HSP 04
Ymchwiliad i ddarparu gofal iechyd a gofal cymdeithasol ar yr ystâd carchardai i oedolion
Inquiry into the provision of health and social care in the adult prison estate
Ymateb gan Hepatitis C Trust
Response from Hepatitis C Trust

THE HEPATITIS C TRUST

# The Health, Social Care and Sport Committee's Inquiry into the Provision of Health and Social Care in the Adult Prison Estate

## Introduction

The Hepatitis C Trust believes that prisons have an important role to play in ensuring Wales reaches its commitment to the World Health Organisation (WHO) target to eliminate hepatitis C as a significant public health threat by 2030. Wales has signed up to the WHO's strategy, committing to reduce new cases of hepatitis C by 90% and hepatitis-related deaths by 65% in the next decade.

However, recent modelling indicates that according to Wales' present trajectory, this goal will be missed by a decade.[1] Targets for treating patients are currently being missed by more than a third, but even if they were met Wales would still fall short of elimination by 2030 by at least a year. The biggest challenge to eliminating hepatitis C is identifying and treating people who are as yet undiagnosed, at least half of people with the virus.[2] Those who have been infected can live for decades without symptoms until encountering serious and life-threatening complications later on.

As an at-risk group for hepatitis C identified by NICE, it is crucial that the prison population is targeted for screening, awareness raising, and treatment in order to get Wales back on track.[3] As well as avoiding the significant health harms that result from chronic hepatitis C, such as fatal cirrhosis and liver cancer, interventions aimed at testing and treating the virus in prisons can have wider benefits. These include addressing associated health problems, improving mental health, and contributing to rehabilitation.

**Hepatitis C and the prison population**

Hepatitis C is a virus spread through blood-to-blood contact and primarily affects the liver. Around 12,000 people in Wales are currently infected with hepatitis C.[4] It has been estimated that as many as one in 20 of all people infected with hepatitis C in Wales are prisoners.[5]

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[1] National Assembly for Wales. (17 January 2019). *Health, Social Care and Sport Committee 17.01.2019.* Accessed April 2019. Available at: http://record.assembly.wales/Committee/5191
[2] Gov.UK. (August 2018). *Hepatitis C in the UK: 2018 report.* Accessed May 2019. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/732469/HCV_IN_THE_UK_2018_UK.pdf
[3] NICE. (2012). *Hepatitis B and C testing: people at risk of infection*. Accessed April 2019. Available at: https://www.nice.org.uk/guidance/ph43/resources/hepatitis-b-and-c-testing-people-at-risk-of-infection-pdf-1996356260293
[4] National Assembly for Wales. (17 January 2019). *Health Social Care and Sport Committee: 17/01/2019.* Accessed April 2019. Available at: http://record.assembly.wales/Committee/5191
[5] Abbvie. (January 2019). *Evidence for the Health, Social Care and Sport Committee's Inquiry into Hepatitis C.* Accessed April 2019. Available at: http://www.senedd.assembly.wales/documents/s82622/H04%20-%20Abbvie.pdf

There are a number of transmission routes, but the most common is through the sharing of injecting drug equipment, with around half of people who inject drugs thought to have ever been infected.[6] Hepatitis C disproportionately affects disadvantaged and marginalised communities and roughly half of people who inject drugs are estimated to have the virus. Around a third of people in prison have injected drugs so rates of hepatitis C infection are particularly high among this population.[7] It is estimated that 7-20% of the prison population have the virus,[8] [9] the most recent estimate putting the number at one in 10 prisoners.[10] This rate is slightly higher than in England, and considerably higher when compared to the general Welsh population, of whom around 0.4% have the virus.[11]

**Recent changes**

There have been positive developments in the approach to hepatitis C in prisons in recent years, such as the introduction of opt-out testing in 2016. However, uptake for testing is still very low and the lack of national guidance and direct resource makes this laudable initiative very fragile. It is crucial that staff are given the necessary training and support to provide prisoners with harm reduction advice, offer them testing, and help them to complete treatment. In our response we have set out how we believe this can best be achieved. Our response will focus on the questions most relevant to hepatitis C policy.

## The effectiveness of current arrangements for the planning of health services for prisoners held in Wales and the governance of prison health and care services, including whether there is sufficient oversight.

The biggest challenge to eliminating hepatitis C in Wales will be identifying and treating those who have not yet been diagnosed. Opt-out testing, staff training to raise awareness, and the structures to allow treatment for a mobile population are all vital to achieving this.

