHS England takeaways from the first 100 days of Emergency Department testing included the following:<sup>120</sup>

- The need to continue collaborative working with ICSs and ODNs to make ED opt-out testing routine in the areas of highest prevalence. NHS England aim to ensure that 100% of sites are testing for the BBVs selected for their site by the end of the year, and support sites to achieve the 95% of testing uptake target.
- The importance of ensuring comprehensive and culturally appropriate access to community support for those identified through ED testing, and report on the offer and uptake of community support for all people newly diagnosed or re-identified.
- The potential benefit of disseminating the learning and good practice from this project through sharing reports, presenting at conferences, supporting clinicians and community groups to publish papers, and publicising through communications across the various NHS channels.
- NHS England will complete discussions with UKHSA and agree the final evaluation proposal for ED BBV testing, and explore the opportunities for a potential NIHR application, to investigate costs avoided through identifying people living with BBV at an early stage and other areas of interest.
- To maximise effective use of resources, NHS England will explore efficiencies related to pathology costs, including consideration of setting a London wide price for HCV reflex testing and bundled tests. They will support ICSs and ODNs in considering how they can use a network approach to support all those who need care within their areas.

Alongside ensuring combined approaches to testing for different BBVs, a key determinant of

success has been the capacity that the ODN has to help with the testing, including setup, staff engagement, providing patient information and taking patients through treatment. Some ODNs have found that larger models of ED testing are not possible without those ODN relationships, though some EDs have fed back that combining blood tests is significantly reducing their workloads. “Consultants and nurses have been very happy to get that because they often don’t get any feedback on what happens when somebody walks out the door, which has been positive”, Mark Gillyon-Powell suggested. NHS England suggested that a next step may be expanding testing to all high prevalence areas if resources can be found.<sup>121</sup>

### Point of Care testing

#### Background need

There is an opportunity to align an offer of testing with ongoing care to people in a variety of settings where there is a higher than normal prevalence of people who currently do or previously did inject drugs. In the past hepatitis C testing often took time, requiring people to wait or return for their results and referral to treatment where necessary. This led to drop-off and hampered effective follow-up in cases where test results were positive and required rapid advancement onto treatment pathways. These settings have included both criminal justice system settings and community settings.

#### About the initiative

##### AbbVie

In the first two years of the tender, AbbVie supported the distribution of 20,000 oral swab kits to prison and drug service settings across the ODNs (around 850 in each ODN, which was requested by NHS England to ensure equity). These kits were useful in the early period of the elimination deal before other forms of testing, such as Dry Blood Spot Testing or Cepheid, became widely available, and AbbVie also provided test kits to a Find & Treat team in London during COVID to test housed homeless people. Elsewhere in 2019, AbbVie aimed to help supply 18,000 point of care testing kits to selected prisons and probation services across all ODNs (approximately 850 kits per ODN).<sup>122</sup>

116 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

117 Fenton, K and Gillyon-Powell, M (2022) ‘Emergency department opt out testing for HIV, hepatitis B and hepatitis C: The first 100 days’. NHS England, 29 November 2022. Available at: <https://www.england.nhs.uk/long-read/emergency-department-opt-out-testing-for-hiv-hepatitis-b-and-hepatitis-c-the-first-100-days/>

118 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

119 Fenton, K and Gillyon-Powell, M (2022) ‘Emergency department opt out testing for HIV, hepatitis B and hepatitis C: The first 100 days’. NHS England, 29 November 2022. Available at: <https://www.england.nhs.uk/long-read/emergency-department-opt-out-testing-for-hiv-hepatitis-b-and-hepatitis-c-the-first-100-days/>

120 Fenton, K and Gillyon-Powell, M (2022) ‘Emergency department opt out testing for HIV, hepatitis B and hepatitis C: The first 100 days’. NHS England, 29 November 2022. Available at: <https://www.england.nhs.uk/long-read/emergency-department-opt-out-testing-for-hiv-hepatitis-b-and-hepatitis-c-the-first-100-days/>

121 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

122 From an interview with Natalie Wood (Business Unit Manager, AbbVie), November 2022

## MSD

Funded and supported by MSD, one strand of the Point of Care Testing project initially aimed to provide rapid hepatitis C RNA testing in prisons in collaboration with Cepheid, but evolved to deliver this service in the community too. In 2019 the initiative included Cepheid machines and rapid finger-prick testing that delivers results in one hour, replacing multiple tests over weeks. This created new and additional testing capability in a setting where there is a higher than normal prevalence of people who currently do or previously did inject drugs. The expected benefits of this approach included streamlining of pathways, increased testing and speed of diagnosis, more people entering into treatment, and tackling inequality of prison provision and access.

