The Hepatitis C Trust's response to Prof Dame Carol Black's Independent Review of Drugs, part 2

August 2020

1. What interventions are the most effective at preventing problematic drug use? Answers can relate to universal or targeted interventions for both adults and young people. Please include any good practice examples

While problematic drug use continues to be addressed as a criminal justice issue rather than one of public health, it will be difficult for the Government to deliver any meaningful preventative interventions. However, promoting health-based interventions – such as blood-borne virus (BBV) testing and treatment – delivered by people with whom those engaged in problematic drug use can identify – leads to greater engagement with services and recovery outcomes.

In addition to adopting a national approach to substance use based around public health rather than crime, we believe that preventing the initiation of drug use, as well as preventing relapse, should be embedded within a holistic approach to health and wellbeing – this might for example be supporting people through hepatitis C treatment – as well as the involvement of people with lived experience (peers) in the design and delivery of services to maximise credibility and relevance. Embedding prevention of BBVs – again, ideally peer led – into drug treatment increases understanding of the wider risks of drug use, and the volunteering and work opportunities peer-based models provide offers a consistent and effective structure through which to support people to move away from drug use.

Addressing health harms

The Hepatitis C Trust's experience – as an organisation that works predominantly with people who inject drugs (PWID) – has been that getting cured of hepatitis C is a crucial first step for most people in taking control of other aspects of their lives, such as addiction and employment. Of course, the health benefits of treating hepatitis C make it a worthwhile intervention in its own right: hepatitis C, like other BBVs, disproportionately affects the injecting drug population and without treatment it can lead to an increased risk of mortality, liver disease, and myriad other health problems. Completing an 8-12-week course of treatment is often the first committed step someone has taken to benefit their health, and this will frequently pave the way to other forms of recovery, promoting positive behaviour change due to the self-conviction it affords.

Problematic drug use is typically rooted in personal experience of adversity in childhood or adulthood: many people with a drug problem have experienced the worst effects of deep social inequalities, often leading to low self-esteem. Such feelings are compounded by a wariness and distrust in public services caused by negative past experiences, such as stigma – perceived or actual – from health, social care and justice systems. This culminates in a culture of disengagement with initiatives designed to help them.

Peer support is absolutely vital to re-engaging people in services, and often contributes significantly towards the patient's more general recovery. The Hepatitis C Trust's model of peer support sees both our paid staff and volunteer peers – all of whom have personal experience of drug use – deliver hepatitis C educational workshops in drug treatment, homelessness and allied services, during which they use their own story of recovery from both hepatitis C and drug use to reduce fear and stigma and to encourage testing and take-up of health care and treatment.

Hearing educational messages about harm reduction, hepatitis C prevention and health promotion from people who have shared experiences has an immeasurably greater impact on people than a talk from a healthcare professional. In addition to direct support around hepatitis C, our peers also frequently signpost people to other services and offer safer drug use interventions including needles and syringes, during outreach to homeless and more vulnerable communities.

At The Hepatitis C Trust we frequently find that many of those we support to complete treatment go on to volunteer for us. By completing our training and gaining invaluable experience and confidence, around 40% of our volunteer peers go on to full-time employment within the first year of volunteering.

---- *Sophie, who was supported by The Hepatitis C Trust, said: "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."*

a. What helps to implement them?

As outlined in our answer to question 1, peer support is vital to engaging people and providing appropriate education and support to specialist services and treatment as needed.

b. What makes implementation difficult?

The Hepatitis C Trust's peer support model is funded by NHS England and involves our peers partnering with already existing drug treatment services and other outreach services (such as those for people rough sleeping). As things stand, drug treatment services, commissioned by local authorities, cannot be expected to deliver harm reduction interventions and peer support initiatives without clear policy direction, and guidance from local authority commissioners. Local authority cuts have left drug services with significantly reduced treatment capacity resulting in non-core but essential harm reduction services unable to respond to immediate drug-related harms evidenced by recent UK increases in drug related mortalities (see Reference 1). For more on funding, please see our response to question 3.

