Hepatitis C: Progress towards achieving elimination in Wales

June 2019
The National Assembly for Wales is the democratically elected body that represents the interests of Wales and its people, makes laws for Wales, agrees Welsh taxes and holds the Welsh Government to account.
Hepatitis C: Progress towards achieving elimination in Wales

June 2019
About the Committee

The Committee was established on 28 June 2016. Its remit can be found at: www.assembly.wales/SeneddHealth

Committee Chair:

Dai Lloyd AM
Plaid Cymru
South Wales West

Current Committee membership:

Jayne Bryant AM
Welsh Labour
Newport West

Angela Burns AM
Welsh Conservatives
Carmarthen West and South Pembrokeshire

Helen Mary Jones AM
Plaid Cymru
Mid and West Wales

Lynne Neagle AM
Welsh Labour
Torfaen

David Rees AM
Welsh Labour
Aberavon

The following Members were also members of the Committee during this inquiry.

Dawn Bowden AM
Welsh Labour
Merthyr Tydfil and Rhymney

Neil Hamilton AM
UKIP Wales
Mid and West Wales

The following Member attended as a substitute during this inquiry.

Darren Millar AM
Welsh Conservatives
Clwyd West
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1. **Background**

1. The hepatitis C virus (HCV) is a blood-borne virus (BBV) affecting the liver. If untreated, four-fifths of those infected develop chronic hepatitis C, which can cause fatal cirrhosis (scarring of the liver which can lead to liver failure) and liver cancer. The virus is spread when the blood of an infected person gets into the bloodstream of another person.

2. The main way HCV is spread in the UK is through drug use, by the sharing of needles. Body piercing or tattooing using unsterilised needles can also spread the virus. On rare occasions it can be spread through sexual contact or from mother to baby before or during birth. Other people at a higher risk of acquiring HCV include those who come into contact with blood, such as healthcare workers and prison officers and people who received a blood transfusion before 1991 in the UK or in countries that do not screen donated blood for the virus. Since 1991, all blood donated in the UK is screened for HCV.

3. There is no vaccine for HCV. New medications are seen to have “revolutionised” the treatment of HCV so that it is now curable in around 9 out of 10 people if treated early. The new tablet treatments are more effective and have far fewer side-effects and treatment takes eight to 12 weeks. Even if treatment does not clear the virus, it can still slow down inflammation and liver damage.

**Prevalence of hepatitis C**

4. The World Health Organisation (WHO) estimates that globally 71 million people have chronic hepatitis C infection. The UK is a low-prevalence country.

5. Around 210,000 people are chronically infected with HCV in the UK, with 12,000-14,000 of these in Wales. The number of laboratory-confirmed cases of HCV in Wales can be viewed on an interactive data dashboard on the Public Health Wales website. The majority of infections are in people who inject drugs.

6. Hepatitis C Trust states that HCV disproportionately affects disadvantaged and marginalised communities, with almost half of people who attend hospital with the virus coming from the poorest fifth of society, and with the latest figures showing that 50% of injecting drug users in Wales have HCV antibodies. Other groups who are disproportionately affected include homeless people and migrant

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1. Laboratory reports of Hepatitis C virus per week
communities from countries with a high prevalence of HCV, such as Pakistan and Poland.

**Terms of reference**

7. The Health, Social Care and Sport Committee (the Committee) agreed to undertake a one day inquiry into hepatitis C, to look at:

- the action being taken to meet the requirements of the Welsh Health Circular (WHC/2017/048) published in October 2017 and subsequently meet the World Health Organization target to eliminate hepatitis B and hepatitis C as significant public health threats by 2030;

- how the knowledge and awareness of the public and health professionals of the hepatitis C virus can be increased;

- the scope to increase community-based activity e.g. the role of community pharmacies;

- the long-term viability of treatment programmes.
2. Targets for Wales and progress

8. The WHO has announced a global health sector strategy on viral hepatitis which sets out to eliminate hepatitis B and hepatitis C as significant public health threats by 2030. The WHO target is a 90% reduction in incidence and 65% reduction in mortality due to hepatitis B & C by 2030. Wales is signed up to this strategy.

9. However, a number of witnesses, including AbbVie (a global research-based biopharmaceutical company), Dr Brendan Healy, Chair of the Blood-borne Viruses Network, Consultant in Microbiology and Infectious Diseases, and national lead for Hepatitis, and the Hepatitis C Trust, raised concerns about the ability to meet this target. Evidence from the Hepatitis C Trust states:

“Despite [...] encouraging progress, there are evidently still challenges that remain if elimination is to be achieved by 2030. Whilst some Local Health Boards are meeting their treatment targets, most are not and there is a significant shortfall in meeting the national annual target. Diagnosis and treatment rates will have to increase significantly if elimination is to be achieved by 2030.”

10. Dr Brendan Healy told us:

“…we really need to start hitting those minimum treatment targets if we’re going to get anywhere near elimination. So, the modelling that shows that we will miss elimination by about 10 years is based on the fact that, over the last two years, we haven’t hit that minimum treatment target. If we hit the minimum treatment target, it’s predicted, on current data, that we’d miss elimination by about 18 months.”

11. Public Health Wales were optimistic that the target could still be achieved but said a concerted effort is required:

“…I think the modelling data that we have now got suggest that, at the current treatment rate, it is true that if the same trajectory continues, we will not hit the 2030 elimination target. But it is important that we’ve got a real opportunity—that if we are able to identify more people who are infected and bring them back into the care system so that the

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2 Written evidence, H06
3 RoP, 17 January 2019, paragraph 206
treatment numbers are increased, we will be in a position to reach that target. And for us to do that, I think it needs a concerted effort. Perhaps other colleagues might have already spoken about it in other sessions. Having a focused strategy on an all-Wales basis, which encompasses all the key interventions, and identifies the roles for different stakeholders with appropriate local delivery plans, is something that will really help us refocus our attention and bring us back to the target of elimination by 2030.”

12. It has also been stressed that the national treatment targets should be seen as a minimum, which health boards should be aiming to exceed. Dr Brendan Healy told us:

“It also has to be set as a minimum target because, as we alluded to earlier, with the modelling, even if we were achieving the 900 minimum target per year, the modelling suggests we’d miss elimination by about 18 months. So, it wouldn’t make any sense to keep that as the ceiling.”

