About The Hepatitis C Trust

The Hepatitis C Trust is the national charity for people affected by hepatitis C. It is a patient-led and patient-run organisation; most of our board, staff and volunteers have had hepatitis C themselves. The Trust's goal is to eliminate hepatitis C in the UK by 2030 at the latest through supporting and advocating for those who are living with, affected by, or at risk of hepatitis C.

As well as providing a helpline and extensive information service on our website (www.hepctrust.org.uk), the Trust also has a rapidly expanding peer support programme of over 100 paid and voluntary staff. Our peer support programme is a key part of the patient case-finding initiatives funded through the hepatitis C elimination deal agreed by NHS England and pharmaceutical industry partners in 2019. Our peers are active in both the community and in prisons across England, Scotland and Wales and have supported over 25,000 people since the programme began in 2010.

The UK drug framework

1) ***How effective is the UK drug framework in today's society? This may consider:***
   a) *its effectiveness in dealing with drug use and addiction;*
   b) *its effectiveness in preventing drug related deaths;*
   c) *its effectiveness in deterring drug related offending;*
   d) *drugs classification under the Misuse of Drugs Act 1971; and*
   e) *what (if any) impact the Psychoactive Substances Act 2016 has had since it came into force.*

2) ***Does the current framework, or a particular aspect of the framework, need to be reformed?***
   a) *If so, how?*
   b) *Could reform align with the UK's international obligations under the Single Convention on Narcotic Drugs of 1961, as amended by the 1972 Protocol; the Convention on Psychotropic Substances of 1971; and the United Nations Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances of 1988?*

The UK has the highest rates of drug use of any country in Western Europe, and drugs deaths are at an all-time high. It is crucial that the Government learn from international, proven examples which demonstrate that policies and legislation criminalising drug use, drug possession and people who use drugs (PWUD) themselves are detrimental to health outcomes for PWUD and are ineffective for society. For an effective drug framework, we believe that the Government must adopt a national approach which treats drug use as a health issue and not a criminal justice issue.

People who inject drugs (PWID) in particular experience significantly worse health outcomes, quality of life and rates of mortality than the general population. The Health Security Agency's 2021 report on injecting drug use shows that of around 300,000 people using crack or opioids in the UK last year, 87,000 inject these drugs.[1] Hepatitis C was the most common infection among them, and this population also face high rates of HIV, hepatitis B, and many other physical and mental health needs as well as homelessness and exclusion from many health and care services.

[1] UK Health Security Agency, Public Health Scotland, Public Health Wales and Public Health Agency Northern Ireland. Shooting Up: infections and other injecting-related harm among people who inject drugs in the UK, 2020. London: UK Health Security Agency, December 2021.

The UK Government is committed to eliminating hepatitis C, as part of the World Health Organization's global elimination programme. Drug use policies focused on criminalisation pose a barrier to hepatitis C elimination by limiting access to harm reduction services and to treatment. Custodial sentences for drug use and possession coupled with the high numbers of PWID who are imprisoned or detained without access to prevention or harm reduction have a damaging impact on hepatitis C care and treatment. These policies further impact people through criminalising their drug use and reinforcing the stigma they suffer, while the prohibition of distributing drug use equipment such as crack pipes poses an obstacle to delivery and uptake of harm reduction services. PWID are also driven away from services due to fear of poor treatment, stigma and/or criminal sanctions, hindering uptake of treatment and prevention initiatives.

While drug use continues to be addressed as a criminal justice issue rather than one of public health, delivery of meaningful preventative interventions to address hepatitis C is greatly impeded. However, promoting health-based interventions – such as blood-borne virus (BBV) testing and treatment, mental support and social support – delivered by people with whom those engaged in drug use can identify – can lead to much greater engagement with services and recovery outcomes.

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 Overdose Prevention Centres (OPCs) 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 PWID.

We believe that in addition to adopting a national approach to substance use based around public health rather than crime, preventing the initiation of drug use should be embedded within a holistic approach to health and wellbeing. However, any such approach must acknowledge and address that not all drug users choose (or need) recovery, and that people can stay healthy and safe during the times they are using drugs is as important as any other intervention.

UK drug policy

5) What is your view on the UK Government's 10-Year Drug Strategy for England and Wales, which was published in December 2021?

We welcome the Government's commitment to invest £3 billion into their drug strategy.