Despite the overwhelming weight of evidence to the contrary, drug use continues to be treated as a criminal justice rather than a health issue (see Reference 2). Without a health-based approach, with necessary evidence-based harm reduction and treatment interventions, it is likely that the health and care of thousands of people across the UK will continue to be compromised, resulting in significant harms and increases in preventable deaths. Interventions including optimal provision of opioid substitution therapy (OST), needle and syringe programmes (NSP), Naloxone distribution and drug consumption rooms (DCRs) are proven to save lives and we believe that policy changes and commissioning guidance can ensure that these programmes are universal and accessible to all people who use drugs (PWUD).

Reference 1: Drug-related deaths in England: Local authorities and how they are responding, NAT, 2019.

Reference 2: The case for a harm-reduction decade, Harm Reduction International, 2016.

2. What interventions are most successful at reducing harm, particularly within vulnerable groups? Please give examples of what has worked well and which vulnerable group they relate to.

NHS England has committed to spending around £1bn on an elimination deal for hepatitis C, with the aim of eliminating the virus as a public health threat by 2030 at the latest. Without adequate harm reduction, the UK cannot eliminate hepatitis C (see Reference 3): not only would this money be wasted but as a country we would lose a historic window of opportunity to get rid of a disease that has plagued the most vulnerable in our society for decades. It is critical that Government acts quickly to implement harm reduction and health promotion initiatives among people who inject drugs as a matter of urgency.

Effective needle and syringe programmes help to reduce the sharing of injecting drug equipment and are therefore vital to preventing hepatitis C transmission. Testing and treating people for hepatitis C reduces the harm that hepatitis C causes and, in addition, can often act as a catalyst for patients engaging in drug recovery. Opioid substitution therapy, drug consumption rooms and Heroin Assisted Treatment have all been proven to reduce harm and offer opportunities to engage with vulnerable groups around BBVs.

Needle and syringe programmes

Public Health England's latest estimates indicate that despite dramatic improvements in the numbers of people accessing effective treatments for hepatitis C – treatments which have only been available on the NHS since 2015 – the number of people acquiring new infections has not fallen. This demonstrates that treatment as prevention, though important, only goes so far: sufficient harm reduction initiatives are necessary if the UK is to finally eliminate this significant public health threat.

NSPs are an incredibly effective, low-cost intervention: high NSP coverage, especially alongside the delivery of optimal OST (see Reference 4), has been shown countless times to be associated with a reduction in health harms related to drug-taking, including decreasing the risk of hepatitis C acquisition. The World Health Organization's Global Health Sector Strategy on Viral Hepatitis calls for a major increase in provision and availability of sterile needles and syringes, aiming for 300 needles and syringes per person who injects drugs per year by 2030. In Scotland the rate is currently just 54 needles per injecting drug user and in England the data are not currently reported. More important still is that people have enough clean equipment for every injection attempt, reducing the need to share. PHE data from 2018 shows that around a third of people who inject drugs self-reported that they had inadequate needle and syringe provision for their needs and 38% of respondents to their injecting survey had shared injecting equipment in the preceding four weeks (see Reference 5). Recent studies have shown that this proportion has grown as COVID-19 has further restricted access to NSP (see Reference 6).

These programmes offer an opportunity to provide education and advice to keep people safe and help them to avoid BBVs. They have also been shown to be acceptable and effective programmes through which to offer BBV testing and link people into treatment.

Sharing of injecting equipment remains common in the UK and levels have remained unchanged for many years. In fact, the latest data (from the Unlinked Anonymous Monitoring survey of people who inject drugs in 2018) found that the level of direct sharing reported by participants in the previous four weeks was the same as in 2008, at just under one in five (18%) and rising to two in five (39%) when including indirect sharing (see Reference 5).

Initial reports are showing how COVID-19 has impacted negatively on NSPs: many drug treatment services and pharmacy-based supplies have had restricted access to NSP. Additionally, the NHS Substance Misuse Provider Alliance has reported that more people, while maintaining social distancing and/or shielding, have been reluctant to visit their needle exchange, resulting in a greater likelihood of reusing and sharing drug paraphernalia. This has been backed up by a study published in July by the International Journal of Drug Policy which found that visits to NSPs declined by well over a third (36%) during lockdown, and provision for those injecting psychoactive drugs halved between March and April 2020, since which point coverage has remained low (see Reference 6).