13. Anecdotal evidence received by the Hepatitis C Trust talks of Local Health Board Finance Directors discouraging hepatology teams from exceeding the treatment target due to financial concerns. The Trust urges the Welsh Government to make it clear to health boards that this approach will result in greater financial costs in the long run and is not compatible with Wales achieving elimination by 2030.

14. Stuart Smith, Hepatitis C Trust, told us:

“I think the point that we would also want to make is that it’s actually a false economy. If you are not spending the money on treating people now, you’re just storing up problems for a later date, because then there’s a risk of someone developing serious liver problems and all of the costs that are associated with that to the health service. So, really, you should be investing now heavily and then, if you eliminate hepatitis C, that’s actually saving money for the health service in the long run. So, I think that what we would really like to see is the Welsh Government..."
making it clear to health boards that treatment targets should be considered a minimum and absolutely not as a cap.”

15. When asked for his views on this, Dr Brendan Healy said:

“...it’s critical that the health boards understand that this is an elimination agenda and there is no sense in saying, ‘Well, you’ve hit your target and that’s your ceiling and we’re not doing any more this year; we’ll wait till next year’, because the more patients we treat in one year, the fewer patients we have to treat overall because, whenever you treat a patient, you reduce the risk of onward transmission as well. So, from my perspective, it’s very important that we get that message right so that health boards understand that the drugs are very cost-effective.”

16. Dr Ruth Alcolado Deputy Medical Director, Cwm Taf University Health Board, told us:

“...we should be having a minimum target, and we should then be saying, within our financial planning, we have to say, ‘And we would anticipate that it would be great if we could exceed that by 10 to 15 per cent’, and then you budget on that basis. And we haven’t done that, because what we’ve set is a target to treat, up until now, and what I think we need to change to, and if we had a strategy document, it would be clear that this would be our minimum target to treat—. So, at the moment, health boards are working with a target to treat, and that’s what they budget for, and I think the wording needs to change around that.”

17. Dr Chinlye Ch’ing, Consultant Gastroenterologist, Abertawe Bro Morgannwg University Health Board, supported this point, noting:

“I did have a conversation with our finance department, because they do not understand the concept of a target. They think that once we achieve our target, whatever we treat is going to cost them more money. Year on year, we achieve our targets and beyond. I told them this year, ‘We haven’t reached our budget’, because the drugs budget was set at the time we received the drugs in the early years. It was more expensive then, but things have changed now and moved on, so it’s

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7 RoP, 17 January 2019, paragraph 68
8 RoP, 17 January 2019, paragraph 266
9 RoP, 17 January 2019, paragraph 267
actually more cost-effective to treat patients with the drugs that we have now.”

18. The Welsh Government published a Welsh Health Circular in October 2017 entitled “Attaining the WHO targets for eliminating hepatitis (B and C) as a significant threat to public health”. The circular requests that measures are put in place for the following three headings:

- reduce and ultimately prevent ongoing transmission of the hepatitis C virus (HCV) within Wales;
- identify individuals who are currently infected with HCV including those who have acquired HCV outside the UK and are now resident in Wales;
- test and treat individuals currently infected with HCV who are actively engaged in behaviours likely to lead to further transmission.

19. Public Health Wales provides leadership for the Hepatitis C Treatment Programme.

20. While the Welsh Health Circular has generally been welcomed, some witnesses drew attention to its lack of specific targets. Written evidence from AbbVie states that:

“While this circular is clear in its intention, the document does not include any targets, timescales or funding to support health boards in the delivery of these objectives. Neither does it address the need for centralised data capture in order to measure progress towards targets.”

21. Gilead Science made a similar point, saying that without a specific delivery plan setting out key actions, resources and measurements it would be hard to measure progress towards meeting the 2030 elimination target.

22. Aidan Rylatt, Hepatitis C Trust, told us:

“… back in October 2017, the Chief Medical Officer for Wales released a health circular on viral hepatitis, and in and of itself that was certainly welcome, but I don’t think we would feel that that goes far enough in

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10 RoP, 17 January 2019, paragraph 270
11 Welsh Health Circular WHC/2017/048 – Attaining the WHO targets for eliminating hepatitis (B and C) as a significant threat to public health
12 Written evidence, H04
13 Written evidence, H07
being a comprehensive plan that really directs people in what needs to happen. So, we’d like to see that be built on and a more detailed and thorough strategy produced.”

23. He went on to say:

“I think we would certainly be concerned if there wasn’t a replacement plan that addressed hepatitis C beyond 2020. The point that we’d be keen to make is that 2030 is really not that far away, so now is certainly not the time to be taking the foot off the gas – quite the opposite, really.”

24. The Trust called for a comprehensive national elimination strategy, with clear targets and allocated areas of responsibility, to ensure coordination of the various actors and actions needed to achieve elimination by 2030. It went on to say that with Scotland having committed to releasing a dedicated Hepatitis C elimination plan in the near future and NHS England having set a more ambitious target of elimination by 2025, Wales must continue to take an ambitious approach to avoid being left behind.

25. Dr Brendan Healy agreed with the need for a more strategic approach:

“I would support having a comprehensive elimination strategy. I think it kind of aligns with what we are already saying in terms of the fact that we want to make sure that things are adequately resourced. We’ve done an amazing job in getting to where we’ve got to through things that happen in the NHS every day—you know, individuals working hard, doing their best under the resources that they have. I think that, with the proper resourcing, we can go even further, and I think that a comprehensive strategy would help us achieve that. I don’t necessarily think there’s a one-size-fits-all strategy. So, for example, the challenges of finding patients in Cardiff might not be the same as the challenges facing Hywel Dda, for example. So, I think what we need is a strategy that identifies the sort of personnel that we need in place, the sort of work that we want to carry out, but then individually developed local plans aligned with that overall strategy.”

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14 RoP, 17 January 2019, paragraph 26
15 RoP, 17 January 2019, paragraph 26
16 Written evidence, H06
17 RoP, 17 January 2019, paragraph 220
26. Lisa Turnbull from the Royal College of Nursing (RCN) told us that the RCN also advocate for an elimination strategy, and said there also needs to be an accompanying workforce plan:

“That workforce plan should include succession planning and look at the consistency of approach across areas. That is what we are missing in Wales at the moment. We issue strategies or plans and standards, which are often excellent, but they don’t have an accompanying workforce assessment with them. So, there’s a general point here, which is really well made, which is: how many do we need? Is it 15, 20? They may not be very large numbers here, because you could make a huge difference with a senior grade nurse who then is responsible for providing education to colleagues, cascading that information out, doing that collaboration work. So, you’re not necessarily talking about extra hundreds, you may literally be talking about 10 or 20.”