**Testing**

Welsh prisons have been routinely testing for blood-borne viruses (BBVs) such as hepatitis C since 2010, though with low up-take. A significant change came towards the end of 2016 when Wales introduced opt-out testing for BBVs. This ensures all prisoners are offered BBV testing within the

[6] Gov.UK. (August 2018). *Hepatitis C in the UK: 2018 report.* Accessed May 2019. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/732469/HCV_IN_THE_UK_2018_UK.pdf

[7] The Hepatitis C Trust. (2016). *The blood-borne virus opt-out testing policy for prisons in England: An analysis of need towards full implementation.* Accessed April 2019. Available at: http://www.hepctrust.org.uk/sites/default/files/The%20blood-borne%20virus%20opt-out%20testing%20policy%20for%20prisons%20in%20England.pdf

[8] Taylor, A., Munro, A., Allen, E. et al. (2012) *Hepatitis C prevalence and incidence among Scottish prisoners and staff views of its management***.** University of the West Coast of Scotland, University of Bristol, NHS Health Scotland.

[9] Public Health England. (9 April 2019). *Hepatitis C in England: 2019 headline data table*. Accessed April 2019. Available at: https://www.gov.uk/government/publications/hepatitis-c-in-the-uk

[10] Public Health Wales. (27 July 2018). *Hepatitis C.* Accessed April 2019. Available at: http://www.wales.nhs.uk/sitesplus/888/page/43746

[11] Public Health Wales. (27 July 2018). *Hepatitis C.* Accessed April 2019. Available at: http://www.wales.nhs.uk/sitesplus/888/page/43746

first few days of imprisonment. Opt-out testing has led to a significant rise in people arriving at prison being tested, from 8% in 2016 to 34% last year.[12]

However, this figure is still a long way off what is needed to eliminate hepatitis C. There are many possible reasons for this. Firstly, while all prisoners may be offered testing, delivery has been inconsistent across the prison estate in Wales.[13] Some people may not be able to get tested at the first instance and after this may have to wait several months for another appointment due to staff shortages and competing health demands. Prison officers need to have access to and attend awareness raising training to ensure they recognise the importance of the BBV screening and assist inmates to attend. Similarly, while lock-downs often cannot be avoided, it is important that staff recognise the need for any BBV clinics cancelled as a result of lockdowns are rescheduled for the earliest possible time. The Hepatitis C Trust also supports the introduction of a staggered target for BBV screening in prisons which is currently being considered.[14]

Secondly, there is a need for the test itself to be destigmatised. The way in which the test is offered has a significant impact on uptake, with people often opting out because of ignorance or fear. Staff training should encourage an emphasis on the ease of the test and of the new treatments, including the short treatment term, high cure rate, and lack of side effects.

Finally, there is a lack of communication within prisons about the roles and responsibilities of the BBV team. This problem was discussed at HCV Action and Public Health Wales's good practice roadshow in Cardiff at the end of 2017, where HMP Parc Bridgend was given as an example of a place where this barrier had been overcome.[15] The BBV team developed a shared care protocol which outlined team roles and responsibilities, and prison substance misuse teams began to be involved in BBV testing. This resulted in 71% of new arrivals at the prison being tested, as well as better prisoner knowledge of hepatitis C, a reduction in stigma, improved attendance at specialist clinics, and increased treatment uptake rates.[16]

HMP Parc Bridgend has also been using a new test which allows for results on the same day. Most tests require samples to be sent off and examined in labs, leading to a wait of several weeks before results come back. In a prison like HMP Swansea, where prison population mobility is high, the prisoner may have been transferred somewhere else before results got back, let alone before treatment starts. Therefore testing technology needs to be fit for purpose and appropriate for the setting: what may work at a training prison where someone will spend an extended amount of time may not at a reception prison where someone may be in and out in five days.

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[12] National Assembly for Wales. (17 January 2019). *Health, Social Care and Sport Committee: 17/01/2019.* Accessed April 2019. Available at: http://record.assembly.wales/Committee/5191

[13] Public Health Wales (2019). *H03 Evidence for the Health, Social Care and Sport Committee's Inquiry into hepatitis C.* Accessed April 2019. Available at: http://www.senedd.assembly.wales/documents/s82621/H03%20-%20Public%20Health%20Wales.pdf

[14] Public Health Wales (2019). *H03 Evidence for the Health, Social Care and Sport Committee's Inquiry into hepatitis C.* Accessed April 2019. Available at: http://www.senedd.assembly.wales/documents/s82621/H03%20-%20Public%20Health%20Wales.pdf

[15] HCV Action. (2017). *HCV Action Cardiff hepatitis C good practice roadshow, 8th December 2017: Summary report.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/sites/default/files/resources/Cardiff%20Roadshow%20Summary%20Report.pdf

[16] HCV Action. (2017). *HCV Action Cardiff hepatitis C good practice roadshow, 8th December 2017: Summary report.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/sites/default/files/resources/Cardiff%20Roadshow%20Summary%20Report.pdf

This inconsistency across prisons shows there needs to be national guidance in place, including a target for BBV screening in prisons.