Secondary exchange describes where someone collects needles, syringes and other injecting equipment from the needle and syringe programme on behalf of others. Typically, it describes an informal process where peers distribute needle and syringes to their using friends or community and although often unofficial, is a standard practice across many areas. More formally the term – either exchange or, better, distribution – is used to describe how a service or NSP actively recruits and trains peers to deliver and promote NSP and prevention education across their communities on behalf of the service. We believe that training peers to deliver needles and syringes can ensure access to communities of drug users who are wary of engaging and effectively promote harm reduction messages and treatment access while delivering essential drug taking equipment (see References 7, 8, 9 and 10).

The reality of persistent levels of sharing over the past decade and the likelihood of more recent increases must be absorbed into policy: there should be optimal and equitable needle and syringe provision for all. This means that NSPs must be properly funded; adequate to people's needs; provided within appropriate distances of where they are needed; and monitored and represented in data collection.

Low dead space syringes (LDSSs) are particularly effective at reducing the risk of transmitting BBVs during sharing: they reduce the amount of "dead space" left in a needle or syringe once the plunger has been depressed, thereby limiting the residual fluid which may harbour BBVs. Current data suggests only around 58% of NSP sites in the UK provide LDSSs. Public Health England's Hepatitis C in England: 2020 report recommends that LDSSs are scaled up in line with current NICE guidance (PH52) to ensure everyone who needs them receives them (see Reference 11).

Finally, recent research by King's College London and the London School of Hygiene and Tropical Medicine has found that, as water is not being provided with NSPs, people are using unsafe water sources including puddles to prepare injections and thereby increasing their risk of serious infections and illness. This has been further compounded in lockdown by the closure of public toilets. At present, provision of water for injection is fragmented and inconsistent, due to cost and ignorance of the change in the law allowing the supply of 5ml water ampoules in 2012. It is critical that clean water is provided alongside sterile needles and syringes, as stipulated by the poorly publicised amendment to the Medicines Act in 2012.

Testing and treatment for blood-borne viruses

Offering testing and treating people for BBVs, such as hepatitis C and HIV, in settings such as drug services and with the support of peers can lead to increased engagement in services and better recovery outcomes. Crucially, such health-improvement initiatives are also paramount in preventing further spread of such potentially fatal diseases and achieving the UK's target to eliminate hepatitis C by 2030 at the latest.

Hepatitis C, the most common infection among people who inject drugs, is a preventable and curable BBV. It affects 89,000 people in England, 90% of whom have acquired the infection through the sharing of drug-taking equipment, on which the virus can survive for up to three weeks. In its initial stages, hepatitis C has few symptoms, with any that are exhibited often being attributed to other causes, resulting in around half of people infected with the virus being unaware they have it until it begins to seriously impede their liver functions. Without treatment, hepatitis C can lead to fatal cirrhosis and liver cancer.

Given that most new infections are transmitted by the sharing of drug-taking equipment, treating hepatitis C is one way to reduce the rate of transmission. This is currently being tested by researchers at the University of Bristol at a site in Dundee. The project, EPIToPe, will treat around 500 people who inject drugs over two years across multiple sites including the community, prisons, pharmacies and addiction services. It is estimated that this will reduce hepatitis C in people who inject drugs in Dundee from nearly 30% to less than 10%.

A critical part of mass treatment is making it available in the community, in settings at-risk populations already access and without requiring painful and invasive investigations or the capacity for patients to attend multiple appointments. This is already happening in much of the UK but needs more consistent implementation; hepatitis C treatment provision (as well as testing) should be embedded in community drug services.

As things stand, the UK will not meet the World Health Organization's Global Health Sector Strategy target of a 30% reduction in new hepatitis C infections by the conclusion of this year, a target which the UK Government signed up to in May 2016. Much more must be done if we are to meet the target of an 80% reduction in new infections by 2030, and thus effectively eliminate the virus. Identifying people with hepatitis C through testing in drug treatment services and outreach work, and going on to support them through to treatment, is critical to reducing health inequalities and an important part of reducing transmission of the virus.