27. She concluded that the priorities should be a strategy specifically in this area, and focusing the investment on the creation of front-line professional posts who can go out, see, assess, and treat.

28. Hepatitis C Trust also spoke about the opportunity for Wales to be the first country in the UK to eliminate the disease:

“Wales has got a relatively small number of people to find and treat with regard to hepatitis C. So, really, they could be the first to eliminate. If there’s a strong, solid elimination strategy that covers all of the areas that we’ve talked about—finding the undiagnosed, getting out into the community, making sure everyone’s tested, taking away any caps because there’s enough incentive for everybody to be treated—you very easily could eliminate hepatitis C way ahead of anybody else.”

29. Hepatitis C Trust told us we have a really rare opportunity to eliminate a disease and save a lot of lives and money.

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18 RoP, 17 January 2019, paragraph 184
19 RoP, 17 January 2019, paragraph 74
3. Action being taken to meet the 2030 elimination target

Reducing and preventing ongoing transmission of HCV within Wales

People who inject drugs

30. Over 90% of ongoing transmission of HCV is via injecting drug use. Therefore, according to witnesses, the most effective way of reducing transmission is through a reduction in the number of individuals injecting and through provision of effective Needle and Syringe Programmes (NSPs).

31. Public Health Wales reports that in 2017/18 there was a total of 14,000 regular users of needle syringe services, and over the last five years there has been a decrease in the proportion of young people injecting drugs and accessing services, from 5.5% in 2013/14 to 2.7% in 2017/18. According to Public Health Wales, the new NSP framework was initiated in July 2017 and has led to the introduction of “single injection kits” in all NSPs.20

32. Dr Giri Shankar, Lead Consultant for Health Protection and Communicable Disease Control, Public Health Wales, told us:

“The needle and syringe programme is a well-established programme across Wales. Currently, we’ve got 270 sites across Wales that deliver this programme. Fifty-five of those are in specific substance misuse settings, 215 of those are in community pharmacy settings. So, we’ve been able to engage the clients, the people who inject drugs, in those services, and every interaction with the service is captured comprehensively in the harm reduction database. So, that is one of the things that we can be very proud of in Wales, and it has been an award-winning flagship IT system that has been put in for improving patient safety.”21

33. Evidence from Dr Brendan Healy says a reduction in the number of individuals injecting is reliant on increased testing in appropriate settings (prisons, drug and alcohol services, needle exchange services, opiate substitution services, criminal justice services, third sector agencies, community pharmacies). However,

20 Written evidence, H03
21 RoP, 17 January 2019, paragraph 319
he goes on to say that “testing rates in all of these settings is currently sub-optimal”.

34. Work is being carried out to improve uptake of testing in these settings. However, Dr Healy warns that these initiatives need to be matched by an appropriate investment in the services so that they have sufficient staff and equipment to facilitate testing of all at risk clients. He also stresses that each health board needs to have a robust mechanism in place that enables individuals to access treatment easily. This will most likely be provided by secondary care services.

35. Evidence from Public Health Wales draws attention to the establishment of the Viral Hepatitis Subgroup, chaired by the National Lead for Hepatitis, which provides strategic leadership and support to health boards in progressing this area of work.

36. It states that the Subgroup has facilitated a number of developments working with other agencies to develop and support increased testing and treatment in a variety of settings, including prisons, drug and alcohol services, third sector services and community pharmacies. This includes the appointment of a National Pharmacy Lead, a National Project and Research Lead and a National Point of Care Testing Lead (although there are some concerns around funding for these posts which will be discussed further in Chapter 5).

37. In addition, the Viral Hepatitis Subgroup has been working with NHS Wales Informatics Service (NWIS) to develop a hepatitis C electronic form that will facilitate live collection of national treatment data in the future.

38. A number of witnesses drew attention to people who inject drugs to improve image or performance as a high risk group, and we heard of a significant growth in this population. According to Community Pharmacy Wales:

“This is a major group that should be more heavily targeted if WHO targets are to be reached in Wales.”

39. It recommends that posters be put up in all gymnasiums, sports clubs and tanning salons to raise awareness of the risk of contracting hepatitis, highlight the

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22 Written evidence, H05
23 Written evidence, H03
24 Written evidence, H01
fact that modern treatments are effective and simple to use and also to promote the walk in advice, test and treat service available at a nearby pharmacy.

40. In Gwent, a steroid clinic has been set up to deal with this problem. Evidence from Aneurin Bevan University Health Board states:

“Gwent has an established problem of use of steroid and image enhancing drugs (SIEDs) in Gwent. To address this problem the BBV team have set up a steroid clinic. This clinic offers harm reduction advice, general health screening, ECG and BBV testing.”

41. Delyth Tomkinson, Clinical Specialist Nurse Hepatology, Cardiff and Vale University Local Health Board (UHB), highlighted an increasing problem with people receiving cosmetic treatments. She told us:

“... we’ve got people now travelling far and wide for fillers, Botox treatment and things. It’s making the general public aware what the risk factors are. We had a case recently where somebody went to a Botox party and they shared needles. That’s just the general public’s lack of awareness, really. But it’s identifying what the risk factors are, and, if they want to have a test, if they think they’ve put themselves at risk, they know exactly where they can go for the test.”

Prison healthcare

42. All prisons in Wales offer treatment for BBVs. Specialist nurses run clinics within each prison to see those testing hepatitis C antibody positive. Portable scanners used within prisons mean that in the majority of cases, individuals can transition from testing to treatment without the need to leave the prison.

43. In November 2016, the Welsh Government issued a formal policy move to opt-out testing for BBVs for all those on admission to prison. Public Health Wales reports that an increase in the numbers of men screened for BBVs was evident following the introduction of this opt-out screening policy.