**Training**

As already mentioned, training for both prison officers and healthcare staff is crucial to ensuring prisoners get to and engage with the BBV screening.

A report from The Hepatitis C Trust in 2016 found that prison healthcare staff were overwhelmingly of the belief that additional training on BBVs for healthcare and wider prison staff was required. This was seen as crucial to ensure the smooth implementation of BBV opt-out testing and the effective provision of in-reach treatment.[17] BBV training should also cover the appropriate response to patients who do decide to opt out of receiving a test. The Hepatitis C Trust is aware of anecdotal evidence that many patients who choose to opt out of receiving a test for hepatitis C do so on the grounds that they have been tested before and are aware that they are hepatitis C positive. Where this occurs, staff should explain that they may have only tested positive for hepatitis C antibodies, requiring a further test to determine whether they self-cleared or are still infected with the virus. Those who are found to be hepatitis C positive should be referred for, and initiated onto, treatment as expediently as possible.

One way to ensure all prison staff have sufficient BBV training is to make this a compulsory component of all staff's personal development plans. This would help to ensure that prison staff are offering BBV testing in an appropriate manner more likely to increase uptake, and are confident in carrying out BBV testing.

**Treatment**

Of course, testing must be matched with services that are able to offer treatment to people when they are identified as having the virus.

Since 2015 different drug treatments have been available for hepatitis C, known as direct-acting antivirals (DAAs). DAAs have considerably shorter treatment durations, markedly fewer side effects, and significantly higher success rates than previous treatments. This provides an unprecedented opportunity to eliminate hepatitis C, particularly if those high-risk groups who are traditionally more difficult to engage in healthcare services, such as prisoners or people who inject drugs, are targeted. This population present the particular challenge of being a mobile group, moving around within the prison estate and out of it, such as into homelessness services or substance misuse services. This can make it difficult to locate a prisoner to give them their test result or to continue treatment.

While in-reach treatment services for hepatitis C operate in some prisons, provision of hepatitis C treatment is far from routine across the prison estate. For example, medical teams at HMP Cardiff work closely with governors to ensure that those who test positive for hepatitis C are placed on 'medical hold'. This should ensure that the prisoner is not moved to another prison during their treatment period, and if they must be moved that their medications go with them, even to England. In other prisons if someone needs to be transferred somewhere else the local hepatology team who were supplying the drugs may have difficulty locating the prisoner and getting their treatment to

[17] The Hepatitis C Trust. (2016). *The blood-borne virus opt-out testing policy for prisons in England: An analysis of need towards full implementation*. Accessed April 2019. Available at: http://www.hepctrust.org.uk/sites/default/files/The%20blood-borne%20virus%20opt-out%20testing%20policy%20for%20prisons%20in%20England.pdf

them. This can be further compounded by healthcare teams not being notified by prisoners' release dates, hampering 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. 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 prison 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.

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.

## The demand for health and social care services in Welsh prisons, and whether healthcare services are meeting the needs of prisoners and tackling the health inequalities of people detained in Welsh prisons.

With one in 10 prisoners estimated to have hepatitis C, there is a clear demand for healthcare services to screen, treat and raise awareness of the virus. Additionally, hepatitis C disproportionately affects disadvantaged and marginalised communities, with almost half of people who attend hospital for hepatitis C coming from the poorest fifth of society.[18] As well as preventing the life-threatening effects of chronic infection, efforts to engage prisoners in testing and treatment for hepatitis C can contribute to further holistic benefits.

The Hepatitis C Trust advocates a syndemic approach to understanding hepatitis C. Such an approach recognises the presence of two or more states that negatively interact with each other, such as hepatitis C, substance misuse, offending, homelessness and mental health problems. These states, as well as the social, environmental and economic contexts in which they occur, negatively affect each other and heighten the vulnerability and inequity faced by the individual.

Crucially, supporting people to address one of these areas of their lives can act as a 'trigger' for addressing the other issues they are facing. The Hepatitis C Trust's peer-to-peer support work in prisons suggests that many people find being cured of hepatitis C is a critical first step to taking control of their lives, including recovering from addictions. This can aid rehabilitation and cut reoffending, in addition to the direct health benefits.