The aim of the initiative was to get people into treatment very quickly and not have to send bloods off to laboratories. With Point of Care Testing, it is possible to get an antibody test, followed by a Cepheid PCR and potentially even initiate treatment within 24 hours. If patients are considered to be particularly high risk, for example if they have engaged in longstanding unsafe intravenous drug use, staff or peers can sometimes take a decision to fast-track testing by skipping the antibody test and going straight to a Cepheid PCR test instead.

Machines have also proven useful as part of prison HITTs, with at least five prisons now operating them as part of their reception testing process, and in remand prisons where turnover of residents is high so securing rapid results is crucial. The Hepatitis C Trust and some ODNs have also acquired Cepheid machines of their own. Machines carry four cartridges for four samples at any given time, so if two machines are available for a HITT, eight sets of results can be obtained within an hour.<sup>123</sup>

While prisons with Practice Plus Group health provision were involved in a Gilead Sciences initiative, MSD were asked by NHS England to support prisons with other health providers. MSD were initially concerned that this would reduce the potential impact from deploying Cepheid machines, as their modelling had been based on the type of high-reception prisons Gilead were supporting in PPG prisons, but it still represented an opportunity to further make use of Cepheid machines to speed up testing and pathways into treatment. MSD signed a new contract with NHS England and spent around nine months building relationships with prison staff and leaderships, while

rolling out Cepheid machines in these new settings. In some instances, MSD worked with Gilead Sciences to provide the machine as part of the prison testing pathways they were supporting.

Where possible, prison healthcare teams or ODN staff were trained to use the Cepheid machines and incorporate them into their Standard Operating Procedures, with MSD taking an approach of optimising existing pathways. A responsibility and accountability matrix was developed to ensure clarity about who was responsible for testing, securing laboratory results and progress along pathways in different areas.<sup>124</sup>

At times MSD and staff from The Hepatitis C Trust worked to move Cepheid machines out of prisons and make use of them in community settings, in instances where machines were not being used to the greatest extent possible in prisons (notably during the COVID-19 pandemic). This led to MSD developing contracts to enable redeployment in community settings such as hostels and homeless shelters, to ensure resources were being used effectively at that point in time.

When the impact of COVID-19 dissipated, MSD later supported a doubling of the number of machines available in prisons as part of a “catch-up programme”, working closely with NHS England to ascertain where need was and map the locations of MSD, NHS England or NHS acute trust-funded machines to reduce duplication. As of September 2022, a push was underway to get Cepheid machines back into priority prisons, particularly reception prisons where short-term residents have complex life circumstances and women’s prisons where prevalence is high.<sup>125</sup>

## Results so far

### AbbVie

In London the Find and Treat team tested nearly 1,000 homeless people using the oral swab kits provided, of whom 14% were antibody positive and 6% were RNA positive.<sup>126</sup> Across ODNs more broadly data is not available on how many people were tested and treated with the kits, but some ODNs reported finding it valuable to have the kits available as an easy to use form of testing at an early stage of the elimination programme.<sup>127</sup>

### MSD

In year 3, MSD reported to NHS England that this initiative had resulted in:

- Over 10,000 people being engaged
- Over 3,000 individuals being tested using a Cepheid GeneXpert machine
- Over 300 individuals testing positive for hepatitis C, enabling introduction to treatment

At HMP Peterborough, for example, a HITT team with a Cepheid machine enabled 35 new cases of hepatitis C to be found, the highest rate anywhere in the country.<sup>128</sup> This was an example of the potential value of these machines being available to strengthen screening.

## Reflections and future plans

Pathways have evolved in varied ways in different areas based on local experiences and the needs of different prison cohorts, with some using an antibody test followed by confirmatory Cepheid tests, while others did Cepheid tests first where active infections were felt to be likely (for example in HMP Bronzefield, the largest female prison in the country).<sup>129</sup>

The priority from work so far has been making the Cepheid machines available to support areas of unmet need including reception prisons, or use them in a mobile fashion in regions where access to machines is limited. For example, in September 2022, one machine was being used in HMP Pentonville but was to be reallocated to Ealing Rise Drug and Alcohol Treatment Services. This demonstrates the flexibility and responsiveness of MSD to maximise testing opportunities.

Funding for Cepheid machines stops in March 2024 with the end of the current elimination deal, so other options are being explored for how this work can be continued. It should be noted that the GeneXpert System can also test for hepatitis B and HIV. Outside of NHS England Health and Justice, some ODNs such as Surrey have also already bought their own machines to ensure continuity of access.<sup>130</sup>

## New initiatives

In July 2022 for World Hepatitis Day, NHS England announced two new initiatives:<sup>131</sup>

- **Home testing:** For those who want to know whether they have hepatitis C, NHS England are to launch a home testing website in 2023. The website will enable the public to order a testing kit for hepatitis C in which they can take a sample for lab testing in the comfort of their

own home. The home testing website has the potential to play an important role in the race to eliminate the virus, as it will empower those who want to know whether they have hepatitis C to order and undergo a test quickly, remotely and discreetly. This will enable access for people neglected by services, or who live far from a place where they could get tested, reaching populations potentially not reached before.