However, we feel that the strategy has an excessive focus on criminalisation and does not prioritise proven harm reduction approaches and initiatives that would create long term solutions for drug users. Although purporting to accept and adopt all recommendations from Dame Carol Black's review of drugs, there is little evidence that the 10-Year Drug Strategy has implemented one of the three key objectives, to divert "away from the criminal justice system, particularly prison."[2]

[2] Review of drugs part two: prevention, treatment, and recovery, Dame Carol Black, 2021

As detailed in our response to question 2, we believe that
drug use must be addressed as an issue of public health, and not solely one of criminal justice. As evidenced in the European Association for the Study of the Liver's policy statement on 'Drug use and global hepatitis C elimination', criminalisation of drug use has far reaching negative effects on sharing of injecting equipment and needle and syringe distribution – both of which are integral to reducing drug harm and eliminating hepatitis C.[3]

As detailed in the strategy, it is evident that Scotland, Northern Ireland and particularly Wales are taking steps to move away from criminal justice-based approaches. We believe that the UK government must learn from the devolved administrations and similarly commit to prioritising harm reduction and safe use of drugs. While the Government's commitment to naxolone provision and needle and syringe programmes in the strategy is very welcome, it is not enough, and must be accompanied by adoption of evidence-based public health measures including improved testing for BBVs, opioid substitution therapy, heroin assisted treatment and overdose prevention centres, as detailed in the following answers.

Although the funding of £3 billion is welcome, we believe that these issues need long term commitment and investment and that three years will not be enough to implement and sustainably establish the changes needed.

6) Are there particular policies at national or local level across the four UK nations that have been effective in reducing:

a) drug use,
b) drug related deaths, and/or
c) drug related offending?

The Hepatitis C Trust's experience – as an organisation that works predominantly with PWID – has been that being cured of hepatitis C is a crucial step for 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 a myriad of other health problems.

Important approaches in reducing drug-related harm include peer support, needle and syringe programmes, blood-borne virus testing, opioid substitution therapy, and heroin assisted treatment.

Peer support

Peer support is absolutely vital to re-engaging people in services, and often contributes significantly towards patients' more general recovery. The Hepatitis C Trust's model of peer support sees both our paid staff and volunteer peers – many 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 or experience of 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

[3] EASL Policy Statement: Drug use and the global hepatitis C elimination goal, European Association for the Study of the Liver, 2020

frequently signpost people to other services and offer
safer drug use interventions including needles and syringes, during outreach to homeless and more vulnerable communities.

Needle and syringe programmes

NSPs are an incredibly effective, low-cost intervention that contribute to reducing drug-related harms and deaths: high NSP coverage, especially alongside the delivery of optimal OST,[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 - the strategy guiding the global programme to eliminate viral hepatitis, to which the UK is a signatory – 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.

However, 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 sterile equipment for every injection attempt, reducing the need to share. UKHSA data from 2022 shows that around a third of people who inject drugs self-reported that they had inadequate needle and syringe provision for their needs, with evidence suggesting an increase in risk behaviour and sharing of injecting equipment during the pandemic.[5] Recent studies have shown that this proportion has grown as COVID-19 has further restricted access to NSP,[6] and that the lockdown has seen significant reductions to harm reduction, treatment, recovery services, and access to peer support.[7]

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[8].

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 was further compounded during lockdowns due to 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, to reduce drug-related harms and deaths.

[4] Needle syringe programmes and opioid substitution therapy for preventing hepatitis C transmission in people who inject drugs, Cochrane Systematic Review, 2017
[5] Hepatitis C in England 2022: Working to eliminate hepatitis C as a public health problem, UKHSA, 2022
[6] The impact of COVID-19 restrictions on needle and syringe programme provision and coverage in England, International journal of Drug Policy, 2020
[7]The impact of COVID-19 on access to harm reduction, substance use treatment and recovery services in Scotland: a qualitative study, BMC Public Health, 2022
[8] Hepatitis C in England 2020: Working to eliminate hepatitis C as a major public health threat, Public Health England, 2020

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 in the UK, is a preventable and curable BBV. It affects 81,000 people in England, 90% of whom are estimated to have acquired the infection through the sharing of drug-taking equipment, on which the virus can survive for up to three weeks[9]. 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.

The UK was not able to meet its target under the WHO hepatitis C elimination strategy to reduce hepatitis C infections by 30% by 2022. Much more must be done if we are to meet the target of an 80% reduction in new infections by 2030, a central part of elimination aims. 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 drug-related harms and deaths.

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

[9]Hepatitis C in the UK 2020: Working to eliminate hepatitis C as a major public health threat, Public Health England, 2020

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[10] [11].

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.

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[12]. 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.

The impact of drug use in the UK

7) What is the impact of drug use? In particular, on:

a) drug users and their loved ones;
b) local communities and wider society;
c) the economy.

Drug use in the UK is the highest of any country in Western Europe, and PWID experience substantially worse health outcomes than the general population. Drug-related deaths are at an all-time high with a 3.8% increase in deaths related to drug poisoning registered in England and Wales and a 5% increase in Scotland in 2020. Both fatal and non-fatal overdose have also increased in the UK. PWID are particularly susceptible to high levels of morbidity and mortality. Health harms from drug use, including BBVs, infections and overdoses, are amplified for PWID due to the existence of structural barriers in accessing prevention, care and treatment services.