44. Dr Giri Shankar told us:

“In November 2016, when the opt-out policy was introduced, we had an uptake of 8 per cent at the time, across Welsh prisons. Now, that’s gone

25 Written evidence, H08  
26 RoP, 17 January 2019, paragraph 152  
27 Written evidence, H03
up to 34 per cent, which is definitely a significant improvement. We want to reach 100, so there is still a little bit of work to do, but that has been really, really helpful.”

45. However, a number of witnesses highlighted a lack of resources for testing in prisons.

46. Evidence from AbbVie states that it is estimated that one in ten prisoners are HCV positive. In April 2018, the prison population in Wales was 4291 so 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. It also states that although opt out testing for prisoners was introduced in Wales in 2016, implementation remains variable due to workforce and capacity issues within the prison healthcare service.

47. Gilead Sciences says that to make prisons HCV free additional resource for staff is required; it calls for a BBV nurse in each prison to encourage normalisation of BBV testing in the prison setting and allow inmates to be tested and treated quickly.

48. Dr Stephanie Perrett, Lead Nurse for Health and Justice, Health Protection Programmes, Public Health Wales, told us:

“... the work we’ve done in the prison—we’ve made some significant gains there, I think, in the last few years in terms of the blood-borne virus agenda, and a lot of that has been done on hard work and goodwill. And, to my knowledge, I’m not aware that the prisons have directly received any additional resource to do that, so we want to maintain those services. But we’re not—. Whilst we’re happy with the progress made, we’re not happy that we’re there yet, so there’s a lot of work still to be done and the resources will need to be looked at for that.”

49. She went on to highlight issues around recruitment and retention within the prison workforce, and the impact on services when staff move on, as areas for further improvement.

28 RoP, 17 January 2019, paragraph 365
29 Written evidence, H04
30 Written evidence, H07
31 RoP, 17 January 2019, paragraph 315
Dr Peter Saul, Joint Chair of the Royal College of General Practitioners, made the point that, when people are taken into the prison and offered testing, there are sometimes not enough resources or staff to do the testing there and then:

“I was told that, if they elect to have testing and they don’t, or they choose at a later date to have testing, they can wait several months before they actually can make their way back to the healthcare centre to have testing.”

He also told us that he was aware of occasions when the local hepatology team will get drugs for a prisoner, and these drugs will be on order, and then the prisoner is moved to another prison, maybe in England, and they have difficulty finding where the prisoner has gone and getting the drugs to the prisoner for treating.

Dr Stephanie Perrett also highlighted some of the difficulties associated with dealing with such a mobile population:

“… whilst we do need to be looking at the prison as a setting, and it’s very right that we do that, these people move into prison, out of prison, into homelessness services, drug services, and we need to be providing clinical services that can keep up with that mobility so that we’re not just losing people around the system. We invest a fair amount of time and resource in services that we deliver in prisons, and that is wasted if those health gains are lost as soon as somebody is released.”

Dr Chinlye Ch’ng said:

“I think in the prisons we just need to increase the number of patients tested. I think Brendan tried out this strategy in Parc prison, using a new technology where the patient can be tested and found to have a positive polymerase chain reaction on the same day, and be treated then, rather than –. The current strategy is that we check, send the card away, wait a week or two for the card to come back, and then test the blood for PCR and then send it away, and then wait for the results to come back. In Swansea prison, it wouldn’t happen, because the prisoner would disappear; they’d be gone to somewhere else. So, we can’t even initiate treatment there. So, we just need the strategy that
we have here now, so we can test and know the patient has a positive PCR at the outset, and this is what we’ve been trying to do now in Parc prison, to see whether it works or not.”

**Identifying individuals who are currently infected with HCV including those who have acquired HCV outside the UK and are now resident in Wales**

54. Public Health Wales is leading the co-ordination and implementation of a national patient re-engagement exercise, which looks to identify individuals with a historical diagnosis of HCV but who have, for whatever reason, not fully engaged with treatment services, with a view to bringing them back into the service and offering them treatment with the new therapies now available.

55. This work is being supported by an implementation group which includes representation from the Hepatitis C Trust, the British Liver Trust and the General Practitioners Committee (GPC) Wales in addition to every health board in Wales. Using historical laboratory testing data as the starting point, work has been undertaken to identify these individuals. From Spring 2019, they will be contacted and offered the opportunity to re-engage with services and be assessed for treatment.

56. Dr Giri Shankar told us:

“... over the last year, what we have been doing is to identify and extract data from that master database of lab testing, which has 22 years’ worth of data, to uniquely identify an individual as an individual. Then, for various reasons, they might not have engaged. Sometimes, it could be because the old treatments were proving to have too many side effects, but we’ve got now newer treatments, etc, so they may not be aware of that.

... we’ve now lined up a fully worked out timetable whereby we’ve got, in the first tranche, up to about 3,000 individuals. We’ve sent the data out to health boards asking them, ‘Do you know these patients? Have they been in treatment before?’ And if they say ‘yes’, we take those people off the list, and the ones that we know are infected but are not yet engaged in treatment—we will be writing to them at the end of

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35 RoP, 17 January 2019, paragraph 274
36 Written evidence, H03
February/early March, inviting them to engage with the services to take them forward.”

57. In relation to individuals who have acquired HCV outside the UK and are now resident in Wales, written evidence from Dr Brendan Healy states that strategies to identify positive individuals from high risk countries are not yet well established. He said that there is still uncertainty with regards to the best way to identify these people and further work will be required on this in due course. Although work has been carried out in asylum services and testing is now routinely offered to individuals accessing these services.

58. Delyth Tomkinson told us about the work she’d been doing through the asylum services in Cardiff to set up a nurse-led outreach clinic, which tests people as they come in through the service.

59. She went on to say that there are, however, difficulties in reaching people who are not seeking asylum:

“It’s very, very challenging, I have to say, because they come in, they don’t know their diagnosis. They may have HIV, hepatitis B, hepatitis C and TB. So, it’s a case of diagnosing them and giving them that support and then linking them into care. And it’s also the ones who go underground, who we have to, sort of, try and get to.”

Testing and treating individuals currently infected with HCV who are actively engaged in behaviours likely to lead to further transmission

60. Given that the prevalence and incidence of HCV infection is highest among individuals with current or historic substance misuse, it is vital that these populations are routinely tested and referred for treatment as soon as identified.

