



# LEAVE NO ONE BEHIND

ENGAGING AND EMPOWERING PEOPLE  
IN HEPATITIS C CARE AND TREATMENT  
THROUGH PEER SUPPORT



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# FOREWORD

The Hepatitis C Trust was the first UK charity set up in response to hepatitis C. It was founded in 2001 by people affected by the virus to raise awareness around hepatitis C and provide accurate information and support to those affected.

The Trust's guiding principle is 'patient perspective', meaning that all views or issues are faced from the perspective of direct personal experience. The majority of the Trust's staff today, both paid and volunteers, have had hepatitis C and cleared it through treatment.

The World Health Organization's global ambition is to eliminate hepatitis C by 2030 – just ten years from now. Today, across the UK, we have the diagnostics, we have treatment for all, we have political will, we have robust and innovative care pathways, but we still need to find more of those affected. It is estimated that there are 143,000 people affected by hepatitis C in the UK, with approximately two-thirds unaware of their infection.

Generally speaking, we know where to find these people, but the greater issue is ensuring engagement from such marginalised groups, including people who inject drugs, people in prison, homeless people and migrants. People who, by nature of their situation, sit outside the healthcare system.

Peers with lived experience of these situations are a big part of the solution. Peers can offer identification, alleviate fear, dispel myths, walk beside the marginalised and vulnerable, and support them in their journey from testing to treatment.

The elimination of hepatitis C will not happen in silos; we need to go beyond the current boundaries of care. It is critical that we recognise the importance of peers in all aspects of hepatitis C care. In doing this we will ensure **no one is left behind** when we eliminate hepatitis C within this decade.

In this report we aim to share our learnings from nearly a decade of work in this field, including the challenges we have faced and how these have been overcome. We also set out the well-evidenced benefits of peer support and the advantages it can bring to people living with hepatitis C.

**Rachel Halford**  
CEO, The Hepatitis C Trust

The Hepatitis C Trust peer support programme has been integral to the work of the South Yorkshire, Bassetlaw and North Derbyshire Hepatitis C Operational Delivery Network (ODN) over the past 18 months. The programme has enabled greater numbers of people living with hepatitis C to access hepatitis C care and to complete direct-acting antiviral (DAA) treatment and achieve cure.

Peer support has underpinned our ODN's successes: in 2018/19 our ODN significantly exceeded our minimum treatment target by initiating 500 new patients onto treatment, a 14% improvement on the previous year. We would not have achieved this target without peer support, which has led to the numbers of patients initiating treatment across our ODN continuing to increase over the first three-quarters of 2019/20 as well.

Our peer workers provide the bridge between people at risk of, or known to be living with, hepatitis C and our clinical teams. They advocate passionately on behalf of people living with hepatitis C in our region: the peers remind us of their complex needs and the multiple barriers that can hinder access to and engagement with hepatitis C care. The peers provide us with honest feedback as to how our services may or may not be meeting those needs and overcoming these barriers, and work with us to improve the way in which we design and deliver our services to make them more patient-centred, less complex, and more flexible.

Equally, our peer workers are keen advocates for the work of the ODN and for hepatitis C elimination: they educate at-risk groups about the importance of hepatitis C testing; they perform testing; they identify people living with hepatitis C who are not accessing care; they encourage, support, and facilitate attendance of people known to have a chronic hepatitis C infection with ODN clinical services. They support and facilitate patient engagement throughout treatment, from initiation to completion to post-treatment follow-up.

We now consider the peer workers from The Hepatitis C Trust to be core members of our team – they are co-workers and our colleagues. Without them, we would not have been able to engage with and treat as many patients as we have done over the past 18 months. Only with them will we be able to upscale hepatitis C testing, diagnosis, treatment, and cure rates to the levels required to achieve hepatitis C elimination across South Yorkshire, Bassetlaw and North Derbyshire. To attempt to achieve hepatitis C elimination without peer support would be futile.

**Dr Ben Stone**  
South Yorkshire ODN Clinical Lead, Sheffield  
Teaching Hospitals NHS Foundation Trust

# EXECUTIVE SUMMARY

*Peer support enables someone to receive help from another person who has lived through a similar experience. The Hepatitis C Trust was founded on peer support.*

## BACKGROUND

The Hepatitis C Trust is the national charity for hepatitis C. Operational since 2001, our aim is to ensure no one dies from this preventable and treatable disease, and it is eliminated from the UK.

As a patient-led organisation we were set up by people with lived experience of hepatitis C, and our working model has always been to put patients and the patient experience at the centre of our work. Our peer-to-peer work is core to this model. Our main points of contact in the early days of our work were through our website and helpline, both of which were, and still are, run by peers with lived experience of hepatitis C — peers who offer advice and support by drawing on their own expertise and personal experiences. Today, while our website and helpline are still thriving, we offer an extensive peer-to-peer programme across the UK, with 140 staff and peer volunteers (52 staff and 88 volunteers).

Our peer support programme has evolved to meet the current needs of patients and the changing landscape of health service delivery throughout the UK. This has been fundamental to reaching those who face the most challenges accessing services.

In May 2016 the UK signed up to the World Health Organization (WHO) goal to eliminate hepatitis C by 2030. The Scottish Government subsequently stated the aim to eliminate hepatitis C six years before this target, while NHS England has set a goal of 2025.

This report puts forward the case for the unique and critical role of The Hepatitis C Trust's peer support work in overcoming the barriers necessary to effectively meet these targets. This work has contributed to successfully paving the way towards meeting elimination goals and will continue to do so in the future.

## ABOUT HEPATITIS C

Hepatitis C is a blood-borne virus that primarily affects the liver. It is thought that around 143,000 people in the UK have the hepatitis C virus, with two-thirds of them unaware they have it. Left untreated, it can lead to fatal cirrhosis and liver cancer.

Hepatitis C disproportionately affects disadvantaged and marginalised communities.

## THE HEPATITIS C TRUST PEER SUPPORT WORK – AN EVOLVING MODEL

The UK health services' ability to increase treatment numbers for those with hepatitis C is currently limited by their capacity to find and treat those undiagnosed, and to re-engage those diagnosed but not previously treated.

Our peers work in a number of challenging settings in which we are uniquely placed to effectively reach these groups. From substance misuse services to homeless shelters and prisons, our peer workers engage with those least likely to be engaged with treatment services. Reaching these groups by sharing their own experiences of hepatitis C and treatment, peers integrate messages that raise awareness, reduce stigma, inform people of transmission routes and treatments, and pass on harm minimisation information.

We have a flexible and constantly evolving peer-to-peer model based on the services we work with and the needs of those at risk of, or who have, hepatitis C.

We began our peer work within the substance misuse community with one peer worker delivering workshops, sharing their own experience of hepatitis C and substance misuse, while facilitating discussion and raising awareness about available services and treatment. Not long after, due to a high patient demand, we expanded this service to train volunteers already working in substance misuse services as hepatitis C peer workers, producing a network of embedded peer volunteers.

Since the peer programme began, we have engaged with over 25,000 people. Today, our peers work across the UK both in the community and the prison estate to reach an average of 107 people every day.