Opioid substitution therapy

Opioid substitution therapy (OST) is a highly effective alternative to injecting drug use and can help to reduce the transmission of BBVs such as hepatitis C and HIV. Expert witnesses questioned during the All-Party Parliamentary Group on Liver Health's inquiry into eliminating hepatitis C in England (supported by The Hepatitis C Trust as the group's secretariat) reported that funding pressures in drug treatment services were preventing staff from encouraging and supporting patients onto OST. Anecdotal evidence indicates that pressure on workers to get people through treatment quickly, with an emphasis on abstinence-based recovery, is still the case, undermining national clinical guidance that describes how evidence-based treatment interventions and optimal prescribing are required to reduce drug-related harms and provide a bedrock for effective recovery (see References 12 and 13).

As a more effective way of transitioning away from injecting drug use for many people and a means of reducing infectious disease transmission, OST should be made available to all who need it. Estimates are currently under development by Public Health England to offer a robust picture of the proportion of people who inject drugs who are on OST in England.

Drug Consumption Rooms

There is over 30 years of evidence to prove that Drug Consumption Rooms (DCRs) – that is, legally sanctioned facilities where people can use illicit drugs, obtained themselves, under the medical

supervision of trained staff – contribute towards the elimination of overdose-related deaths; a reduction in public injecting; improvements in hygiene restricting the transmission of BBVs; and engaging highly marginalised populations with services. Like services offering NSPs, DCRs also offer a critical entry point for interventions focused on recovery from drug use to be delivered, as well as being crucial for raising awareness of BBVs transmitted through the sharing of drug-taking equipment, such as hepatitis C.

Often the first concern about implementing a DCR is that it may lead to an increase in drug use and drug-related crime in the area. However, there is no evidence that the availability of DCRs is associated with an increase in drug use: evidence from a supervised injecting facility in Sydney showed no increase in drug-related crime and the study actually noted a decrease in public injecting and the number of syringes found in the area.

The Home Office has long argued that under current legislation DCRs are illegal and their introduction would require a change to the Misuse of Dugs Act 1971. Yet there have been various exemptions in recent years which demonstrate that ways around the Act are possible. The Loop has been working at festivals around the UK since 2016, testing people's drugs and sharing the contents and potency information with them, as well as giving individualised, confidential advice to reduce drug-related harm. More recently, the Home Office granted a licence for the first time allowing a pilot drug-checking service in North Somerset to be run. This will provide a similar service to the festival testing, with clients able to discover the results of the testing in 10 minutes, during which time they have a conversation with a substance misuse practitioner as part of the harm reduction package. Given this scheme has gained exemption to the Act from the Home Office, it should be possible for a similar arrangement to be made regarding DCRs.

The introduction of DCRs was supported by a 2017 report commissioned by Westminster's Drugs, Alcohol and Justice Cross-Party Parliamentary Group, which cited evidence that such rooms offer numerous benefits to the community and to drug users. The UK Government has long opposed DCRs; however, with the number of deaths registered from drug use in 2018 at the highest level since ONS records began in 1993, a strategically placed pilot DCR must be urgently considered.

Heroin Assisted Treatment

Randomised controlled trails have shown Heroin Assisted Treatment (HAT) is effective at engaging people in treatment, reducing polydrug use, reducing reoffending, and reducing injecting-related harms (see Reference 14). In Middlesbrough, a city with opiate/crack cocaine use four times greater than the national average, a pilot HAT facility was established last year, offering people addicted to heroin doses of medical-grade heroin twice a day. As well as giving people a safe environment in which to take drugs and thereby reduce the risk of overdosing, the facility also acts as a signposting service, helping people to access support for other areas of their lives such as employment and housing. As results come out from the Middlesbrough pilot, the Government should consider opening HAT facilities in other areas with high drug use.

Reducing harm in vulnerable groups

Hepatitis C disproportionately affects disadvantaged and under-served communities; almost half of the people with hepatitis C who are admitted to hospital come from the poorest fifth of society. Other communities with a high prevalence of the virus include people experiencing homelessness, people in prison, men who have sex with men, and Eastern European and South Asian populations.