## What the current pressures on health and social care provision are in Welsh prisons, including workforce issues and services, such as mental

[18] The Hepatitis C Trust. (2013). *Hepatitis C in England: The State of the Nation.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/sites/default/files/resources/The%20Uncomfortable%20Truth.pdf

**health, substance misuse, learning disabilities, primary care out of hours, and issues relating to secondary, hospital-based care for inmates.**

The Health, Social Care and Sport Committee's oral evidence session for its inquiry into hepatitis C earlier this year, which The Hepatitis C Trust spoke at, heard that frequently the structures in place for testing and treatment for hepatitis C were reliant on the good will of governors and healthcare staff.

The opt-out screening initiative has led to an impressive rise in the number of prisoners tested, but the inconsistency of its delivery leaves much to be desired. This is in most part due to the lack of any additional direct resource for either prison or healthcare staff as a result of introducing opt-out testing, despite the added costs of both screening services and treatment. Frequently, these programmes are reliant on either staff volunteering out of hours on top on their regular workload, or on the ability of individuals to persuade governors that it is worth doing, both of which are unsustainable in the long term. When these key drivers leave or another pressure comes along, the opt-out testing becomes incredibly vulnerable and can be rapidly lost.

While the aim is to have a BBV nurse in every prison, it reflects more general staffing capacity issues that frequently this role is cut back in order to cover the basic running of the prison. Having a BBV nurse encourages the normalisation of BBV testing in the prison setting and allows prisoners to be tested and treated quickly. This is impossible under the system in a prison such as HMP Wrexham, where there are 1,000 prisoners but only two nurses providing one clinic per month.

High staff turnover, an increasing prison population, and a rising older population in prisons all exacerbate the pressure on staff. Without additional resources supporting opt-out testing, it will be impossible to eliminate hepatitis C in prisons. In the short term, one way to support healthcare staff may be to reconsider the role of substance misuse workers and involve peer support workers in prisons to raise awareness of hepatitis C.

**Peer support workers**

In 2017, Public Health England commissioned The Hepatitis C Trust to run a pilot peer-to-peer programme in prisons. The Trust's Peer Model consists of delivering basic BBV staff training and facilitating peer workshops with inmates to raise awareness of hepatitis C, including discussions of transmission routes and treatment. Following the pilot's success, this model is now being rolled out nationally.

The Hepatitis C Trust has seen first-hand the positive outcomes which come out of peer-to-peer support, both for the well-being and growth of the person doing the supporting and for the person being supported. Additionally, given the pressure the prison workforce is under, peer support workers are in a position to support staff with clinics, group sessions and training.

While groups particularly at risk of getting infected with hepatitis C are more likely to be aware of the virus than the general population, they are often unaware of the post-2015 treatment. This means they are put off seeking testing or treatment because of outdated information about the significant side effects associated with the old drugs. Peer-to-peer support and peer groups are a particularly effective way of addressing such myths and improving knowledge and awareness among at-risk groups. This is because the talks and training are delivered by people who have had personal experience of having hepatitis C and being in prison, and so may be easier to build trust with than

prison staff. Frequently, we have seen prisoners reluctant to engage with healthcare teams or be seen with BBV nurses because of stigma originating in a lack of understanding and awareness. Connecting to these groups using peers through substance misuse or education services is generally much more effective.

The Hepatitis C Trust also trains people who we have interacted with in prisons and who have expressed an interest to become peers themselves. Being a peer is an empowering opportunity for many people, giving them a voice to tell their own story as well as being an important step towards rehabilitation and a means of gaining experience to get back into work.

Peer-driven action is essential to normalise hepatitis C within the prison setting, enabling people to get tested and treated while in prison or supporting them into community services on release.

## How well prisons in Wales are meeting the complex health and social needs of a growing population of older people in prison, and what potential improvements could be made to current services.

It is particularly important for older people in prisons to get tested for hepatitis C. With most people only experiencing hepatitis C-related complications 20 to 30 years after being infected, this age group is in a vulnerable position if the virus is not identified. Undiagnosed cases can lead to fatal cirrhosis and liver cancer which, as well as being awful for the individual, also comes at a significant cost to prison and hospital health services. In addition, older people who have been in prison for a long period of time may not have been tested under the more recent opt-out BBV policy, which only applies to new arrivals. It is crucial that efforts to engage this age group are increased to avoid health difficulties later.

## What the current barriers are to improving the prison healthcare system and the health outcomes of the prison population in Wales.

We have already laid out the inconsistencies in the delivery of opt-out testing due to a lack of resource, the poor links for sharing prisoners' health information both between prisons and with community teams, the lack of training of prison staff, and the support needed for the under-pressure workforce. As well as the suggestions set out above, we think introducing a needle exchange programme in prisons should be considered.