## THE CRITICAL AND EVOLVING IMPACT OF OUR PEER WORK ON ELIMINATION TARGETS

### The different strands to The Hepatitis C Trust's peer programme:

- **Talk and test.** Being able to deliver testing immediately after our peer-to-peer workshops has meant that we have been able to increase the number of people being tested. In 2016, we implemented 'Talk and test' in Birmingham with the support of local clinic teams. ***We found that half of those attending talks sought a test afterwards, following which they were referred on to ODNs and supported to complete treatment by our peers.***
- **'Follow Me'** Our 'Follow Me' programme is designed to support the most disengaged and marginalised client groups with hepatitis C, those who often have chaotic lives and very limited or no contact with health services. We train peer workers to personally support people, from initial diagnosis to treatment, helping them to overcome the barriers they face while accessing care. Peer workers accompany patients to their hospital appointments, help them to understand often complex medical language, and assist them in negotiating the care pathway. ***Since beginning the 'Follow Me' project in June 2018, we have directly supported almost 2,000 people, seeing many of them through treatment.*** Having support from a peer worker who has experienced similar challenges is paramount to this success.
- **'Open slot clinics'.** In all the areas where our peers are active in the 'Follow Me' programme we have secured access to 'open slot clinics'. ***This fast track system has enabled our peers to identify hepatitis C-positive patients in the community and offer them an assessment at a clinic without prior appointment, significantly speeding up their treatment pathway.*** We also partner with other organisations who offer our services to their own clients. We have national partnerships with substance misuse service providers, as well as local NHS Trusts.
- **Mobile outreach van.** We have run mobile 'Test and treat' clinics in London since 2011, and in the South East since 2018. Accessing hepatitis C testing can be difficult for those who are at risk but not engaged in substance misuse services, communities such as people experiencing homelessness or those with insecure housing. ***With this service we are able to reach these communities and offer an incredibly fast test and treat service, before they have moved on.*** Along with street hotspots, the mobile clinic also works with local services — such as hostels, shelters, and substance misuse services — to run events. In November 2018, we introduced a new service to work with rough sleepers in Lambeth, Southwark and Lewisham. In the seven months the service has run, we have tested 349 people, 50 of whom were hepatitis C positive.
- **Prison work.** We launched our Health and Justice Prison Peer Project in April 2017 as an adaptation of our community peer programme. The number of prisons we work in has quadrupled each year since 2017. ***Since the programme began, we have reached over 5,200 people in prison through peer-to-peer workshops, awareness training, and one-to-one interventions.***

### Significant outcomes of The Hepatitis C Trust's peer programme:

- **Awareness-raising and myth-busting.** People are often put off getting treatment due to misinformation about the side-effects of treatment. Many people are unaware that hepatitis C can now be treated in eight to twelve weeks using tablets with very few side effects, and a 95% cure rate. ***One-to-one peer support and peer groups are a particularly effective way of addressing myths and improving knowledge and awareness among at-risk groups.***
- **Addressing stigma.** We have found that the more informal relationships peer workers are able to build with patients, the more open a discussion about stigma surrounding diagnosis and treatment can be. ***Meetings between our peer workers and patients are more likely to occur away from healthcare environments, where a patient is unlikely to hold negative associations from previous bad experiences.***



- **Extended reach.** We have found that information discussed in peer workshops has the potential to reach a much wider audience if workshop attendees go on to discuss the session with their friends and networks. This extended reach to those who are not engaged with services, and who are consequently more likely to be at risk of being infected and passing on hepatitis C, is an important part of our peer work. ***The evaluation from an independent review conducted on a pilot The Hepatitis C Trust ran in the South West found that over 40% of those interviewed for the evaluation explicitly mentioned that they had shared information about the workshop with friends and acquaintances.***
- **Tackling misinformation and stigma in prisons.** Social hierarchies within prison can often lead to people not seeking testing and treatment for fear that others will find out. ***Building connections with people in prisons using Peer Support Leads through substance misuse or education services has been effective in changing this.*** Last year, 1,219 people in prison attended our peer-to-peer talks, and over half of those attending asked to be referred for testing, a proportion we aim to increase as we see our programme in prisons expand. Our Peer Support Leads also deliver frontline training to prison staff, providing information about blood-borne viruses as well as, more specifically, how to talk about hepatitis C testing and treatment with patients. In 2018/19, 892 prison staff attended our Hepatitis Awareness Training.
- **Influencing the care pathway.** Meeting the individual needs of patients when developing healthcare services is core to NHS values. Healthcare decision-makers are keen to hear from patients and peer workers about the best way to achieve ‘fit for purpose’ treatment pathways. ***By engaging with these key actors in the local area Peer Support Leads are able to argue for improvements from a patient’s perspective in the care pathway within their local area.***
- **Opportunities for Peer Mentors.** Becoming a Peer Mentor is seen by many of our volunteers as a way of giving back, and showing an appreciation for the support they themselves received. Volunteering is often an important step in an individual’s recovery, giving them a purpose and allowing them to help others. ***Roughly 40% of our Peer Mentors go on to full-time employment within the first 12 months of volunteering. In Hampshire, for example, out of the 40 people trained as Peer Mentors, 36 are now in full-time employment.***

An independent evaluation of our work, and our own data collection, has shown that the use of the personal stories and experiences of peers boosts engagement with patients at every stage, from awareness to testing, through to treatment. The benefits are not only restricted to those being supported: Peer Mentors undertaking this work gain self-confidence, invaluable experience, and the opportunity to give back to services that supported them.

## OVERCOMING THE CHALLENGES OF PEER WORK

As an organisation, we have confronted many challenges over the years in our approach to peer work, which we have worked to effectively address. We have laid out the strategies we used to overcome these challenges and in so doing provide a resource for other organisations currently working, or planning on working, within such a framework.

**“Quite simply, people like me – like many chaotic drug users and anyone who doesn’t identify as a drug user who might be homeless – would not make it to treatment completion. No matter how easy treatment is now and it is very, very easy... in my opinion without this support most wouldn’t finish treatment or even get diagnosed.”**

*Adam, Peer Mentor*

# INTRODUCTION

Hepatitis C is a blood-borne virus primarily affecting the liver. Around 143,000 people in the UK are estimated to be infected, of whom around two-thirds are unaware they have the virus.<sup>1 2</sup> This is because people often experience no symptoms after exposure to hepatitis C, and those that do occur are frequently attributed to the flu or other causes. People can therefore live with hepatitis C for decades without being diagnosed, despite the fact that untreated cases can cause fatal cirrhosis and liver cancer. Hepatitis C is the third most common cause of liver disease, one of the five 'big killers' in the UK and the only one where mortality is rising.<sup>3</sup>

Hepatitis C can also have a much broader impact on an individual's health and has been linked to cardiovascular disease, kidney problems, and musculoskeletal pain.<sup>4</sup> People often find a hepatitis C infection can also impact on their mental health. Patients regularly report experiencing 'brain fog', which covers a range of symptoms including difficulty concentrating and poor memory. Stresses associated with hepatitis C infection, which can include a changed financial or social situation, can also impact on a patient's mental health.<sup>5</sup>

There are a number of transmission routes, but the most common is through the sharing of drug equipment, which accounts for around 90% of new infections.<sup>6</sup> Some people who received blood products or blood transfusions through the NHS in the early 1990s, before adequate screening was in place, are also at risk. Other, much less common routes of transmitting hepatitis C include the sharing of toothbrushes, scissors and razors, mother-to-baby transmission, needlestick injuries, and unprotected sex where blood is involved.<sup>7</sup> Receiving medical treatment, getting a haircut or shave, and getting a tattoo overseas in a country where sterilisation is not common practice are also routes of transmission.