In order to ensure the needs of these populations are met, it is essential they are involved in the design and evaluation of drug treatment services. In addition, the benefits of peer workers are even more pronounced in groups who may feel alienated or disassociated from other professionals trying to engage them; the bond of shared experience of hepatitis C or drug use often overcomes other differences and creates a platform in which to have open discussions about harm reduction behaviours.

Reference 3: Drug-related deaths in England: Local authorities and how they are responding, NAT, 2019.

Reference 4: Needle syringe programmes and opioid substitution therapy for preventing hepatitis C transmission in people who inject drugs, Lucy Platt, Silvia Minozzi, Jennifer Reed, Peter Vickerman, Holly Hagan, Clare French, Ashly Jordan, Louisa Degenhardt, Vivian Hope, Sharon Hutchinson, Lisa Maher, Norah Palmateer, Avril Taylor, Julie Bruneau, Matthew Hickman, Cochrane Systematic Review, 2017.

Reference 5: Shooting Up: Infections among people who inject drugs in the UK, 2018, Public Health England, 2019

Reference 6: The impact of COVID-19 restrictions on needle and syringe programme provision and coverage in England, Mark Whitfield, Howard Reed, Jane Webster, Vivian Hope, International journal of Drug Policy, 2020

Reference 7: Needle and syringe programmes, Public health guideline [PH52] NICE, 2014; "We get by with a little help from our friends": Small-scale informal and large-scale formal peer distribution networks of sterile injecting equipment in Australia, Newland J, Newman C, Treloar C, International Journal of Drug Policy, 2016

Reference 8: Peer helpers' struggles to care for "others" who inject drugs, Dechman MK, International Journal of Drug Policy, 2015; Secondary syringe exchange among injection drug users, Snead J, Downing M, Lorvick J, et al, Journal of Urban Health, 2003

Reference 9: Secondary distribution of injecting equipment obtained from needle and syringe programmes by people injecting image and performance enhancing drugs: England and Wales, 2012-15, Rachel Glass, Vivian D.Hope, Jacquelyn Njoroge, Claire Edmundson, Josie Smith, James McVeigh, John Parry, Monica Desai, Drug and Alcohol Dependence, 2019

Reference 10: Patterns of Peer Distribution of Injecting Equipment at an Authorized Distribution Site in Sydney, Australia, Loren Brener, Joanne Bryant, Elena Cama, Lucy Pepolin & Mary Ellen Harrod, Substance Use & Misuse, 2008

Reference 11: Hepatitis C in England 2020: Working to eliminate hepatitis C as a major public health threat, Public Health England, 2020

Reference 12: Methadone and buprenorphine for the management of opioid dependence: Technology appraisal guidance, NICE, 2007

Reference 13: Drug misuse and dependence: UK guidelines on clinical management, Clinical Guidelines on Drug Misuse and Dependence Update 2017 Independent Expert Working Group, 2017

Reference 14: Supervised injectable heroin or injectable methadone versus optimised oral methadone as treatment for chronic heroin addicts in England after persistent failure in orthodox treatment (RIOTT): a randomised trial, Prof John Strang, MD, Nicola Metrebian, PhD, Nicholas

Lintzeris, PhD, Laura Potts, MSc, Tom Carnwath, MRCPsych, Soraya Mayet, MRCPsych et al, The Lancet, 2010

a. What helps to implement them?

Simple pathways with safety nets to prevent people falling between the gaps are critical to engaging people in services, many of whom have multiple and competing demands on their time. Peers can help people navigate barriers to getting what they need by acting as a link between services and advocating on their behalf. For more on the benefits of using peers, please see our response to question 20.

b. What makes implementation difficult?

As set out in our answer to question 1b, funding and political will have been consistent barriers to improving services for people who inject drugs. For more on the importance of adequate funding, please see our answer to question 3.

3. What do you think the government could do to support the implementation of harm reduction interventions?

When making recommendations to Government, it should be borne in mind that many problems have local solutions and a centralised approach can only achieve so much. Having said that, some responsibilities resting with central Government must be acknowledged and acted upon, such as funding and reform. Our answer to this question applies to the implementation of both drug prevention initiatives and harm reduction initiatives. For further details on specific interventions for each of these please see our answers to questions 1 and 2 respectively.