In 2017, 9% of a random sample of prisoners tested positive for drug use in prisons in England and Wales, up from 7% in 2015.[19] Given that drugs are a problem in prisons, and that a lack of sterile needles or syringes will inevitably lead to the sharing of drug equipment, the introduction of a needle and syringe programme (NSP) in prisons could prevent the transmission of hepatitis C and other BBVs. NSPs have been seen as best practice in the community for harm reduction, and in the

[19] House of Commons Library. (2018). *UK Prison Population Statistics*. Accessed April 2019. Available at: https://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN04334

last 30 years have expanded to prisons in more than 60 countries.[20] Evaluations have been consistently positive, though many of these are unfortunately outdated.[21] [22] [23] They indicate that NSPs in prisons do not contribute to increased drug use, but instead to significant decreases in overdoses and referrals to substance misuse services. One evaluation from 10 years ago in Moldova found that no prison with a NSP had recorded a case of hepatitis C due to intravenous drug use since the implementation of the programme,[24] and nor had there been any recorded instances of prisoners using the needles as weapons.[25]

There are many models of NSPs in prisons, from syringe dispensing machines, to hand-to-hand distribution by prison healthcare staff or charities.[26] However, the model providing the greatest access to harm reduction information is distribution from peer support workers.[27] A pilot using this model should be introduced at a prison in Wales to reduce the transmission of BBVs.

## About The Hepatitis C Trust

The Hepatitis C Trust is the national charity for people with hepatitis C. It is a patient-led and patient-run organisation; most of its board, staff and volunteers have had hepatitis C themselves. We are committed to ensuring that all our actions are for the benefit of patients. Our strategy is based around pillars of better prevention, more diagnosis, and treatment for all.

The Trust's work in prisons began in 2015 and has rapidly expanded in recent years. This is due to being commissioned by NHS England to roll out a peer-to-peer programme across the prison estate, involving both delivering training to prison staff and offering peer-to-peer support to inmates on transmission routes and treatment. We also run a designated prison Freephone helpline service for prisoners across the UK, on top of our long-running national helpline. Both are run by staff and trained volunteers who have all had personal experience of living with hepatitis C.

Our policy and parliamentary team works across the UK Parliament and the devolved nations to ensure hepatitis C stays firmly on the political agenda. We publish a range of reports and resources

[20] Van der Meulen, E., and Ka Hon Chu, S. (2018). *Harm reduction behind bars: Prison-based needle and syringe programs.* Accessed April 2019. Available at: https://www.catie.ca/en/pif/spring-2015/harm-reduction-behind-bars-prison-based-needle-and-syringe-programs
[21] Dolan, K., Rutter, S., Wodak, A. (2003). 'Prison-based syringe exchange programmes: A review of international research and development,' in *Addiction*. 2003;98(2):153–8.
[22] Jacob, J., and Stöver, H. (2000). 'The transfer of harm-reduction strategies into prisons: Needle exchange programmes in two German prisons,' in *International Journal of Drug Policy*. 2000;11:325–335.
[23] Nelles, J., Fuhrer, A., Hirsbrunner, H., and Harding, T. (1998). 'Provision of syringes: The cutting edge of harm reduction in prison?' in *British Medical Journal.* 1998;317:270–3.
[24] Hoover, J. and Jürgens, R. (2009). *Harm reduction in prison: The Moldova model*. New York, NY: Open Society Institute.
[25] Jürgens, R. (2007). *Interventions to address HIV in prisons: Needle and syringe programmes and decontamination strategies.* Geneva: World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS.
[26] Van der Meulen, E., and Ka Hon Chu, S. (2018). *Harm reduction behind bars: Prison-based needle and syringe programs.* Accessed April 2019. Available at: https://www.catie.ca/en/pif/spring-2015/harm-reduction-behind-bars-prison-based-needle-and-syringe-programs
[27] Van der Meulen, E., and Ka Hon Chu, S. (2018). *Harm reduction behind bars: Prison-based needle and syringe programs.* Accessed April 2019. Available at: https://www.catie.ca/en/pif/spring-2015/harm-reduction-behind-bars-prison-based-needle-and-syringe-programs

on the hepatitis C care pathway, such as our 2016 analysis[28] and guidance[29] on the opt-out policy in prisons. Additionally, we coordinate HCV Action, a network bringing together health professionals from across the patient pathway, which has also produced various reports on hepatitis C in prisons.[30] [31]

We are committed to eliminating hepatitis C in the UK by 2030 at the latest.