Hepatitis C disproportionately affects disadvantaged and marginalised communities;<sup>8</sup> almost half of the people with hepatitis C who go to hospital come from the poorest fifth of society.<sup>9</sup> Other communities with a high prevalence of the virus in the UK include people in prison, men who have sex with men, people experiencing homelessness, and South Asian and Eastern European populations.<sup>10</sup>

## ELIMINATING HEPATITIS C BY 2030

The UK signed up to the World Health Organization (WHO) *Global health sector strategy on viral hepatitis, 2016-2021* in May 2016. This aims for elimination of hepatitis C by 2030, where 'elimination' means an 80% reduction in incident (new) chronic hepatitis C infections compared with 2015 levels, 80% of those eligible being treated, and a 65% reduction in mortality from hepatitis compared with 2015.<sup>11</sup> In addition, the Scottish Government has announced it wants to achieve elimination six years before the WHO target, by 2024,<sup>12</sup> and NHS England has similarly set out an ambition to eliminate the virus earlier, by 2025.<sup>13</sup>

While the UK is making good progress towards achieving these aims, some significant challenges still exist.

Two-thirds of people living with hepatitis C in the UK are unaware they have the virus, so diagnosing and treating this group is key to elimination.<sup>14</sup> Finding the people who have fallen between the gaps comes with its own challenges caused by complex care pathways, low awareness, and a lack of engagement with services among the populations most affected by hepatitis C.

This report sets out the case for peer support playing a crucial role in overcoming these barriers.

# WHAT IS PEER SUPPORT?

In essence, peer support involves someone receiving help from another person who has lived through a similar experience, which often leads to a greater sense of identification.

This emphasis on shared experience is what makes peer support unique to other approaches. It recognises the expertise of the peer as an important way of supporting those living through a challenging situation.

Peer support encompasses many different approaches and may occur before, during or after treatment. The support given can vary from educational to emotional to practical, and so can take many forms, including the delivery of awareness workshops, one-to-one support, testing, and direct support towards attending clinical appointments.

Peer support work has gained traction in recent years as a means of assisting and lessening the burden on some under-staffed NHS services.<sup>15</sup> In particular, peer support in mental health is rapidly expanding, with an additional 8,000 new roles announced in Health Education England's mental health workforce plan which will include peer support workers.<sup>16</sup> The growing body of evidence in support of peer work means that it is likely these roles will receive more interest and investment over the coming years.

***“We are not hospital workers, we're not drug workers, we're not key workers, we're not people of authority—we're just people who have lived through the same journey that they're going through. We're people who understand the power of addiction and the stigma that comes with hepatitis C. We're just there as a friendly face so they are not going through it alone, we're going through it together.”***

*Sam, Peer Mentor*

## THE EVIDENCE

The majority of research into peer support comes from programmes in mental health and HIV services, although there are some evaluations of peer work in hepatitis C services. In 2018 a randomised controlled trial of a peer support intervention for people with hepatitis C found overwhelmingly positive results.<sup>17</sup> The trial was based in London and participants were approached through outreach services for substance misuse and homelessness. Those who were in the peer support group, rather than the standard of care, were two-and-a-half times more likely to successfully engage with healthcare systems than those who were not.<sup>18</sup>

Other studies have shown peer-based interventions for people with hepatitis C can lead to a better understanding of treatment,<sup>19</sup> reductions in perceived stigma,<sup>20</sup> greater understanding of hepatitis C more generally,<sup>21</sup> and better engagement from people who did not traditionally engage in services.<sup>22</sup> One evaluation from a peer support programme in Canada even showed that those who had received peer support experienced significant improvement to their housing status and income, demonstrating the wide-ranging impacts peer support can have.<sup>23</sup>

In addition, numerous benefits for the peer workers themselves have been found, such as a sense of purpose and 'giving back', increased self-confidence, and professional experience that can lead to future employment.<sup>24</sup> Interviews with our own peer workers back up this evidence, which will be explored later in the report.



# THE HEPATITIS C TRUST'S PEER MODEL

The Hepatitis C Trust was founded on peer support and it remains core to the work we do today.

Initially, we sought to provide accurate information about hepatitis C through our website and telephone helpline, both run by people who had or had cleared the virus, and which continue to operate to this day. In the days of interferon-based treatment, getting people onto treatment was less of a priority due to the low success rates and debilitating side-effects. It was more important to raise awareness among people engaging in behaviours which put them at risk in order to educate them on prevention and how to look after themselves if they were infected.

The vast majority of new infections are transmitted through injecting drug use, so when our peer programme began we targeted those attending substance misuse treatment services. People coming to these services generally did not respond well to the usual channels of accessing health information. It was reasoned that they might be more receptive to information from someone who shared the same lived experience as them, both of hepatitis C and of substance use.

When The Hepatitis C Trust's peer programme began in 2010, we had one peer worker who delivered hepatitis C awareness workshops in substance misuse services, sharing their own

experience of hepatitis C and substance use, while integrating key hepatitis C messages with the aim of raising awareness, encouraging testing, and providing education on harm minimisation. It quickly became clear that one employed peer worker would not be enough to deliver workshops on a national scale, which led to us developing a new strategy and expanding the model.

The expanded peer model involved working in partnership with substance misuse services to recruit volunteer Peer Mentors. We trained these peers so they could deliver awareness sessions within workshops across local services embedding these into the services' existing volunteer structures. Alongside this, we delivered education and awareness sessions to staff across the services in order to ensure they had the skill set and knowledge base to address the needs of people affected by hepatitis C accessing their services. This model allowed the Trust to expand our peer service across a wider area while ensuring peers were fully supported.

Over the next few years, our peer service expanded across a wider geographical area. However, at the same time we saw funding for substance misuse services reduce significantly, impacting on volunteer structures. In 2014, we adapted our peer model again, bringing the full delivery of this service model directly under the Trust and employing Peer Support Leads to run local peer services.



As our services grew, the hepatitis C landscape also changed. Direct-acting antivirals (DAAs), replaced interferon as the main treatment in 2015 and allowed almost everyone to be cured within only a few months and generally without side-effects. This provided a realistic opportunity for hepatitis C to be eliminated both across the UK and globally. In line with these changes, our aims broadened to include supporting people onto care pathways to ensure access to treatment for all.

Today, we work extensively with community services such as substance misuse services, hostels, and homeless shelters, and we have also expanded to provide support for patients in secure settings. People in prisons have been identified by the National Institute for Care and Excellence (NICE) as an at-risk group for hepatitis C,<sup>25</sup> with around 7% of the prison population in England having antibodies for hepatitis C (i.e. they either have had or currently have the virus).<sup>26</sup> Our peers deliver hepatitis awareness workshops and offer one-to-one support to raise awareness, reduce stigma and promote access to testing and treatment.

Our model has always been flexible and constantly evolving based on the services we work with and the needs of service users. Currently, three main channels make up our peer support model: workshop delivery, 'Talk and test', and 'Follow Me'. Our peer programme is delivered within communities and prisons across the UK, and we also have a mobile outreach van based in South East England. Additionally, we provide training for professionals who work with individuals likely to come into contact with hepatitis C, mostly based in substance misuse services and prisons.