Funding

Services cannot be expected to run much more than a skeleton system of support on current funding. Any policies recommended as part of the independent review must take into account the spending cuts drug treatment services have faced over the past decade: on average this amounts to a 27% reduction; in some areas budgets have been decimated by as much as half.

It is telling that, although harm reduction and drug treatment sits under public health, NHS England has asked all hospitals to scope the possibility of a mobile van with needle and syringe provision, peers, and BBV testing, in recognition of the importance of this as a means of protecting people from harm and engaging them in health services. It should not be down to NHS England to provide such services: local authorities must be supported to provide the services their populations need, particularly as the devolution programme continues to expand and local areas gain autonomy.

Reform

The Misuse of Drugs Act 1971 has not been reviewed since it was implemented. We welcome this review as part of that process and urge the Government to go a step further and consult changes to

the Act itself, including legalising drug consumption rooms and introducing a health-based approach to drugs. This is essential if the Government is to make true its promise in the 2019 manifesto to introduce "a new approach to treatment so we can reduce drug deaths".

National monitoring & data

There is currently a lack of data around harm reduction measures, such as on provision of needle and syringe programmes. Such data should be collated and published by Public Health England or the Department of Health and Social Care.

11. What are the best models for commissioning and providing drug treatment and recovery services?

We hope the argument set out in our answers to questions 1 and 2 are persuasive of the importance of addressing health harms in supporting people towards recovery. In order for the treatment of hepatitis C and other BBVs to be adequately prioritised in drug treatment services, effective commissioning is absolutely crucial. This can in turn contribute to a reduction in mortality from liver disease among people who inject drugs, reduce future costs, and address health inequalities. Commissioning contracts for drug treatment and recovery services should include robust measures around hepatitis C and wider BBVs, including on staff training, client education, testing and treatment. Including peers with personal experience of drug use as well as current patients in the commissioning and designing of services is also critical to the success of the service in being able to engage and support people.

a. What are the best ways to secure effective accountability for those services across different organisations at a national and local level?

Services must have robust Key Performance Indicators (KPIs) and be financially supported to deliver on these. KPIs should include measurable involvement of patients in the design and evaluation of services; BBV awareness or education programme uptake; the number of people offered (and proportion who take up) a BBV test on arrival and thereafter every six months they are in the service; the number of people who test positive for a chronic infection requiring treatment; the proportion of those people who are referred to treatment or access it on site; waiting times between diagnosis, referral and treatment; the number of people who begin treatment; the rate of "did not attend" (DNAs) during the treatment process; the number of people who achieve 'cure' (SVR-12). For a comprehensive template service specification for drug treatment services relating to hepatitis C please see HCV Action's Hepatitis C Commissioning Toolkit (see Reference 13).

Reference 14: Hepatitis C Commissioning Toolkit, HCV Action, 2018.

b. What levers or mechanisms could be introduced to ensure that services are effective and respond to the needs of local populations?

Harm reduction initiatives such as needle and syringe programmes, Naloxone and opioid substitution therapy provision should be monitored and fed into a published national database such as PHE's Public Health Database online. Local authorities should be able to monitor prevalence of different types of drug use, and of BBVs, in their population down to specific geographies and

provide services accordingly. They can be assisted in this by Public Health England's Hepatitis C: Operational Delivery Network (ODN) profile tool which provides ODN-level data – though this is only broken down into 22 areas and local authorities will need to collect their own data for more localised breakdowns.

Again, it is critical that the service is designed with the patient at its heart to ensure it is truly responding to people's needs. Peers and patients must be involved in all aspects of the service for it to be effective.

20. How can peer support/mentoring, mutual aid and recovery communities be better supported and improved?

Peer support, with its emphasis on a relationship built on shared experience and identification, plays a crucial role in overcoming the barriers people face to accessing services. Peers use their personal stories to boost engagement at every stage, playing a key role in education around harm reduction and supporting people to achieve health and recovery outcomes, such as by awareness-raising, tackling stigma, and influencing the care pathway by working with Operational Delivery Networks (the systems responsible for giving out treatment for hepatitis C).