61. Testing and treating individuals who inject drugs is the fastest way to reduce the overall prevalence; it will be the key to achieving WHO elimination targets and will reduce the overall cost of reaching the elimination target (each individual successfully treated can reduce the overall number of individuals that need treatment as onward transmission is prevented).

62. Public Health Wales has developed a Harm Reduction Database (HRD) Blood Borne Virus Module, which has been implemented in all specialist substance

57 RoP, 17 January 2019, paragraph 345
58 RoP, 17 January 2019, paragraph 169
misuse services across Wales and in a number of pilot community pharmacy sites. It is envisaged that a national roll-out across all relevant community pharmacies will commence over the next few years.

63. The HRD blood borne virus module provides a system for recording routine testing, in line with the implementation of routine opt out testing in all substance misuse services in Wales. In addition, the database enables the testing and outcome history to follow the patient wherever they are in Wales, and over time. The database provides a mechanism for screening, diagnosis, referral and treatment milestones including commencement, Sustained Virological Response (SVR) and reinfection.

64. According to Public Health Wales, over 1600 individuals in contact with substance misuse services were tested in 2017 and this has increased by over one third in 2018. However, a significant proportion of individuals remain untested and it is important that services are appropriately resourced to enable all “at risk” clients to be tested on an annual basis.

65. In addition, Public Health Wales has supported Welsh Government in the reintroduction of a Key Performance Indicator (KPI) for all substance misuse services. This will facilitate the testing of all individuals in contact with services on at least an annual basis until no longer at risk of HCV infection. The KPI will be monitored for each site via the HRD, which ensures an individual patient record of testing, diagnosis and treatment. The system also reduces the likelihood of an individual testing reactive for HCV from being lost to services, or “falling through the net” which has been an issue in the past.
4. Increasing knowledge and awareness of HCV

Healthcare professionals

66. Low knowledge and awareness among some health professionals is an ongoing issue, and according to written evidence from Public Health Wales, “is one of the most challenging areas of the elimination plan”.39

67. The Hepatitis C Trust conducted interviews and focus groups with patients, and heard that patients often encountered low levels of knowledge of HCV from health professionals. While the excellent care provided by specialist hepatology teams was emphasised, patients reported less positive experiences with other health professionals, such as GPs and non-specialist nurses.

68. Many patients said they had been visiting their GP for years with symptoms consistent with hepatitis C infection but had never been offered a test. Others were given incorrect advice and information, such as being told that the virus is transmitted through sexual contact, which contributed to stigma encountered by patients.

69. Evidence from the Royal College of General Practitioners (RCGP) states that GPs are in a unique position within society to engage with groups at risk of contracting hepatitis C infection and encourage them to get tested for the virus. It draws attention to work it has undertaken, in conjunction with the British Liver Trust, to develop a liver disease toolkit40 which provides specific guidance on hepatitis C and its management in primary care, and is available as an online resource for primary care practitioners.

70. The Hepatitis C Trust says that while there have been various initiatives to improve the situation, there remains a need for GPs and other primary care workers to be provided with regular information about HCV and presented with opportunities to undertake training as part of continued professional development to ensure increased levels of awareness and knowledge.41

39 Written evidence, H03
40 Royal College of General Practitioners: Liver Disease Toolkit
41 Written evidence, H06
71. The Royal College of Nursing (RCN) made a similar point about the need for continuing professional development. Lisa Turnbull told us:

“... there is an issue around the difference between the awareness of health professionals who are working specifically in that field, and that is their job—their bread-and-butter job, as it were—and, of course, what’s also equally important is the more general awareness of how to access those services from healthcare professionals working in other generalist fields. So, that’s around continuing professional development and awareness, and, of course, there are some very specific issues there.”

72. Dr Peter Saul, RCGP, said that the College has been very active in terms of educational support for hepatitis C:

“We’ve got what we call a clinical champion covering the whole of the UK whose job is to try and push the agenda and develop the agenda. We’ve had a number of educational initiatives. There’s one that occurred in Cardiff at the end of last year aiming for primary care professionals, and updating them about some of these issues. There’s a hepatitis study day at the college in London later this month, and there are educational learning modules that we’ve developed for GPs and for other health professionals to push that agenda.”

73. Dr Mair Hopkin, Joint Chair, RCGP, highlighted the importance of protected learning time and raised concerns that staffing levels were having a detrimental impact on this:

“GPs have had in the past protected learning time, which would be a half day when the practice was covered by the out-of-hours service, and all the GPs from an area could attend an educational event, often with a health board-led agenda. So, something like this where the health board would have an initiative would be ideal. But recently, certainly in Cwm Taf, these have been cancelled because of lack of out-of-hours provision, so there’s no availability for GPs to be released for protected learning during the working day.”

74. Stuart Smith highlighted the role e-learning could play in helping health professionals keep up to date in the management and treatment of HCV:

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42 RoP, 17 January 2019, paragraph 102
43 RoP, 17 January 2019, paragraph 110
44 RoP, 17 January 2019, paragraph 137
“...it doesn’t actually need as much learning and training as people think. I think GPs only need to brush up for a 15-minutes online course on it, for example—so, looking at e-learning and something that you can roll out with that method, educational films. And I think—. In England, we have done work. Public Health England had commissioned some e-learning through the Royal College of General Practitioners to be rolled out. But it really came down to promotion, because it was one thing getting those materials together, but what happened with Public Health England was that they really pushed it to nurses and drug services in community settings, and they got over 1,000 people to take that e-learning module. So, promotion is really important if you’re going to develop learning.”

75. In December 2017, a good practice hepatitis C roadshow was held in Cardiff. This event was organised by HCV Action and Public Health Wales, and aimed to bring together professionals working with hepatitis C in a variety of contexts, identify challenges and solutions for tackling hepatitis C locally, and showcase and share examples of good practice in prevention, testing, and treatment. Written evidence from the RCN also highlights a number of good practice examples, including:

- BBV training days held on a monthly basis and open to all staff across all sectors of health & social care who want to be involved in BBV testing in Cardiff & Vale;
- All Wales Hepatology Nurse Forum annual conference, which is aimed at health professionals across Wales;
- the Cardiff & Vale UHB hepatitis C social media campaign #GetTestedGetCured which has been effectively supported by the health board’s communications and media team. This is a long-term campaign which involves infographics being displayed on media screens across Cardiff & Vale UHB.