For the purposes of this report, 'Peer Support Lead' refers to a paid member of staff who is responsible for the recruitment, training, and management of volunteer peers (referred to as 'Peer Mentors') for any given area. Peer Mentors will support the Peer Support Lead in delivering awareness campaigns using their own lived experience and may also support individuals to access testing and through their treatment journey. These volunteer peers will usually join the programme for a few months as part of their own recovery and deliver their story to support groups. When employment opportunities arise, Peer Mentors are encouraged to apply to become a paid member of staff as a Peer Support Lead. Finally, the term 'peer worker' is used to refer more generally to any of these roles.

## WORKSHOPS

In 2018/19, we delivered 181 peer-to-peer workshops in the community, directly reaching over 1,600 people considered to be at risk of hepatitis C infection. Over this period, we referred over 790 people on for treatment.

Peer-to-peer workshops are held in a variety of services, from substance misuse to homeless shelters, and consist of peers telling their personal stories of hepatitis C and treatment. They might also involve talking about peers' experiences of substance use and recovery. Their stories weave in messages to raise awareness of hepatitis C, reduce stigma, inform people of transmission routes and new treatments, and to pass on harm minimisation information.

Generally, workshops will last for one hour and consist of a peer telling their personal story, a group discussion, and a short quiz to test understanding at the end of the session. Feedback questionnaires are then collected from all participants.

*“We share our stories about our personal journeys, our drug use, how we contracted hepatitis C and how we established a journey into treatment and through treatment. [...] The stories resonate with the people we are sharing them with because certain elements will be true of their journey as well.”*

*Will, Peer Mentor*

## 'TALK AND TEST'

'Talk and test' came into being when peer workers found that immediately after delivering workshops people were coming up to them and asking to be tested. We recognised that if we could get the infrastructure in place to deliver testing immediately after workshops, we would be able to increase the number of people being tested within this group. In 2016, we implemented 'Talk and test' in Birmingham with support from local clinic teams to conduct the testing. Half of the people attending these talks sought a test afterwards, following which HCV+ patients were referred on to the ODN and supported to complete treatment by our peers.

## 'FOLLOW ME'

The 'Follow Me' model was developed following peers' feedback regarding the number of people who were already aware they had hepatitis C at the workshops yet, for a number of reasons, were not linked into treatment. The programme is designed to support the most disengaged client groups with hepatitis C, those who often have chaotic lifestyles and very limited or no contact with health services. Peer workers provide bespoke one-to-one support to this group, from initial diagnosis to accessing treatment, helping them to overcome the barriers they may face while accessing care.

**“With the Trust, we're not just going to get you an appointment. We're going to link you to one of our peers, who will go to your address, buy you a coffee, build a professional and trusting relationship, take you to a clinic, wait around while you're in the clinic and chat to you afterwards to settle your nerves and reassure you that treatment is going to be ok. I would say 98-99% of people I have engaged have completed their treatment.”**

*Chris, Peer Lead*

Peer workers accompany patients to their hospital appointments, helping them to understand sometimes complex medical language, and assisting them in negotiating the care pathway. Everyone needs a different approach, so the amount of contact required will vary from person to person. For some, one or two phone calls a week will be enough, while for others more may be necessary, including home visits.

In all areas where our peers are active, we have been able to secure 'open slot clinics' with the treating hospitals. This fast-track system enables peers to identify hepatitis C-positive patients in the community and offer them an assessment at clinic without prior appointment, significantly speeding up their treatment pathway and simplifying the patient experience.

We work in partnership with other service providers to ensure that access to peer support is available to all those who need it. We have national partnerships with substance misuse service providers, as well as local NHS Trusts. Having only begun the 'Follow Me' project in June 2018, we have directly supported almost 2,000 people, many of whom have been supported through treatment.

## CASE STUDY 1: SUPPORTING 'THE UNTREATABLE'

After seeing people fail to turn up to their appointments time after time, healthcare professionals can take on the mindset that it is impossible to treat certain demographics, namely people who use drugs. The work our peers do breaks down barriers medical staff cannot, due to their connection with patients based on shared experience and trust. One of our Peer Leads for South Yorkshire, found that peers are in a unique position outside of the traditional healthcare structure to be able to push harder than others might, in order to get people onto treatment:

“We had a patient who was deemed untreatable due to a chaotic lifestyle and previous DNAs [‘did not attend’, a.k.a. missed appointments]. She wasn't engaging with anyone, but our peers were able to engage her. When we took her up to hospital, they basically refused her treatment, saying she needs to address her substance misuse issues first. There's a lot of stigma coming from the medical staff. We didn't let it go, we kept at it, met with the lead consultant, took it to the ODN [Operational Delivery Network, the system responsible for giving out treatment for hepatitis C]. Eventually the lead consultant themselves un-discharged the client and accepted her on treatment. She successfully completed treatment. That helped us and the ODN change the pathway and gave us credibility among the medical staff.”

## MOBILE OUTREACH VAN

We have run a testing van since 2011, which has been developed to provide mobile 'Test and treat' clinics in London and the South East since 2018. The van engages rough sleepers in Lambeth, Southwark and Lewisham.

Accessing hepatitis C testing can be difficult for people who are at risk but not engaged in substance misuse services, such as those who are homeless or in insecure housing. For example, the service offering testing may be far away, people may not want to engage with substance misuse services, they may not know they are at risk, or simply it is not a priority within their chaotic lifestyle. The van is crucial to overcoming some of these barriers as it targets transient populations in areas where testing is not easily accessible. Our mobile outreach van facilitates a needle and syringe exchange service as a further means of engaging drug users within this population.

We have a dedicated outreach worker who works in partnership with nurses from King's College Hospital NHS Foundation Trust to deliver both testing and treatment. The rapid test used by the service allows someone to know whether they have hepatitis C antibodies within 15 minutes, which, if positive, necessitates a further test to check whether the virus is active. This can be done immediately, leading to a treatment decision within a week. Treatment will then be delivered from the van to the individual in the community. This type of outreach service delivered in local communities is for some people the only way that they will be accessing any healthcare service.

***“The advantage is that we actually take the hospital to them. We do Fibroscanning on the bus, we've actually started treating people who are really chaotic off the back of the bus, so we've delivered their medications, followed them up, all that stuff, so we're engaging people who historically would not be able to get through treatment.”***

*Rob, King's Hepatitis C Outreach Officer*

The van not only goes to street hotspots but also runs events with local services such as hostels, shelters, and substance misuse services. These will be publicised in advance to ensure a good turnout and steps will be taken so that the right facilities and onward referral pathways are in place.

In the last year, the mobile outreach van has tested 701 people, of whom 96 were RNA positive. 36 people have commenced treatment delivered directly from the van, making it one of the first hepatitis C 'one stop' clinics. In addition, over 2,000 interventions have been offered at the van, from needle exchanges to referrals into hostels to signposting for services.

***“I think peers have made follow-up in the community possible which is particularly important with our patient population. I believe that with the peers' help, we are more likely to get people through treatment and hopefully achieving SVR12 [sustained virologic response, or no detectable amount of hepatitis C, following 12 weeks of treatment].”***

*Sarah Montague, Biomedical Research Associate at King's College Hospital, working to evaluate The Hepatitis C Trust's mobile outreach van*



## OUR WORK IN PRISONS

The Health and Justice Prison Peer Project was launched in April 2017 as an adaptation of our community peer programme. It was developed to support the implementation of the national blood-borne virus opt-out policy, which began a few years earlier. This policy aimed to dramatically increase the number of people in prisons being tested for hepatitis C, turning testing into a routine procedure when people enter prison unless they choose to opt out. It has had a significant impact on the proportion of people being tested, on average from 5% in 2010/11 to 19% in 2017/18.<sup>27</sup> In the last year, we have seen further increases in this figure, with most prisons aiming for more than 80% of people being tested.