- **Opportunistic testing:** This final phase of elimination will also see a move towards what NHS England describes as ‘opportunistic testing’, where the NHS will take the opportunity to test people for hepatitis C at the same time they are having blood tests for other purposes, such as during antenatal screening or in Emergency Departments.

## Home testing

This will involve NHS England publicising the ability to get onto a website and get a test sent to your home to send back. It is hoped that home testing will extend access to new groups who are unlikely to be offered testing elsewhere or may wish to access it privately. Addiction services, criminal justice and GP practices have been addressed by other initiatives to varying degrees, but home testing has remained an avenue to be pursued to find further unmet need. For example, some people do not want a positive hepatitis C test on their GP record, but still ultimately need to be reached.

As of late 2022, market research was being undertaken by a company that has developed a similar portal for sexual health services. This will interview subject matter experts and patients, in order to ensure that language used is clear to those who need to be reached and that the types of data requested by the online portal meets monitoring needs, but does not put patients off from ordering a test. NHS England will be investing in advertising on partner websites and creating leaflets and posters with QR codes for easy access to the portal – these may be placed in GP practices or other community settings. The website will feature landing pages in English, Urdu and other languages, along with text documents in other languages and QR codes in relevant community publications. The test will be an antibody test, followed by a reflex RNA – if they are positive, they will be linked to their nearest ODN. The result will not go straight to the patient, however – an ODN nurse will deliver the result, so individuals can receive immediate support.<sup>132</sup>

123 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

124 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

125 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022 & from an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

126 HCV Action (2020) ‘HCV Action Webinar: National Hepatitis C ODN Stakeholder Event – 6th October Summary’. Available at: [http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report\\_0.pdf](http://www.hcvaction.org.uk/sites/default/files/resources/HCV%20Action%202020%20ODN%20webinar%20summary%20report_0.pdf)

127 From an interview with Natalie Wood (Business Unit Manager, AbbVie), November 2022

128 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

129 From an interview with Kuldip Sembhi (HCV Elimination Programme Lead, MSD), September 2022

130 From an interview with Sean Cox (Director of Prison Services, The Hepatitis C Trust), September 2022

131 Professor Graham Foster (2022) ‘World Hepatitis Day 2022: Marking the start of the final leg in the race to eliminate hepatitis C’, NHS England. Available at: <https://www.england.nhs.uk/blog/world-hepatitis-day-2022-marking-the-start-of-the-final-leg-in-the-race-to-eliminate-hepatitis-c/>

132 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

## Testing in antenatal services

This will build on previous pilots in antenatal services, including both opt-out and targeted approaches, and an NHS England survey amongst maternity services at the beginning of 2021 that asked about the potential need for training among staff for hepatitis C and blood borne virus testing and the perceived needs of their patient groups. One concern this raised around targeting was that National Institute for Health and Care Excellence (NICE) questions about risk factors will often touch on stigmatising factors around drug use and criminal history that will alienate women in these services with children, creating more of a case for opt-out testing. This approach has already been piloted in West London, with some success in demonstrating prevalence in that setting, though the National Screening Committee (NSC) rejected the data as being “not representative of the country as a whole”.

NHS England is still pursuing a further review from the NSC, which oversees screening nationally and can recommend hepatitis C screening to midwifery teams, but there is also the prospect of a development proposal that NHS England are putting forward separate to the NSC review. It is felt that emphasising to services that this will be a “targeted, time limited, patient finding exercise amongst those utilising midwifery and antenatal services” may secure more buy-in.<sup>133</sup>

## Conclusions

### Overall outcomes of the programme

The most recent data we have from 2021 shows the impact the elimination programme is having, with hepatitis C-related deaths down 30.8% and overall prevalence down 43.3% since 2015. England is leading the way globally in tackling hepatitis C, with elimination a very real prospect.<sup>134</sup>

In December 2022, NHS England reported that it was on track to eliminate Hepatitis C by 2025, five years ahead of the 2030 World Health Organization target, and attributed this to the “pioneering” elimination programme and pharmaceutical deal.”