76. The RCN states that education, across the public sphere and within the health profession, is needed to help overturn negative messaging and dispel some of the myths about testing and treatment.

77. Similarly, Delyth Tomkinson told us:

45 RoP, 17 January 2019, paragraph 46
“...we have some issue with the fact that a lot of people that may want to come forward for testing—and there’s a huge stigma around viral hepatitis—may approach their GP in the first instance, but then maybe they don’t know actually where they can go and be tested. So, maybe, again, if we could work with our GP colleagues to say, ‘If they do want testing in a GP surgery, that could take place’, because a lot of people—on most occasions, they are directed to sexual health clinics, but a lot of people wouldn’t want to go to sexual health clinics to be tested. So, I think, it’s again public awareness of where they can get a test done confidentially, and then be referred into care.”

General public and “at risk” populations

78. Knowledge and awareness of hepatitis C among the public remains low, reflected in the roughly 50% of undiagnosed patients and continuing stigma around the virus.

79. To mark World Hepatitis Day 2018, The Hepatitis C Trust commissioned a UK-wide poll of members of the public to assess awareness of hepatitis C. Despite 80% of respondents stating that they were aware of what hepatitis C is, less than 40% knew that it infects the liver, and less than 30% knew the virus is curable. Awareness of symptoms was also low, with only a third of respondents accurately identifying signs of infection, and less than half aware that symptoms are not always obvious and can go unnoticed for many years. When asked how hepatitis C is transmitted, 30% incorrectly said it was through exchanging saliva.

80. The Trust also says that myths and outdated messages are still prevalent even among particularly at-risk groups. For example, while injecting drug users are more likely than the general population to be aware of hepatitis C, many are unaware of the availability of the newer DAA treatments, with outdated information related to the significant side effects associated with the older interferon treatments often passed on. Such misinformation can have serious consequences, with some patients choosing not to access healthcare services due to fear of the old treatments.

81. Dr Ruth Alcolado talked about the role the third sector could play in helping dispel some of these myths:

“I would say that the key message that we’re trying to get out now, certainly to our third sector partners, is that this is really worth doing. So,
a lot of people have still got the memories of some of the really difficult treatments that we’ve had for hepatitis over the years and still are worried and saying to patients, ‘Are you ready to have that treatment yet? Are you ready to be tested?’, whereas actually the more information you get out there about actually how easy it is now, how well tolerated treatments are, how short the treatments are—I think we can get much more of that information out there and people will understand that this is actually a really positive move, and, for many patients, actually, a start to one of the things they want to do to move on in their lives.”

82. However, she felt that there was still further work to do in this area.

83. Addressing the issue of stigma, Dr Brendan Healy told us:

“Another key message for me is that, unfortunately, sometimes, infectious diseases come with a stigma. So, we’ve seen that with HIV, you see it with TB in some communities, and you see it with hepatitis C. A key factor in getting rid of stigma is if there’s a treatment available. For me, I’m really keen to try and change the attitude towards hepatitis C from one of ‘If you’ve got it, then you’re stigmatised’ to one of ‘If you’ve been tested, you’re being responsible because you’re then able to get treated and prevent onward transmission’.” 47

84. The Hepatitis C Trust compares the lack of public knowledge of hepatitis C with awareness of HIV, which saw huge increases in public awareness following government-backed awareness campaigns and campaigning activity by high-profile individuals. The Trust would like to see the Welsh Government work with other key stakeholders to develop a nationally co-ordinated series of local awareness-raising campaigns, including messaging tailored to specific at-risk groups highlighting transmission risks, the importance of testing and the availability of the new treatments. Rachel Halford told us:

“I think, ideally, we would love to see – and I don’t know if we’ll ever see - something like the HIV campaigns, a national campaign that raised awareness with everybody. I think that— you know, it’s well known that the stigma with hepatitis C is enormous, and what that does is instil a lot of fear so people are afraid to come forward.” 48

47 RoP, 17 January 2019, paragraph 281
48 RoP, 17 January 2019, paragraph 36
85. Dr Brendan Healy also suggested that consideration should be given to funding a focussed awareness raising campaign designed to specifically target the groups in society who are at risk of infection.

86. According to Dr Healy, local education and awareness raising is currently dependent on the enthusiasm and work of the local BBV teams. He states “whilst there has been some success in this regard, it is fair to say that public awareness raising / advertising is not the skill set of these teams”. He notes local awareness raising initiatives that have been carried out such as:

- education of primary care teams;
- awareness raising on World Hepatitis Day;
- engagement with media when Hepatitis C is in the news;
- support for Hepatitis C awareness raising events.

87. However, he says, “impact of these initiatives is uncertain but there is no evidence of a significant impact so far”.

88. Dr Ruth Alcolado advocated targeted rather than more general awareness raising, saying:

“... we need to be really careful about targeting, because when we have put out very generic information, what we tend to get is the worried well. And what we want to do is get out targeted information to targeted client groups—so, the patient level—but also, as I say, to those sorts of health and social care professionals who are likely to be interacting with those groups rather than a more generic awareness-raising campaign.”

89. Dr Giri Shankar also highlighted the need for a focused campaign. He told us that this was not to just say that general awareness raising around liver disease or hepatitis was not needed, but, for this particular risk group, we need specific, tailored messaging. He went on to say:

“...So, if we are considering developing an elimination strategy, the communication bit will be an integral part of that strategy. It is

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49 Written evidence, H03
50 RoP, 17 January 2019, paragraph 241
imperative that we do that in partnership with the voluntary sector and charities as well.\textsuperscript{51}
5. The scope to increase community-based activity

90. According to witnesses, the need to go into the community to proactively seek out “at risk” individuals is crucial, and making treatment available in settings that patients access regularly, as well as removing the need for referral to secondary care is likely to increase treatment uptake.

91. Dr Ruth Alcolado told us:

“...I think the issue for us is that what we’ve done, as you said, is treat those who are already on our books, already engaged with healthcare, and so they’re relatively easy to reach. So, what we’ve got is the more difficult to reach communities, and they are more costly to reach because if you sit in a clinic, you can see seven, eight, nine, 10 people. If you go out into the community, you might only see two in an afternoon. So, there is a cost to moving things out into the community, but it will undoubtedly be necessary if we’re going to hit those targets.”