With an initial low uptake of testing, The Hepatitis C Trust was commissioned to deliver a prison peer support service that, through workshops, training and one-to-one support, would raise awareness, dispel myths, reduce stigma, and encourage more people to get tested. Following this initial pilot across London prisons in 2017, our prison peer support service has expanded rapidly across the national prison estate. By the end of 2020, we will be active in more than 90 of the English prisons. Since the prison programme began, we have reached over 5,200 people in prison through peer-to-peer workshops, awareness training, and one-to-one interventions. We have also delivered key information about hepatitis C, hepatitis B and HIV to over 1,200 prison staff members.

The work we do varies significantly from prison to prison. It will depend on the arrangement with the governor, our access, services already in the prison, and whether the prison is for men or for women. For example, in one prison we provide one-to-one support for people who have recently been diagnosed, in another we work closely with the substance misuse team to run half-hour workshops informing people about hepatitis C and its associated risk factors, and in another we run intense, whole-wing testing days. We also hold peer talks, run staff training, and organise wellbeing and recovery days with both staff and inmates.

A lot of our work is alongside substance misuse services rather than healthcare. This is because very early on we discovered that when someone goes to healthcare services others will want to find out why, whereas people can go to substance misuse services on a daily basis without any questions being asked. Following the session, if attendees want to get tested onward referrals will be made to healthcare.

*“Often they don’t have anyone else to talk to. They don’t have that kind of relationship with prison healthcare.”*

*Jane, Women’s Prison Peer Lead*

## TRAINING SERVICE PROFESSIONALS

We offer comprehensive training for staff on the issues surrounding hepatitis C as a major health concern. In 2018/19, we delivered awareness training workshops to 422 substance misuse service professionals. This bespoke training places the experience of people who have had hepatitis C at the heart of the training module. The training aims to assist practitioners in identifying those at risk, diagnostics, testing issues, social and interpersonal impact, support needs, confidentiality, treatment options and delivery of medication. With many health and substance misuse professionals feeling their knowledge of blood-borne viruses to be inadequate, this training is crucial to ensuring people are not missed and every opportunity is taken to test and treat people who may be at risk.

*“The gentleman presenting the session was very good, and very honest about his own experience of having the virus and going through treatment – it really helped to be told about it by someone who had actually been through it – I think that made it more memorable.”*

*Hepatitis C training attendee and staff member at a substance misuse service, Manchester*



# THE CASE FOR PEER SUPPORT TO TACKLE HEPATITIS C

Health services' ability to increase treatment numbers is limited by their capacity to find and treat those as yet undiagnosed, and to re-engage those who have been diagnosed but not previously engaged with treatment. The evidence from interviews with peer workers, an independent evaluation of our work, and our own data collection indicates that through using their personal stories, peers boost engagement at every stage, from awareness raising to testing through to treatment. The benefits are not only restricted to those being supported either; Peer Mentors gain self-confidence, invaluable experience, and the opportunity and support to address their own issues and change their lives.

## A NOTE ON DATA COLLECTION

This report has been informed by conversations with our peer workers, patients, and staff from the services we work in, as well as the data we gather. We have also incorporated some of the evidence that came out of an independent evaluation of our peer work in the South West in 2017. Our data is collected and monitored by Peer Leads following data collection training. Our feedback from workshops comes from hard copy data collection sheets completed by attendees and collected by Peer Leads after workshops and then collated centrally. To date, we have collected over 7,000 feedback forms.

It is worth noting that the data on how many people each intervention has reached relates only to those who have attended the session or been directly assisted via one-to-one support. The numbers do not include the many others who have been reached indirectly through conversations with people who had attended our workshops, or those who have come into contact with service staff whom we have trained.

Finally, we have experienced a dramatic expansion in staff and services over the time this report has been written. The number of employed staff at the Trust has more than tripled between the start of 2018 and the start of 2020, from 16 to 54. To allow for consistency across the report, data from the financial year 2018/19 has been used, but the significant growth in the services we provide over the course of 2019 means we are now exceeding this level of service delivery.

## AWARENESS-RAISING AND MYTH-BUSTING

At The Hepatitis C Trust, we still regularly receive calls from people who are put off accessing treatment due to misinformation about the side-effects and effectiveness of the drugs. Many people are unaware that hepatitis C can be treated in eight to twelve weeks using tablets with very few side-effects and a 95% cure rate. Interferon-based treatment, with its debilitating side-effects, long treatment term and low success rate, has not been routinely used in the UK since 2015. Understandably, people who have heard about the horrific side-effects of interferon-based drugs may be reluctant to engage or re-engage with treatment.

Peer workers, with the right training, are in a good position to tackle such misinformation. One-to-one peer support and peer groups are a particularly effective way of addressing myths and improving knowledge and awareness among at-risk groups. The more informal relationships peer workers are able to build with patients allow for a more open discussion about the stigma surrounding diagnosis and treatment. These conversations are informed by the peer worker's expertise from their own lived experience, often making them more relatable to patients than clinicians. Meetings between peer workers and patients are also likely to occur away from a healthcare environment which may hold negative associations for the patient due to previous bad experiences.<sup>28</sup>

The independent review conducted on a pilot The Hepatitis C Trust ran in the South West suggests that our peer education work significantly increases attendees' knowledge of hepatitis C, leads to behaviour change to prevent transmission, and has led to significant increases in the numbers of people tested in participating services. Surveys completed during the peer education pilot found that 70% of community workshop attendees said their knowledge of hepatitis C had increased 'a lot' or 'massively' following training. Additionally, almost nine in 10 attendees (89%) correctly answered all of the post-workshop questions testing their knowledge of hepatitis C, and, significantly, there was almost universal recall of the key messages in follow-up telephone interviews. Around half of those people who attended the workshops asked to get tested at the end.<sup>29</sup>

***“The problem is that there hasn’t previously been any education or outreach in prisons about BBVs [blood-borne viruses] so there’s a huge stigma and we spend a lot of time breaking down stereotypes.”***

***Rebekah, Greater London  
Prison Peer Coordinator***

Information discussed in these workshops has the potential to reach a much wider audience if workshop attendees go on to discuss the session with their friends and networks. This is one of the most important outcomes of the peer work; those who are not attending the workshops – and so are not engaged with services – but are still injecting drugs are most likely to be at risk of being infected with and passing on hepatitis C. If this group can be accessed indirectly through conversations with people who have attended the workshops, the messages we deliver about harm reduction and getting treated will have a much broader reach among a group who we would otherwise struggle to contact. The evaluation of our pilot found that over 40% of those interviewed for the evaluation explicitly mentioned that they had shared information about the workshop with friends and acquaintances.<sup>30</sup>

Under some circumstances, peers can also run training for healthcare staff to build on their understanding and knowledge of hepatitis C, as well as how they can effectively work with patients.