The Hepatitis C Trust's peer support model has won plaudits from clinical leads in ODNs, NHS England colleagues, and, most importantly, from the people we are supporting. This has led to our rapid expansion since 2018, and a doubling of our Peer Leads planned in the next year or so.

---- *Adam, supported by our peer programme: "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."*

---- *Dr Ben Stone, South Yorkshire ODN Clinical Lead: "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 year before. 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."*

Crucially, 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 (both for service users and staff), testing and outreach, and one-to-one support through treatment. Our Peer Leads roughly correspond to the 22 ODN areas and recruit volunteer peers who they train to deliver workshops. This gives people who may be at any stage in their recovery journey a safe environment in which to gain confidence and develop new skills.

Services should be patient-led and informed by people with lived experience of addiction in all aspects. A Key Performance Indicator for peer/patient involvement should be considered in all drug service specifications.

The Hepatitis C Trust's continued growth, driven by recognition of the value of peer support in NHS England and in NHS Trusts, shows that peer support is most successful when it is treated as an integral part of programmes. This means funding it properly, and running projects which wholly embrace the value of lived experience, rather than treating it as an add-on or 'nice to have'.

The Hepatitis C Trust's structure is one in which most of our leadership team, staff and volunteers have lived experience of hepatitis C, drug use and the criminal justice system. Whilst the incorporation of lived experience and peer support in such a wholesale way may not be possible for every service which supports people who use drugs we believe that the value and importance of lived experience and peer support means it should be made as integral as possible to services.

22. What needs to be done to help those in custody address their drug misuse and continue their recovery?

The Hepatitis C Trust has been delivering interventions in prisons since 2017 and we have seen first-hand the huge impact getting treated for hepatitis C can have on people's lives. While working in prisons comes with its own challenges (particularly those of getting access and addressing stigma), the controlled prison environment can provide a unique opportunity to engage people in treatment services for long enough to clear hepatitis C, often the first step in taking control of other areas in their lives. The lack of trust in services which acts as a barrier to engagement is often even more pronounced in prisons, given the higher likelihood of previous negative experiences of other public services.

Peer workers are critical to engaging people in services by building relationships based on shared experience and identification, something prison staff by and large cannot offer. Many studies have found 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.

Additionally, we have found that peer interventions focusing on supporting someone through treatment for their hepatitis C can lead to a critical first step for people in prison taking control of other areas of their lives which may previously have been chaotic, including areas such as substance use, homelessness, and mental health problems. Addressing these factors can aid recovery and cut reoffending, in addition to the direct health benefits.

The Hepatitis C Trust therefore recommends further peer programmes in prisons, with clear routes of access to allow admission to peers who, by nature of their shared experience with prison residents, themselves can often be barred from entry through the DBS process. As in the community, people in prison should be included in all stages of the service design and evaluation process.

a. How can we improve the pathways between prison and community-based drug treatment, including 'through the gate' services when people are released?

Clear care pathways and data sharing play important roles in preventing people falling between the gaps on release from prison. The Hepatitis C Trust has heard cases of healthcare professionals not being made aware of residents' release dates, which hampers forward planning of care. The current system for transferring a prisoner's care does not ensure that records go with the patient and so relies on each Operational Delivery Network (ODN) linking up. Lack of integration can be compounded by residents being released late on a Friday afternoon, not allowing services time to join up and get in contact. It is essential that a national structure is put in place that enables people to be treated wherever they are, and makes sure that on release prisoners are registered with a GP who can receive their medical records.

Communication must be improved between prisons, with clear accountability for treatment and associated costs, to prevent people falling between the cracks. This also holds true for the links between prisons and community healthcare, with better continuity and cooperation needed between the two (as well as homelessness services and drug and alcohol services) to enable treatment to continue outside of the prison estate.

24. What lessons can be learned from the way that drug prevention, treatment and recovery services have responded to coronavirus (COVID-19)?

There has been some very positive innovative working in drug treatment services throughout this pandemic, particularly impressive in the face of years of funding cuts. Many of these changes should be maintained as lockdown restrictions continue to ease.