92. Dr Chinlye Ch’ng agreed, stating:

“Looking at the ABMU health board, my colleagues used to have five patients every week, but now they only have one or two. So, most of these patients are now out in the communities, so we have to certainly send our staff out there, but we just don’t have enough staff to do so.”

93. Community Pharmacy Wales (CPW) say that drug users are “notoriously poor at engaging with NHS and Social Care providers” and recommends that “a comprehensive support service should be made available at every location where there is contact with this vulnerable group and this includes community pharmacy.”

94. It states that where community pharmacies are providing services to drug users they have already developed a degree of rapport and trust with these individuals, and this could form the basis on which to deliver further support through hepatitis testing and treatment.

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52 RoP, 17 January 2019, paragraph 210
53 RoP, 17 January 2019, paragraph 212
54 Written evidence, H01
95. While CPW would be supportive of hepatitis services initially being available from all pharmacies providing sterile injecting equipment and/or a supervised administration service, it says that it is essential that promotion of these services is not limited to current service users:

“Those currently not actively engaged with services such as the homeless and sex workers should be made aware that their community pharmacy provides a walk-in advice, test and treatment service. It is important that all care workers are also aware that they can refer at risk individuals to a community pharmacy for support.”

96. CPW would also wish to see arrangements put in place to encourage local blood borne virus nurses to work in partnership with nominated community pharmacies so that they can operate collaboratively to meet the needs of their local population. CPW therefore recommends that the current Community Pharmacy Collaborative Working Scheme is extended to include local blood borne virus nurses.

97. The Hepatitis C Trust notes that a range of community outreach activity has already been rolled out in Wales, particularly in relation to testing. However, it maintains that there is a need for increased community-based activity to ensure the 2030 elimination target is met. For example, it believes that dried blood spot (DBS) testing must become routine in settings such as substance misuse services and sexual health clinics, where prevalence rates among clients are likely to be higher than among the general public. It states:

“The imminent introduction of routine opt-out BBV testing in substance misuse services is a very welcome development and is a significant opportunity to diagnose and treat more patients. However, with substance misuse services facing significant financial challenges, it is essential that the policy is adequately resourced to ensure sustainability.”

98. The Hepatitis C Trust would encourage more frequent testing in other community-based settings, including pharmacies, homeless hostels, and mosques. It also says peer support programmes should be commissioned to take place in a range of community services to ensure this support is in place.

99. The Trust reasons that with the simplicity of the DAA treatments for hepatitis C making them highly suitable for delivery in the community, there should be a

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55 Written evidence, H01
56 Written evidence, H06
move towards treatment being made available in any setting where testing takes place.

100. Dr Brendan Healy told us:

“We do know, from my perspective, that we need to resource the blood-borne virus teams more effectively to enable them to test and treat in the community. The investment required for that is relatively small. We’re talking specialist nurse level—maybe two community nurses per health board, helped by band 4 level staff.”

101. Written evidence from AbbVie suggests that the introduction of new oral treatments – which offer shorter treatment duration with few side-effects and a high cure rate – have transformed how HCV services can be delivered, but goes on to say:

“… yet treatment in Wales is still predominantly focussed within secondary care and those services that are community-based are fragmented and variable by health board.”

102. Delyth Tomkinson told us that in Cardiff they are fortunate enough to have community BBV nurses who go out on the front line and into the communities where they are needed. However, she went on to say:

“But a lot of my colleagues throughout Wales don’t have the capacity any more to actually do that. So, we need dedicated specialist nurses. We need substance misuse services to actually screen so we can actually treat. So, yes, we need a lot more investment in community teams.”

103. Evidence from the RCN says there are many positive aspects relating to existing community-based activity, including:

- a complete map of community pharmacies across Wales that carry out needle exchange and “Opiate Substitute Therapy” (OST) has been established. A BBV Pharmacist lead for Wales has been recruited to oversee and co-ordinate the national pharmacy projects in BBV screening & treatment. Cardiff have already performed some pilot projects in some community pharmacies with some positive outcomes;

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57 RoP, 17 January 2019, paragraph 259
58 Written evidence, H04
59 RoP, 17 January 2019, paragraph 130
the Harm Reduction Database developed by Public Health Wales as part of their Substance Misuse Programme captures Hepatitis (BBV) activity and risks in the community. Substance misuse services are required to complete these online database forms each time a client/individual is screened for BBVs. This is an ongoing project with progress still to be made but improvements have been seen following biannual Wales network meetings.

104. It goes on to highlight areas where there is scope to increase community-based activity, such as:

- increasing access to portable fibroscanners; one fibroscanner is used and shared by the specialist nursing team across all the community services in Cardiff and Vale for instance. Having access to additional fibroscanners would enable more community clinics to use the technology in patient assessments;

- “point of care testing” (for example via Oraquick mouth swab) can enable teams to provide Hepatitis C antibody results within 30 minutes and initiate diagnosis or further testing and treatment options where required. A virology point of care testing lead based at University Hospital Wales has been able to oversee the roll-out of the scheme across Cardiff & Vale;

- working with homeless people, rough sleepers and other vulnerable groups such as the pilot project run in Cardiff in 2017 in conjunction with the Salvation Army & Cardiff Council night bus. A double-decker bus provided temporary shelter as well as equipment and volunteers to enable screening for BBVs and fibroscans with a view to improving liver health. Having specialist nursing teams with a presence in homeless shelters and hostels, drug and alcohol units, and prisons is also worthwhile;

- harm reduction advice is key to the prevention of acquiring BBVs and individuals at risk should be aware that following eradication, they can be re-infected with the virus if exposed to further risks.

105. It concludes its written evidence by stating that Welsh Government funding for BBV services, medication and awareness raising programmes is essential if the eradication target is to be met.
6. Sustainability concerns for treatment programmes

106. With the cost of DAA treatments having reduced significantly since they came onto the market, the Hepatitis C Trust says it is important that these savings are reinvested back into hepatitis C care. The Trust would like to see Local Health Boards reinvesting money saved on treatment cost reductions into finding individuals living with an undiagnosed infection, providing funding for designated staff and/or peers to support the delivery of testing and treatment in community services, and ensuring adequate staffing in secondary care hepatology teams. As testing rates increase in pharmacies and substance misuse services, there is likely to be a consequent rise in referrals into treatment, which secondary care services must be prepared for.