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[28] The Hepatitis C Trust. (2016). *The blood-borne virus opt-out testing policy for prisons in England: An analysis of need towards full implementation.* Accessed April 2019. Available at: http://www.hepctrust.org.uk/sites/default/files/The%20blood-borne%20virus%20opt-out%20testing%20policy%20for%20prisons%20in%20England.pdf

[29] The Hepatitis C Trust. (2016). *Guidance: Hepatitis C prevention, diagnosis and treatment in prisons in England.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/resource/guidance-hepatitis-c-prevention-diagnosis-and-treatment-prisons-england

[30] HCV Action. (2018). *Tackling Hepatitis C in Scottish Prisons.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/resource/hcv-action-roadshow-tackling-hepatitis-c-scottish-prisons-glasgow-presentations

[31] HCV Action. (2011). *Tackling Blood-Borne Viruses in Prisons: A framework for best practice in the UK.* Accessed April 2019. Available at: http://www.hcvaction.org.uk/resource/tackling-blood-borne-viruses-prisons-framework-best-practice-uk

# Rethinking Hepatitis C Services in Prisons in Wales

## A report from a policy roundtable meeting, May 2019

**Background**

The Welsh Government has made a commitment to eliminate hepatitis C (HCV) as a public health concern by 2030 in line with World Health Organization targets.

It is conservatively estimated that one in ten prisoners are HCV positive. In April 2018, the prison population in Wales was 4291.[1] If the estimated prevalence is correct, the HCV positive prison population could account for as many as one in 20 of all HCV cases in Wales.

The introduction of new oral treatments for hepatitis C – which offer shorter treatment duration with few side effects and a high cure rate[2] – have transformed how hepatitis C services can be delivered.

In May 2019, AbbVie, a global pharmaceutical company, in partnership with The Hepatitis C Trust, held a policy roundtable meeting at the National Assembly for Wales, to consider whether there is an opportunity to rethink hepatitis C services in prisons in Wales. A list of delegates is provided in Appendix 1.

**Key issues:**

- Developing a national approach to eliminating HCV in prisons would support the Government's ambition to eliminate HCV as a public health concern in Wales.
- Political leadership to develop and drive an action plan for HCV in prisons is required.
- Opt-out testing on reception at prison is considered the optimal time to engage prisoners in treatment.
- Streamlined models of care are required in the prison environment. Point of Care Testing models piloted in Cardiff and Swansea can provide useful insights on reforming pathways across the prison estate.
- Where prisoners have tested positive for HCV and are released into the community during or before commencing treatment, it is vital that they are supported to link into the community BBV services.
- Delivering micro-elimination prison by prison in Wales is achievable. Undertaking an intensive approach to testing and treating in individual prisons can ensure that all HCV positive prisoners are identified and entered into treatment.

**Prison Policy in Wales**

Justice is a matter reserved to Westminster, while health services are a matter devolved to the National Assembly for Wales. In a 2016 White paper *Prison Safety and Reform,* the UK Government proposed a fundamental shift in the way the prison estate is organised and operates in England and Wales[3]. It identified a need to reorganise the prison estate and developed three new operating models for prisons: reception, training

[1] Dr Robert Jones, Imprisonment in Wales: a factfile, University of South Wales June 2018 [available at: https://www.cardiff.ac.uk/__data/assets/pdf_file/0008/1195577/Imprisonment-in-Wales-A-Factfile.pdf]

[2] Wold Health Organization Factsheet – Hepatitis C, 2018 [available at: https://www.who.int/news-room/fact-sheets/detail/hepatitis-c]

[3] Ministry of Justice, Prison Safety and Reform, Cm 9350, November 2016, Chapter 7: Building the right estate for reform.

and resettlement. The prison estate in Wales is currently undertaking the necessary changes in order to adopt these models by 2021[4].

In July 2018, the UK Government Department of Justice published *Strengthening probation, building confidence*[5] a consultation which sets out proposals to improve the operation of the probation system. The outcome of this consultation and the publication of the National Probation Services Strategy is still awaited at the time of writing.

The National Assembly for Wales Health, Social Care and Sport Committee is currently undertaking an inquiry into prison healthcare. This paper will be submitted to the Committee to inform its considerations and we look forward to the Committee report on this subject.

**Disease awareness / Reducing the stigma**

The Hepatitis C Trust has developed a Peer Support Programme in prisons in England where people with a lived experience of HCV, and of prisons, work to support prisoners to be tested and receive treatment. They also work to identify future peers and train them to share the message that hepatitis C can be treated and cured. The peer workers support the implementation of BBV testing in prisons, raising awareness, challenging the stigma that still exists, and provide education and training to prison staff.

The Hepatitis C Trust reflected that a 'whole prison approach' which involved the Prison Governors, prison staff, substance misuse staff and blood borne virus specialist nurses, is crucial to the success of initiatives to improve testing and treatment in the prison environment.