Following a hepatitis C diagnosis, people can be left scared and isolated as a result of a basic lack of information or misinformation about HCV, how it can be treated, the impact on their personal lives and how it may affect the lives and relationships of those around them. The impact of an HCV infection can be catastrophic, leading to physical and mental ill health and far-reaching negative effects on many aspects of patient lives. As a blood-borne virus that predominantly infects the cells

[10] Methadone and buprenorphine for the management of opioid dependence: Technology appraisal guidance, NICE, 2007
[11] Drug misuse and dependence: UK guidelines on clinical management, Clinical Guidelines on Drug Misuse and Dependence Update 2017 Independent Expert Working Group, 2017
[12] 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, The Lancet, 2010

of the liver, HCV can result in inflammation and significant damage. It can also affect the liver's ability to perform its essential functions. Globally 25% of hepatocellular carcinoma (HCC or liver cancer) is thought to be attributable to the hepatitis C virus (HCV).

Studies suggest that chronic infection with hepatitis C will almost invariably result in cirrhosis. The time that this takes varies. From those who develop a chronic or long-term infection (between 70-80% of those infected with hepatitis C) around 20-30% will develop cirrhosis within 20 years. For some it may be quicker while for others it may take up to sixty years, meaning they will probably die of unrelated causes first.

Cirrhosis is categorised in two stages depending on the extent to which the liver has become damaged. Compensated cirrhosis is when the liver is still able to cope with the damage and continues to carry out most (or even all) of its functions. Decompensated cirrhosis is when the liver is unable to cope and is no longer functioning.

Although it has always been regarded as a liver disease - 'hepatitis' means 'inflammation of the liver' - recent research has shown that the hepatitis C virus (HCV) affects a number of other areas of the body. These can include the digestive system, the lymphatic system, the immune system and the brain. In addition to the effects on the liver it is now clear that HCV also causes a variety of other symptoms, including:

- Chronic fatigue,
- Aches and pains**,**
- Pains in the upper part of the abdomen**,**
- Dry eyes, irritable bowel and irritable bladder**.**

Due to its contagious nature, its association with injecting drug use, and the widespread misinformation from lack of awareness; hepatitis C is a widely stigmatised disease that can affect all areas of patients' lives. Injecting drug users who contract hepatitis C often report experiencing high levels of stigma, which can have the effect of contributing to exclusion from society. This stigma can also lead to loss of income, financial instability, housing insecurity, isolation and depression.

Moreover, the lack of awareness of hepatitis C among patients and members of the public can lead to patients feeling ashamed and unable to confide in others. This is further compounded by the lack of awareness among some health professionals, which can have the undue consequence of incorrect or poor-quality advice, late diagnosis, and less access to testing, treatment and primary care.

International comparisons

8) Are there laws, policies or approaches adopted in other countries that have been effective in reducing:

a) drug use,
b) drug related deaths, and/or
c) drug related offending?

9) If so, could they reasonably be expected to work in the UK?

Decriminalisation

Decriminalisation of drug use is developing in many countries, with the example of Portugal – which decriminalised all drugs is 2001 – particularly well known. The years following the reform saw reduced levels of harmful drug use, particularly injecting, and concomitant falls in hepatitis C, HIV and hepatitis B infections. Overdose deaths also declined. Although the reasons for this may be complex, evidence from this and other countries including decriminalisation of cannabis use in the United States consistently indicates that drug use does not increase with decriminalisation, whilst drug harms tend to fall, and criminal justice systems can incur significant financial savings.[13, 14]

Harm reduction

Overdose Prevention Centres (also known as Drug Consumption Rooms) are legally sanctioned facilities where people can use illicit drugs, obtained themselves, under the medical supervision of trained staff. These have been introduced in a number of different countries around the world. A study from 2018 notes 90 such facilities operating in locations across Germany, the Netherlands, Spain, Norway, Luxembourg, Denmark, Greece, France and Switzerland[15].

The Hepatitis C Trust recently joined with many medical Royal Colleges as well as prominent academic, health and third sector organisations in calling for OPCs to be piloted in the UK. There is over 30 years of evidence to prove that OPCs reduce 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, OPCs 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 an OPC 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 OPCs 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 OPCs 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 OPCs.

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[13] Scheim AI, Maghsoudi N, Marshall Z, et al. Impact evaluations of drug decriminalisation and legal regulation on drug use, health and social harms: a systematic review. BMJ Open 2020;10:e035148. doi:10.1136/ bmjopen-2019-035148

[14] Hughes, CE and Stevens, A. What Can We Learn From The Portuguese Decriminalization of Illicit Drugs. *The British Journal of Criminology.* 2010, Vol. 50, 6, pp. 999-1022

[15] Drug consumption rooms: an overview of provision and evidence, EMCDDA, 2018

The introduction of OPCs 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. OPCs have also garnered cross party support in the Scottish Parliament, and have seen a targeted recommendation from the London Assembly Health Committee, calling for a pilot of OPCs in London. The UK Government has long opposed OPCs; 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 OPC must be urgently considered.