107. The Hepatitis C Trust says the Welsh Government should also consider developing a new funding arrangement for hepatitis C treatment, which allows for a longer-term, strategic approach and incentivises case finding. With NHS England currently in negotiations with the pharmaceutical industry over a new procurement deal, there may be an opportunity for Wales to follow England’s example if such a deal is agreed. The proposed deal in England is expected to result in longer-term budget certainty for the NHS, introduce a role for the pharmaceutical industry in finding undiagnosed patients and incentivise higher treatment numbers. It feels there would therefore be considerable benefits to Wales in considering such an approach.60

108. Written evidence from Dr Brendan Healy and Public Health Wales states:

“Treatment programmes are currently supported by a combination of Health Board level Blood Borne Virus teams and national roles (National Pharmacist, National Lead for Hepatitis, National Project and Research Lead, National Point of Care Testing Lead). The national roles are supported by the Liver Disease Implementation Group. Funding for those roles is uncertain beyond 2020. If testing and treating is to be upscaled to the point that elimination by 2030 is to be achieved then it is imperative that these roles are sustained beyond 2020.”61

60 Written evidence, H06
61 Written evidence, H03 and H05
In his oral evidence, Dr Healy confirmed that they have not had specific reassurances that this would be the case, and said:

“So, for me, it’s critical that there’s ongoing support for the central roles that we have in place. We’ve had tremendous success with the blood-borne virus plan, which then became part of the liver disease implementation group. The successes of that group are phenomenal in terms of network, equitable, transparent access to care, savings to the NHS around procurement, equitable access for health boards to those savings—so, all health boards getting the same price around medication. And it’s been a huge success.

We’ve got a point of care test lead who works on a national level to increase testing in a variety of environments. We need to have those individuals in place so that we can get those strategies working in all the health boards, and I think it would be very hard to keep that central progress going without those individuals in post.”

Aidan Rylatt also raised concerns about the uncertainty of funding beyond 2020 for these key roles, saying:

“We would certainly be advocating that they should continue beyond that. As I said, it’s certainly not the time to be losing momentum.”

Dr Giri Shankar, however, said he understood that a one year extension had been granted, although there was still uncertainty over what would happen beyond 2021:

“So, it is correct that the liver disease implementation group, which oversees the liver disease delivery plan, is funded until 2020. But, more recently, in the last few weeks, we’ve been given to understand that there will be a further one-year extension to that plan. It is yet to be confirmed in writing to us, but this is what we’ve been given to understand verbally. So, that’s in 2021. But, still, that doesn’t give us clarity of what happens beyond 2021. So, we are in discussions with Welsh Government to see how best to take this forward, through the viral hepatitis sub-group, which links into the liver disease implementation group.”

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62 RoP, 17 January 2019, paragraphs 244-245
63 RoP, 17 January 2019, paragraph 26
64 RoP, 17 January 2019, paragraph 305
Dr Jane Salmon, Consultant in Health Protection, went on to say:

“... clearly, it is something that we are concerned about. I understand that health boards have been drafting business cases to try and attempt to keep the roles that have been supported through the liver disease implementation group maintained within core funding post 2020.”

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65 RoP, 17 January 2019, paragraph 306
7. Conclusions and recommendations

113. We agree with the Hepatitis C Trust that we are presented with a fantastic opportunity to eliminate a disease in Wales, and that with a concerted effort, Wales could even be the first country in the UK to achieve elimination.

114. However it is disappointing that we are not currently on track to meet the 2030 elimination target, and it is very concerning to hear about the uncertainty post 2020/21 in terms of strategy and funding, particularly for dedicated posts. Without urgent action to address these matters, the elimination opportunity will be lost.

115. We agree with witnesses that the elimination of hepatitis C is achievable, but only with a commitment from the Welsh Government to produce a clear elimination strategy without delay, with sustainable funding, ambitious targets, and a workforce plan. There was a strong consensus in the evidence we received that a dedicated strategy and sustained investment is needed to deliver progress.

116. It is also vital that caps are not placed on local treatment targets by health boards, and that it is made clear that these are minimum requirements not maximum targets. As we heard from health board representatives, an aim to exceed the targets should be built into financial planning and budgeting, as this will result in cost savings further down the line.

117. It is clear to us that the need to get out into communities to proactively seek out, test and treat “at risk” individuals is crucial, along with increased funding for testing and treatment in prisons.

118. We welcome the move to opt out testing for Blood Borne Viruses for all those on admission to prison. However, implementation of the opt out testing remains variable due to workforce and capacity issues within prison healthcare. Further, testing levels are still below par, and there is currently a lack of resources for testing in prisons. We believe that further investment is required.

119. We recognise the difficulties in providing clinical services to such a mobile population and the need to get prisoners tested and on a care pathway quickly before they are moved.

120. While prisons are not devolved, prison healthcare is, and the Welsh Government has a clear set of responsibilities in providing health and social care services to prisoners held in Wales. We want to see more effective joint working arrangements between the Welsh Government and Her Majesty’s Prison and
Probation Service to ensure all prisoners receive a high quality prison healthcare service.

121. There is still stigma around the condition and past treatment options. We need to address this, and get the message out there that treatment is simple, safe and effective, with a targeted public awareness campaign.

122. We also note the evidence we heard about the need for protected learning time for health professionals for training and awareness raising. We heard that such training does not need to be time consuming, and can be delivered online.

**Recommendation 1.** We recommend that the Welsh Government produces a comprehensive national elimination strategy for hepatitis C, with clear ambitious targets, and workforce planning built in, and provides sustainable funding until elimination is achieved. This must be done as a matter of urgency, given that the current plan will end this year, and funding for dedicated posts is only confirmed until 2021.

**Recommendation 2.** The strategy must include a targeted awareness raising campaign to reach out to at risk communities and also provide for education and training for health professionals.

**Recommendation 3.** The Welsh Government must write to Local Health Board Finance Directors and Chief Executives to emphasise that national treatment targets for hepatitis C must be considered as minimum targets, to be exceeded wherever possible, if the elimination target of 2030 is to be achieved in Wales.

**Recommendation 4.** We recommend that the Welsh Government provides additional investment to improve Hepatitis C testing in Welsh prisons.