There is a need to challenge two misconceptions. Firstly, that HCV treatment is difficult; oral treatments that which have minimal side-effects are now available and offer a cure which can be completed in as little as 8 weeks. Secondly, work needs to be done to tackle the stigma that exists around hepatitis C and more should be done to encourage people to take up the opportunity to be tested for the virus.

By engaging prisoners in treatment for HCV, there is an opportunity to address wider health issues and engage individuals to make more positive decisions about their health and lifestyle.

Dr Brendan Healy, BBV Lead in Wales highlighted the importance of developing a national approach to eliminating HCV in prisons in order to deliver the Government's ambitions for a hepatitis C free Wales.

**Opt out testing**

There was agreement that opt out testing on reception at prison is the optimal time to engage prisoners with the service. However, this can be hard to deliver, particularly in busy remand prisons, such as HMP Cardiff where 200-300 prisoners enter the prison each month. An opt out model relies on how the question is asked. As an example the following wording has been circulated to Prisons in England:

"We screen everybody entering this prison for hepatitis B, hepatitis C and HIV. Screening is free, confidential, and the sample will not be used for anything other than this test. You can be infected and still feel healthy, so it is important to test even if you feel fit and

[4] 7 HMPPS, Her Majesty's Prison and Probation Service Annual Report and Accounts 2017-18, HC1175, p22

[5] Ministry of Justice, July 2018, Strengthening probation, building confidence

well. If you have hepatitis C, we can treat you with new medication that works in almost all cases, usually with no side effects. Are you happy to proceed?"
There was agreement that the presumption should be on testing everyone on arrival, and that where individuals know that they can be cured relatively quickly, it is a more attractive proposition.
If the opportunity to screen on reception is missed, it can be very difficult for the healthcare teams to find and identify prisoners later, as there is limited access to patients, and they may have already been moved or transferred.

**Developing Pathways**

The consensus was that there is support for the micro-elimination of HCV in the prison estate. The appropriate medicines are available for fast and effective treatment, but changes are needed to how services are funded, commissioned and the way in which prison pathways are delivered.
Remand prisoners can be released or moved to a different prison after 12 weeks so there is a limited opportunity to test and treat in the prison environment. Louise Davies, Point of Care Testing (POCT) Lead at Public Health Wales provided an insight into pilot projects to improve testing and treatment in HMP Cardiff and HMP Swansea.
POCT offers rapid results and placed on medical hold (where appropriate) in order to commence treatment before being moved or released from remand. In Swansea, following a positive test for HCV, individuals can be initiated onto treatment on the same day which removes the need for medical hold.
Given the benefits of quicker testing methods, there was a broad consensus that this should be rolled out across the prison estate in Wales, but it is acknowledged that there will be challenges around resource, staffing levels and funding of testing equipment.

**Funding and Staffing**

As with many other public sector services, funding is limited and there are competing demands in order to provide comprehensive healthcare services in prisons. However, eliminating HCV is a national public health priority and a commitment by the Welsh Government. The opportunity to cure a disease and eliminate it as a public health concern is a rare and unique public health solution and therefore there is a case for ring-fenced budget to deliver micro-elimination in the prison estate.
Staffing issues were a recurrent theme in terms of how certain pathways succeed. High turnover of prison nursing staff and shortages of skilled professionals is also a challenge. There may be an opportunity to review the skill mix of staff working in prison health services, for example by increasing the employment of pharmacists and pharmacy technicians. Incentives to retain staff in post was a suggested solution to reduce turnover.

**Consistency across the prison estate**

There is no common approach to eliminating HCV in the 5 prisons in Wales. Different prison profiles may require different approaches, for example HMP Cardiff has a high turnover population of short-term remand prisoners, while Parc has a smaller but more long-term prison population. Therefore, customised pathways may be appropriate, however there should be established standards, targets and milestones to maintain progress towards elimination. The main challenge is the disconnection between services.
The introduction of KPIs for HCV testing in drug and alcohol services in the community was also highlighted as an opportunity to improve consistency of approach within the

prison environment although it was not clear if these KPIs applied to the prison services and what impact they might have on improving the service. It was suggested that clarity on how these KPIs would be implemented in Prison services and the lines of accountability would be welcome.

**IT and Information Sharing**

Where prisoners have tested positive for HCV and are released into the community during or before commencing treatment, it is vital that they are supported to link into the community BBV services.

There was a broad consensus that information sharing between healthcare professionals and agencies is a significant problem and that IT remains poor.

By joining up information and services, healthcare teams can focus on testing, treating and follow up, with the services working side by side in a co-ordinated approach.