In prisons, tackling misinformation and stigma is also of great importance because of the social hierarchies that often dominate and can prevent people seeking both testing and treatment for fear that others will find out. We have frequently seen people in prison reluctant

to engage with healthcare teams or be seen with blood-borne virus nurses because of this. In one case, the prison team tried to set up a support group but despite 30 people on the wing having hepatitis C, not one person attended the group due to the stigma they thought they would face.

Connecting to people in prisons using Peer Support Leads through substance misuse or education services has been highly effective. Additionally, running sessions delivered by Peer Mentors (recruited from within the prison and trained by our team) works particularly well. With most prison talks delivered by external speakers, having Peer Mentors from within the prison talk about their own experiences can be both more engaging and more empowering. In 2018/19, 3,275 people in prison engaged with our peer support service and 60% of the people attending our talks in prisons asked to be referred for testing.

Limited knowledge of hepatitis C by prison staff can act as a significant barrier to accessing care.<sup>31</sup> Peer Support Leads can deliver frontline training to prison staff, providing information about blood-borne viruses as well as specifically how to talk about hepatitis C testing and treatment with patients. It is crucial that all staff, including Governors, officers, clinicians, and substance use workers, understand the importance of testing so that if appointments are missed due to competing health demands or lockdowns, they can be rescheduled and the patient supported to make the new appointment. In 2018/19, 910 prison staff attended our Hepatitis Awareness Training (HAT).

Questionnaires completed by prison workshop attendees found that following one of our workshops, people increased their rating of their own understanding of hepatitis C from an average of two to four on a scale of one to five.

## **CASE STUDY 2: FINDING THOSE LOST TO SERVICES**

John was in a residential rehab in South London where our peer workers delivered a hepatitis C awareness workshop. He already knew he was positive for hepatitis C when he attended the event. Having talked to our peer workers, John gave us his consent to help him to access hepatitis C treatment. However, rather than starting treatment within the target time frame of three weeks from engaging with us, John was discharged from rehab for using drugs and lost to the HCV clinic. One of our Peer Leads followed up with John and was able to persuade him to start treatment. John was admitted back into a residential rehab and able to continue his hepatitis C treatment.

Since then he has cleared hepatitis C, is drug free, and has offered to volunteer as a Peer Mentor for The Hepatitis C Trust. John has been trained as a Peer Mentor and is about to start delivering awareness workshops in drug services and rehabs in London.

## SUPPORTING PEOPLE THROUGH TREATMENT

There may be any number of factors preventing people from accessing treatment following a positive diagnosis, such as a lack of information, previous negative experiences with healthcare systems, addiction, and difficulties navigating the care pathway.<sup>32 33</sup> Some people face barriers which do not have a medical basis, such as insecure housing or stigma, which peer workers can be better-placed to navigate than healthcare professionals.

Problems arise from the fact that many people with hepatitis C are disillusioned by statutory services, having had challenging experiences with public services in the past, and so may be less willing to engage with healthcare services.<sup>34</sup> Engaging vulnerable communities who have been under-served by standard healthcare services and pathways can be problematic, with this group frequently being labelled as 'hard-to-reach'.<sup>35</sup> However, unless these key, high-prevalence groups are engaged with and successfully treated, eliminating hepatitis C will be impossible.

Peer support is a means of enabling active engagement with healthcare services among marginalised groups.<sup>36 37</sup> The sense of mutual understanding founded on a common experience and identification is particularly valuable in the context and history of feeling misunderstood or ignored.<sup>38</sup> Having support from a peer worker who has experienced similar challenges and who is not part of the traditional care pathway can encourage patients to engage with treatment where previously they may have been indifferent or reluctant.

Many people living with hepatitis C have lives which are incredibly busy, often with already conflicting demands. These may include acute health concerns, caring responsibilities, addiction, and insecure housing.<sup>39</sup> Having to attend hospital appointments on top of an already packed schedule for a health issue which may so far have never perceptibly affected them will, for most people, not be a priority. Even if an individual did prioritise their health, some groups face further barriers. For example, there is a well-documented association between homelessness and having hepatitis C antibodies, yet the homeless population face additional barriers when trying to access services, such as not having an address when registering for a GP.<sup>40</sup>

**“ She came to every appointment with me and supported me the whole way through the journey. Because she'd been through that process herself I felt very comfortable with her. I suffer with anxiety so that really helped me. Without her I don't think I would have done it. ”**

*Holly, who was supported on the 'Follow Me' programme*

While pilots are ongoing to identify a better care pathway through community pharmacies,<sup>41 42</sup> peer workers can provide tailored support. A peer worker can assist with a wide range of social issues, helping to organise someone's time and advocating for their access to care. Additionally, people living in rural areas may be put off attending treatment appointments by the transport costs and time commitment.<sup>43</sup> Having a peer worker to assist with some of these problems and clarify the often confusing and compartmentalised healthcare system can be very useful when engaging people in treatment.

'Follow Me', our service offering support to people who may find the treatment pathway more difficult to navigate, supported clinic visits for 636 people in 2018/19, with over 1,750 support calls made. Much of the feedback we have had from nurses and patients alike indicates that the majority of these people had previously missed appointments and would not have cleared their hepatitis C without the support of peers to guide them through.

## INFLUENCING THE CARE PATHWAY

Meeting the individual needs of patients when developing healthcare services is core to NHS values. This is of particular importance when designing hepatitis C care pathways where traditional models of care have not worked. Healthcare decision-makers are therefore increasingly keen to hear from patients and peer workers about the best way to achieve 'fit for purpose' treatment pathways. By engaging with key actors in the local area and using their status as experts by experience, Peer Support Leads advocate for improvements in the care pathway in their local area. This can lead to more accessible treatment services, a less complex treatment structure, increased communication between providers, and ultimately a better experience for patients. For example, our peer workers' engagement with commissioners in South Yorkshire successfully led to the establishment of a two-appointment system, making it easier and quicker for people to be treated (see 'Case study 3').

Having conversations with healthcare professionals has also led to peer workers being trained up by nurses to conduct dry blood spot testing. This allows them to carry out initial antibody testing, as well as RNA testing to check whether someone has a chronic infection.

Bodies responsible for delivering hepatitis C treatment in England (Operational Delivery Networks), Scotland (Managed Care Networks), Wales (Local Health Boards) and Northern Ireland (the Managed Clinical Network) have monthly targets to promote access to treatment for marginalised people. Peer support workers have been shown to be an effective means of promoting the treatment pathway, as recommended by the WHO strategy on viral hepatitis: 'peer-support workers play an important role in reaching marginalized groups, linking people with chronic hepatitis to care, supporting treatment adherence and providing chronic care.'<sup>44</sup> As such, peer workers are key to these networks successfully achieving their targets and preventing people falling between the gaps.

“The Trust has been able to prove the effectiveness of the model and clinicians increasingly understand patient needs and the role peer work plays in the patient pathway. NHS England puts a lot of weight into peer projects. The Trust anticipates that peer work will feature very strongly in the new procurement arrangements for treatments and services. The Trust's helpline receives at least one call every week from a clinician or a drug service worker to ask what peer support is available in their area.”