Longer scripts

Lockdown has led to many drug treatment services and pharmacies giving out longer scripts of OST, alongside faster prescribing, leading to an important shift away from punitive dispensing practices. The majority of people appear to have done much better on less restrictive regimes: longer scripts allow people to have greater control over their medication and for many this has led to reconsidering their levels of use and self-reducing. It has also reduced the number of missed pick-ups; offered more flexibility to people who work; improved relationships with providers; and reduced the necessity to frequently be in potentially triggering environments through exposure to dealers. Without having to observe and supervise people taking their medication, pharmacists and drug service workers had more time to dedicate to other aspects of the service, such as NSP and BBV testing.

On the other hand, a "one size fits all" approach cannot work and it is crucial to recognise that everyone's needs are different. A significant minority of people have struggled with the shift away from daily routine, while some providers have reported anxiety about the additional risks involved in giving out more medication.

A patient-centred approach promoting choice should be adopted in the future. The Government should also consider ringfencing the money previously paid to staff to supervise people taking their scripts and redirect it to other parts of the service, such as improving and expanding NSP coverage.

Delivering medication

During lockdown, many areas delivered hepatitis C medication to the patient – either by courier, peer or nurse – rather than requiring them to attend a clinic in hospital or travel to the drug treatment service. This afforded greater convenience to the patient as well as increasing the number of people completing treatment, and should be continued in the future.

Postal testing

Postal BBV testing has been piloted by Change Grow Live as part of its "Hepatitis C Strategy". This aims to overcome the barriers of lockdown by still encouraging people to get tested for BBVs. Data from this pilot should be kept under constant review to determine whether such pilots should be rolled out nationally.

Outreach testing and treating homeless populations in hotels

Some of the most impressive work has been the nation-wide drive to test people temporarily housed in hostels and hotels by local authorities. From May, with the aid of personal protective equipment and social distancing, peers and workers from drug treatment services and homelessness charities have been working to test people accommodated in hotels and hostels who would otherwise be rough sleeping.

The Hepatitis C Trust has been involved in many of these initiatives. In the areas where this testing has been carried out, almost 1,500 people have been tested and those positive for hepatitis C have been started on treatment. Rates of hepatitis C antibodies (markers of current or previous infection) among homeless communities were very high in many areas: 31% of people tested in Nottingham, for example, had had the virus and in the highest-prevalence service the rate was 41%. In hostels in the West Midlands, 51% of people tested had antibodies, of which 58% had a chronic infection (and were successfully supported into hepatitis C treatment).

A Needs Assessment in two of the London homeless hotels found that 30% of clients were previously entirely unknown to services. Health services often have significant difficulty in reaching and engaging this cohort, yet the initiatives resulted in many engaging in treatment. For example, in the West Midlands area, 41 of the 42 individuals found to have a chronic infection commenced treatment. This is a huge success and demonstrates the impact that can be had through highly proactive, targeted outreach for very vulnerable and marginalised groups.

The success of these events has been a result of excellent multi-agency partnership working: The Hepatitis C Trust's peer support workers used their lived experience of hepatitis C to provide support and combat the stigma and myths which persist around this virus while nurses and doctors have provided testing with rapid turnaround on results. This all happened alongside other support services' work to address other issues like mental health and drug and alcohol needs.

We can draw multiple lessons from these successes: not only can we test and treat those who are thought of as the hardest to engage, potentially arresting the spread of hepatitis C among the most vulnerable in our society, but we can also give holistic support via different agencies when services work together. People were able to get tested and treated for hepatitis C at the same time as their drug and alcohol or mental health needs were being addressed – we do not have to choose which issues we help people address.

Ensuring stable, safe accommodation is vital to preventing these gains from being lost. It is also important that local authorities and commissioners build on this work by ensuring they commission effective hepatitis C prevention and testing services, including the involvement of partnership working.

a. Looking to the future, how do they need to respond to the impact of the pandemic?

Drug treatment services should take forward the positive changes outlined above even when restrictions have lifted. While some changes will not have been right for everyone, ensuring patient choice is crucial to keeping people engaged in services and supporting them in whatever way they require.