## Lessons

While the evolution, focus and partners involved across different initiatives has varied, we can identify some key themes common to many of them:

- **The impact of access to peers:** Peers have been key for finding people further from services in communities, building links within specific communities or prison populations, sharing lived experience, combating stigma, navigating services, and providing ongoing support. The success of incorporating vastly expanded peer working into the national elimination programme is exemplified by how peers have been a working part of other initiatives, such as prison HITTs, and have been mainstreamed throughout the country by NHS England or accepted even by ODNs that did not request peers in the early days of the programme.
- **Importance of building partnerships with service staff (e.g. in prisons and drug services):** This has been vital for allowing ODN staff and staff and volunteer peers from The Hepatitis C Trust to operate in these services and reach people. It can also lay the groundwork for training service staff in terms of hepatitis C awareness and how to perform testing, which could help with achieving and maintaining elimination beyond the point when all of the resources and external support provided by the present elimination programme are present.
- **Testing and treatment in criminal justice:** Consistent reception testing in criminal justice settings, including strengthening processes around it in prisons where it is already a requirement, is vital to maintain consistent counts of hepatitis C prevalence among prison residents. Elimination will also require continued testing and treatment efforts in higher prevalence or turnover parts of the prison estate, along with processes to ensure through-the-gate support for residents of short-term justice settings who have already been found to be hepatitis C positive but leave during the course of their treatment.

- **The value of partnership working and pharmaceutical company involvement:** A key takeaway from the elimination programme has been the strength of the partnership model between NHS England, the pharmaceutical industry, The Hepatitis C Trust, ODNs and other bodies. Professor Graham Foster suggested that “this is a deal that’s delivered real value to all parties, there are synergies that we haven’t expected and it could be applied to other areas” beyond hepatitis C.<sup>135</sup> Foster has particularly noted the role of pharmaceutical companies in leveraging their relationships, data and resources to “sell” the need for the elimination drive to other partner organisations such as drug services and GP practices, strengthening buy-in.
- **Easing rollout in clinical settings:** In clinical settings, finding ways to use separate resource to ease burdens on staff or demonstrate incentives has been key to take-up. For example, in Emergency Departments, combining different BBV tests and ODNs playing a big practical role has been key and has enabled staff to more see more quickly how it can benefit patients, while for Patient Search Identification in primary care, an “integrated approach to case-finding in primary care” is being emphasised to reflect that GP practices should hand as much of the work as possible to ODNs. In pharmacies, insufficient financial incentives have been cited by some as a barrier to wider take-up of testing and so direct testing provision by on-site nurses was mooted as one potential solution.
- **The benefits of a ‘local laboratories’ approach:** The structure of the programme has meant that innovations in some areas of the country can be mainstreamed by NHS England when they were working well, to ensure equity once efficacy has been demonstrated. This was particularly the case early on in the life of the programme when ODNs were still working out their ultimate needs on the ground. This has included the expansion of the peer programme across all ODNs and ensuring that prisons with a healthcare provider other than Practice Plus Group can still receive HITTs.

“ This is a deal that’s delivered real value to all parties, there are synergies that we haven’t expected and it could be applied to other areas. ”

Professor Graham Foster, National Clinical Chair for the Hepatitis C Delivery Networks at NHS England

## Next steps

The current strategic procurement deal comes to an end at the end of March 2024, and NHS England leaders suggested they are considering other potential options for replacement to ensure some continued resource. This may not be a further full strategic procurement agreement, however, but other models such as a framework deal or a Memorandum of Understanding between continuing partners are possible. Clarity on future arrangements should be provided as soon as possible to ensure those involved in the hepatitis C elimination programme are able to plan for the next stage following the deal’s conclusion.<sup>136</sup>

Recent data also shows that improvement in terms of diagnosing and treating people with hepatitis C has been undermined by a lack of progress in reducing new infections. This demonstrates the need for measures to prevent new infections, alongside continued commitment to testing and treating those at risk, in order to both achieve elimination and maintain it thereafter.<sup>137</sup>

An extended elimination programme and continued harm reduction must be underpinned by a comprehensive national strategy. This will require buy-in across the NHS, UK Health Security Agency and other partners, in order to align priorities, foster collaboration, and integrate the hepatitis C response with wider work to tackle health inequalities.

133 From an interview with Mark Gillyon-Powell (Head of Programme – Hepatitis C Virus Elimination, NHS England), Professor Graham Foster (Clinical Lead for Hepatitis C Virus, NHS England), Georgia Threadgold (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England) and Specioza Nabiteeko (Senior Project Manager – Hepatitis C Elimination, Specialised Commissioning, NHS England), October 2022

134 UK Health Security Agency (2023) ‘Hepatitis C in the UK 2023: Working to eliminate hepatitis C as a public health threat. Data to end of 2021’. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1133731/hepatitis-c-in-the-UK-2023.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1133731/hepatitis-c-in-the-UK-2023.pdf)

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137 UK Health Security Agency (2022) ‘Hepatitis C in England 2022 – Working to eliminate hepatitis C as a public health problem. Full report’. Data to end of December 2020. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1057271/HCV-in-England-2022-full-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1057271/HCV-in-England-2022-full-report.pdf)

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