Stuart, Director of Community Services

### CASE STUDY 3: CREATING NEW CARE PATHWAYS IN YORKSHIRE

Getting buy-in from health services can be difficult, particularly when they have experienced so many occasions where people have not turned up to their appointments. Most of our South Yorkshire team's work is with drug and alcohol services, though we also work alongside housing support services, food banks, soup kitchens and council services. The team is flexible to the needs of each service, often embedding itself to the extent that we become like members of staff. The team has worked hard to build good relationships with managers at health services: peers are always brought along to meetings with commissioners and senior managers. This both empowers the peers and helps the commissioners to understand the value of the work we do. After successfully getting one individual, who had been branded by healthcare staff as untreatable, through treatment, the team gained credibility and was able to request drop-in sessions from them on the basis that the peers would be able to bring people along. This created a more flexible and rapid care pathway, with a two-appointment system – one for assessment and the next for treatment. Engagement with health services has also led to peers becoming permanent members on the ODN board.

Our Peer Lead for the area said: “We've been really influential in rebuilding the pathway and making it more aligned to people's lives. [...] There always will be barriers, but it's about how you negotiate them. Barriers have been built up from years of services' negative experiences working with our client group, but now we have a fresh and positive approach. If we get pushback, we have to re-evaluate ourselves and how we presented our service, and go back and try again.”

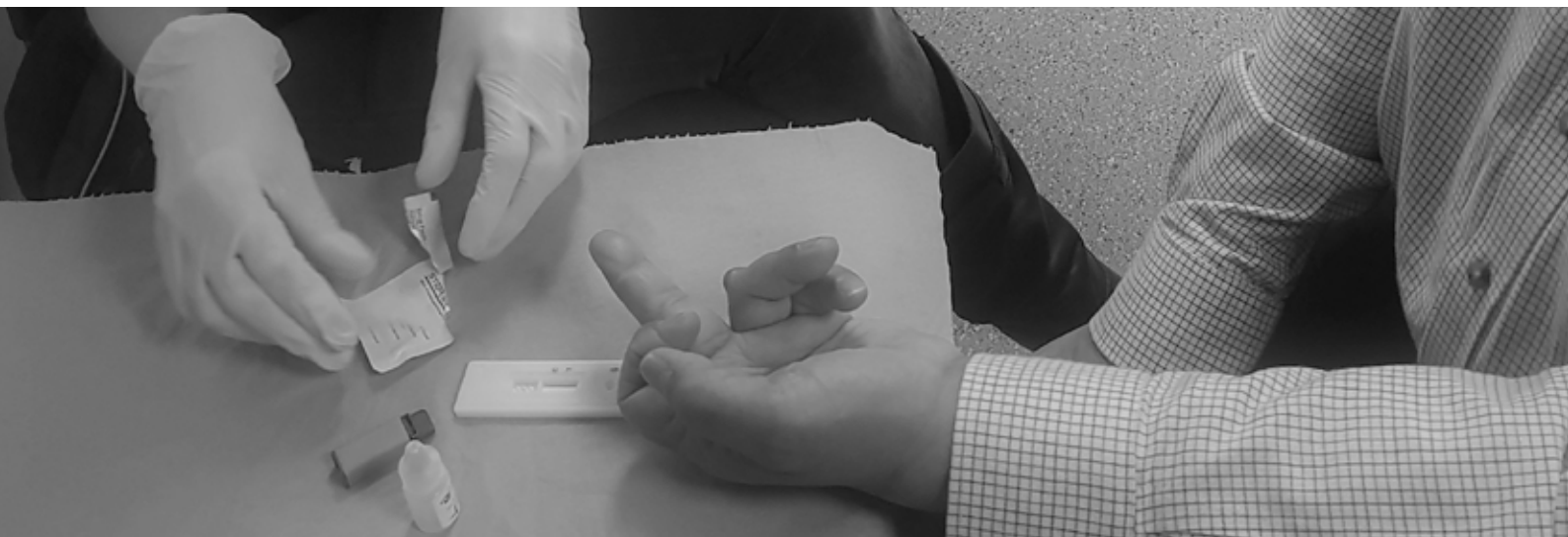


## SPECIFIC BENEFITS FOR THE PRISON POPULATION

Along with other marginalised groups, people in prisons experience barriers to testing and treatment. However, the controlled prison environment can provide a unique opportunity to engage people in treatment services for long enough to clear their hepatitis C. Just like in general healthcare settings, a lack of trust in services can act as a barrier to engagement. This is often even more pronounced in prisons, given the higher likelihood of previous negative experiences of other public services. It is also important to note that the impact of stigma within the prison setting is significant and should not be underestimated.

Peer workers are able to engage people with services by building relationships based on shared experience and identification, something prison staff by and large cannot offer.<sup>45</sup> Studies show that peer education interventions in prisons are effective at reducing risky behaviours, have a positive effect on recipients both emotionally and practically, and are able to engage people in services.<sup>46</sup>

Additionally, we have found that receiving treatment for hepatitis C can be a critical first step for people in prison taking control of other areas of their lives which may previously have been chaotic, such as substance use, homelessness, and mental health problems. Addressing these factors can aid rehabilitation and cut reoffending, in addition to the direct health benefits.



## OPPORTUNITIES FOR PEER MENTORS

Becoming a Peer Mentor is seen by many of our volunteers as a way of giving back and showing an appreciation for the support they themselves received. Volunteering is often an important step in an individual's recovery, giving them a purpose and allowing them to help others.

The professional experience that Peer Mentors gain is also not to be undervalued. The confidence and skills that peers gain allows them to seek out full-time, paid employment elsewhere, where their experience working for The Hepatitis C Trust adds greatly to their CV. This is evidenced by roughly 40% of our Peer Mentors going on to full-time employment within the first 12 months of volunteering. In Hampshire, for example, out of the 40 people who were trained as Peer Mentors, 36 are now in full-time employment.

In particular, volunteering as a Peer Mentor within a prison offers both a meaningful way for people to spend their time and useful experience to heighten prospects of employment on release.



# CHALLENGES OVERCOME IN THE COMMUNITY

While peer support overcomes many of the difficulties people with hepatitis C face in the care pathway, it also comes with its own challenges. This section of the report sets out some of the issues we have faced in the years we have been delivering peer support, and how we have overcome them.

## RECRUITMENT OF PEER MENTORS

Peer volunteers are crucial to the success of the peer programme, and as with many organisations we continually face challenges in recruiting and retaining passionate volunteers. This is due in part to the experience that Peer Mentors gain from working with us, which often leads them into employment elsewhere. We are proud that so many of our Peer Mentors use their skills, gained in a professional environment whilst working with us, to move into full-time jobs. However, this constant movement of people does present challenges.

Our Peer Support Leads do a good job of recruiting new peer volunteers, who are often attendees of peer-led workshops or people who have been directly supported by our peers through treatment. This creates a cycle of peer workers who originally come to us as clients, become involved in our work as volunteers, then move on to full-time employment. For those individuals who have not worked in a professional environment before, it is important there is a full support structure in place with excellent training, a gradual induction, and shadowing until peers feel confident enough to deliver their own story.

*“It was the first time I’d actually completed anything in my life. My confidence built up a little bit, speaking to people. Through the support of Rachel and Imran I’ve become a peer myself. It’s fantastic, the journey, you couldn’t make it up. It’s been amazing.”*

*Sophie, who was supported on the ‘Follow Me’ programme*

## SUPPORT FOR PEER WORKERS

Providing ongoing support for peer workers is crucial to the success of the peer programme and the individual. A comprehensive induction and training package for all new starters is followed by ongoing monitoring and support. This is particularly relevant given many Peer Mentors are at an early stage in their own recovery journey, and can be delivering talks in places which may cause some difficulties, such as substance misuse services where people are currently using. Building frequent supervision, open lines of communication, and robust structures of management and governance are essential to our work with peers.