Information sharing and IT challenges are not unique to BBV services or prisons, but it is a matter which requires national leadership in order to deliver a solution that can work within health services and with the key external agencies involved in providing care to individuals.

NHS Wales Informatics Services is working to digitise the paper patient record and make the record available across healthcare settings. In Secondary Care the Hepatitis C Electronic Consultation Note has been developed and can be accessed, viewed and updated in the Welsh Clinical Portal. This is being piloted in the prison setting.

**Linkage into care on release**

There was consensus that there needs to be a much more co-ordinated prison release system. Some individuals require a wide range of support on release, engaging the services of multiple agencies from housing, substance misuse, benefits etc, but none are joined up. Supporting individuals into housing is essential so that they can be followed-up and supported to continue (or enter into) treatment. The group heard about the work of Waverly Care Prison Link Worker Project in Scotland, which offers this type of whole-person approach.

**Micro-elimination "Hit Squads"**

Delivering micro-elimination prison by prison is achievable. Undertaking an intensive approach to testing and treating in individual prisons can ensure that all HCV positive prisoners are identified and entered into treatment. This approach could be highly effective in prisons with a longer-term population. It was suggested that with strong political leadership and a commitment to provide the resources required, micro-elimination in prisons could be delivered within a period of just a few months, and Wales could lead the UK in adopting such an approach.

**Recommendations**

It is acknowledged that with the reconfiguration of the prison estate and the eagerly awaited probation strategy, the Prison Service is undergoing significant reform. However, the following recommendations can offer both short, and longer term, solutions to improve HCV services in prisons:

- The Welsh Government should make a clear commitment to deliver micro-elimination in prisons as part of its wider ambitions to eliminate HCV in Wales.
- An action plan setting clear targets and milestones for improving HCV testing and treatment in prisons should be developed.

- Peer support workers should be introduced into every prison in Wales.
- Opt-out testing is fundamental to deliver HCV elimination in prisons. Greater emphasis should be placed on the delivery of this in a consistent manner and, if necessary, additional resource should be made available to deliver this.
- Linking prisoners into care on release is essential and could be incorporated into the terms of probation, in line with current guidelines around communicable diseases.
- The Welsh Government should explore projects such as the Waverley Care Link Worker Project in Scotland to identify solutions that can be adapted for the Welsh environment in order to link prisoners into care on release.
- The Welsh Government should create a 'hit squad' that can move from prison to prison delivering comprehensive testing and treatment for prisoners to achieve elimination at a national scale.

Where the recommendations above require additional funding/resource, it should be noted that the tender process for procuring hepatitis C treatments have significantly reduced the cost of medicines and to date, the savings have not been significantly reinvested into hepatitis C services. Therefore, there is an opportunity to use these savings to deliver elimination.

**Appendix 1:**

**Rethinking Hepatitis C Services in Prisons in Wales**

**Delegates:**

Antonis Papasolomontos, Director of Government Affairs, AbbVie
Dr Brendan Healy, BBV Lead for Wales
David Rees AM, Assembly Member for Aberavon
Dawn Bowden AM, Assembly Member for Merthyr Tydfil
Delyth Tompkinson, Clinical Nurse Specialist Hepatology, Cardiff and Vale Health Board
Dr Bethan Roberts, Forensic Medicine Committee, BMA
Dr Dai Lloyd AM, Assembly Member for South Wales West
Dr Giri Shankar, Lead Consultant for Health Protection and Communicable Diseases, Public Health Wales
Dr Jane Salmon, Consultant in Health Protection, Public Health Wales
Dr Mair Strinati, Primary Care Leader, Cardiff
Dr Peter Saul, Joint Chair, Royal College of GPs
Elin Llŷr, Deryn Consulting (Observer)
Gail Grant, Senior Government Affairs Manager, AbbVie
Jo Kiernan, Deryn Consulting (Observer)
Katie Wilkes, Point of Care Testing Co-ordinator
Laura Lewis, Health Lead for Wales, HM Prison and Probation Service
Leanne Bruford, Substance Misuse Manager, CGL Taith and Entry into Drug and Alcohol Services Cardiff
Louise Davies, Point of Care Lead for Wales
Neil Harding, Lead for Criminal Justice/Probation Services, G4S
Nicki Palmer, National Hepatitis C Project Lead, G4S
Rachel Halford, Chief Executive, The Hepatitis C Trust
Aidan Rylatt, Policy and Public Affairs Adviser, The Hepatitis C Trust
Rosie Raison, Policy and Public Affairs Officer, Royal College of Nursing Wales
Thomas Cox, Lead Prison Pharmacist, HMP Berwyn/Royal Pharmaceutical Society