The nature of the work – engaging with people who may be experiencing poor physical or mental health – can also be emotionally draining for peers. All our Peer Support Leads receive regular clinical supervision, consisting of one-to-one counselling which addresses the impact their work may be having on them.

*“As the Trust is a patient-led organisation, the majority of its staff have lived experience of hepatitis C. As the organisation expands, it always recruits people who can engage with patients at their level. Many new employees are not used to working in a professional environment and the Trust gives them space, patience and support to develop and adapt.”*

*Stuart, Director of Community Services*

## PARTNERSHIP WORKING

A significant current challenge for Trust peer workers is encouraging overloaded substance misuse service staff to dedicate time and energy to raising awareness of hepatitis C. Cuts across local authority budgets have meant that substance misuse service providers are being asked to do more with less funding. Joint working with substance misuse services and hepatitis C treatment providers is key to the success of the peer support programme. However, hepatitis C work is often seen as an 'added value' service amongst community services that may be already over-stretched and under-funded. As such, group work and workshops are frequently dropped from the services offered.

Historically, NHS staff have also been resistant to some aspects of peer work due to a scepticism of their ability to engage people in treatment. This is based on past experience of no-shows as well as staff preconceptions

about people who use drugs and the view that individuals cannot be treated if they are currently using. However, the landscape is changing – in part because of the work of the peer programme. With the support of a peer worker, people who were previously thought to be 'untreatable' have been effectively cured of hepatitis C. Getting buy-in from NHS services can be challenging but is achievable when clinicians see the positive outcomes of engaging people into treatment in this way. The incredible results of partnerships we have formed with NHS nurses in recent years, such as the mobile outreach van, is testament to this.

Fundamental in establishing the peer model across the UK has been in our building strong relationships with service providers and clinicians. Crucial to this has been our having an understanding of the challenges they face in their day to day work, and being able to adapt our peer service delivery to relieve pressure around the hepatitis C care pathway.

**“ My own personal experience working with peers has been very successful. With a coordinated approach, peers are a very effective way to engage patients/clients into treatment and improve equity of care for often the most marginalised in society. I also feel that the benefit for the peers themselves cannot be underestimated, increasing their levels of confidence and utilising their skills and strengths to support others in itself is very rewarding. ”**

*Janet, Nurse Consultant at King's College Hospital*



# CHALLENGES OVERCOME IN PRISON

## GETTING ACCESS

The peer programme works on the basis of a shared experience between people, which helps to develop trust and open communication. In the context of prison work, this means that our peer workers will have had experience of being in prison themselves, as well as having had hepatitis C. Getting access to prisons is more difficult for people with criminal records, particularly if they need to be a key-holder which enables easier access to the prison. Without keys, external staff need to be accompanied by a prison worker the whole time which is time-consuming for prison staff and not conducive to intimate group discussions.

Standard vetting processes generally reject anyone who has previously been in prison, so Peer Support Leads have found a different way of getting keys by asking for permission from each prison Governor. Although this way of achieving access takes longer and requires renewal more frequently, it is slightly more successful.

## STIGMA

The lack of outreach and education about blood-borne viruses in many prisons means there is a high degree of stigma. This is exacerbated by an entrenched social hierarchy where people who use needles to inject drugs are often considered to be very low in the pecking order and having hepatitis C puts them lower still. A fear of being found to be infected with hepatitis C puts many people off being tested, let alone accessing treatment or participating in group workshops.

Getting people to come in and tell their story is a key part of breaking down this stigma and working against the bullying which can originate from a positive diagnosis. Talks from Peer Mentors can encourage people to think about hepatitis C differently and have honest discussions based on facts rather than myths. This in turn can encourage testing and treatment, even inspiring people to become Peer Mentors themselves and act as champions in their wing or prison. Having Peer Mentors inside prison is a great way of breaking down stigma and stereotypes. However, as in the community, there needs to be strong networks of support.

**“People are very receptive to my training because I am an ex-prisoner and we share that life experience. Staff often come up to me and say, ‘I have never seen that group so quiet and so engaged.’”**

*Eddie, Senior Peer Educator*

## MOBILE PRISON POPULATION

A big challenge with working in the prison estate is the mobility of the population, both in terms of getting people treated and recruiting Peer Mentors. Remand prisons pose particular difficulties because people can be in and out in a very short space of time. Our Peer Support Leads in prisons have developed close links with community services to ensure people who have been diagnosed in prisons continue to be supported on the treatment pathway when they leave, with our Peer Support Leads in the community also able to aid this transition. Additionally, the rapid movement of the prison population means that Peer Mentors need to be trained quickly to deliver talks before they are moved on or released.

## GETTING PRISON STAFF BUY-IN

Prison staff have a large number of demands on their time and sometimes facilitating workshops is not high on their list of priorities, particularly if Peer Support Leads need to be constantly accompanied due to not having keys. Frequently, the structures in place for testing and treatment for hepatitis C are reliant on the goodwill of Governors and healthcare staff, and this varies greatly from prison to prison. To get staff support for workshops and events, we have built good relationships with stakeholders within the prisons. Training on blood-borne viruses can also help prison workers appreciate the importance of peer work, and indeed a report on the opt-out policy in 2016 found that prison healthcare staff overwhelmingly thought that additional training on blood-borne viruses for wider prison staff was required.<sup>47</sup>

## FURTHER SUPPORT

Offering further support is more complicated in prisons than in the community, where having a cup of tea with a patient is not so simple because of the rules and governance structures. In order to give people the help they need following a positive diagnosis, we work closely with Blood-Borne Virus Leads in the prisons and nurses from the area's ODN to ensure people get access to treatment as soon as possible. We also support people on a one-to-one basis with both Peer Support Leads coming into prisons and our volunteer Peer Mentors within prison, as well as over the telephone on our prison helpline.

## CONCLUSION

Our peer support programme has addressed stigma, raised awareness among both people at risk and service staff, and ultimately increased the number of people who have been tested and treated. The shared experience between clients and peer workers establishes a trust which other professionals sometimes struggle to form, and helps to engage those who are most at risk of becoming infected by hepatitis C.

Public Health England's latest report on hepatitis C called for a 'radical change in our approach' to tackling hepatitis C among people who inject drugs, though such a change should not be restricted solely to this group.<sup>48</sup> A significant shift is needed across the board towards outreach and working with, and alongside, people who have had hepatitis C. People's lived experience is incredibly valuable and, given the right training, can break down barriers that may exist for other professionals.

Empowering people to share their stories with others going through similar experiences is greatly beneficial for Peer Mentors too. Supporting others acts as an important step in a peer worker's own recovery and allows them to build experience and confidence while providing an opportunity to give back to a network which supported them in the past.

Eliminating hepatitis C will not be possible without peer support to encourage testing and support individuals along the treatment pathway. The people most likely to be affected by hepatitis C are often marginalised, vulnerable, and have frequently been let down by statutory services. Being able to talk to someone who has shared experience nurtures a relationship built on trust. It is only with these personal connections that we can successfully find and treat all those at risk or affected by hepatitis C. We can then shut our doors as The Hepatitis C Trust, satisfied in the knowledge that hepatitis C has been eliminated in this country and that **no one has been left behind.**





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27 Crosby Row  
London SE1 3YD

**020 7089 6221**  
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