

Hepatitis C inquiry – Evidence from The Hepatitis C Trust

Background

Hepatitis C is a blood-borne virus affecting the liver. Four-fifths of those infected develop chronic hepatitis C, which can cause fatal cirrhosis and liver cancer if untreated. Around 210,000 people are chronically infected with hepatitis C in the UK¹, with 12,000-14,000 of these in Wales².

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, and with the latest figures showing that 50% of injecting drug users in Wales have hepatitis C antibodies³. Other groups who are disproportionately affected include homeless people and migrant communities from countries with a high prevalence of hepatitis C, such as Pakistan and Poland.

With direct acting antiviral (DAA) treatments available without restriction through the NHS in Wales, offering high cure rates with very few side effects, achieving the elimination of hepatitis C by 2030, in line with the Welsh Government's commitment, is an achievable goal. However, with Wales currently falling significantly short of its target to treat 900 patients per year, efforts to find the roughly 50% of patients who remain undiagnosed must become a public health priority to ensure the opportunity of achieving elimination is seized.

Action being taken to meet the requirements of the Welsh Health Circular and 2030 elimination target

There is some encouraging progress being made towards meeting the requirements of the Welsh Health Circular and the elimination target of 2030.

The Hepatitis C Trust welcomes the variety of community outreach pilot projects that have been trialled across Wales, including assessing the effectiveness of testing in GP clinics and within specific populations, such as image and performance enhancing drug users, the homeless community, sex workers and asylum seekers. Initiatives such as these are a valuable way of determining how to most effectively target testing campaigns. The implementation of opt-out testing in prisons has also increased testing rates, and it is to be expected that these rates will continue to increase as the policy is further embedded.

A further positive development is Public Health Wales' ongoing roll-out of a re-engagement exercise for patients diagnosed with hepatitis C in the past but never treated. As noted in the Welsh Health Circular, there is an urgent need to refer these individuals for further testing and treatment to minimise ongoing liver damage, and The Hepatitis C Trust has been pleased to contribute to planning meetings for the exercise to provide the perspective of a patient organisation.

¹ Public Health England, [Hepatitis C in the UK: 2018 report](#), August 2018

² National Assembly for Wales, [Written Assembly Questions tabled on 14 January 2015 for answer on 21 January 2015](#), January 2015

³ Public Health England, Health Protection Scotland, Public Health Wales, and Public Health Agency Northern Ireland, [Shooting Up: Infections among people who inject drugs in the UK, 2017](#), November 2018

The ambition to increase the level of testing and treatment in community pharmacies will be greatly enhanced by the recent appointment of a National Pharmacy Lead. Pharmacies are a particularly effective setting to test for hepatitis C, with many current or former injecting drug users who may not be attending substance misuse services accessing them to collect clean injecting equipment or opioid substitution therapy (OST). Increasing testing in this setting is therefore likely to lead to greater numbers of patients being diagnosed and referred for treatment.

Despite this 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.

The release of the Welsh Health Circular was a very welcome step but The Hepatitis C Trust believes this must now be followed by 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.

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.

Increasing awareness of hepatitis C

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

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 tiredness, loss of appetite, vomiting and abdominal pains as 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.

This lack of public knowledge contrasts markedly with awareness of HIV, which saw huge increases in public awareness following government-backed awareness campaigns and campaigning activity by high-profile individuals. The Hepatitis C Trust would like to see the Welsh Government work with other key stakeholders to develop a nationally coordinated 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. Increasing awareness also helps to reduce stigma, which enables people to feel more comfortable about coming forward to get tested or access treatment. With Public Health Wales implementing a patient re-engagement exercise in late 2018/early 2019 and the UK-wide Infected Blood Inquiry also due to begin hearing evidence in April 2019, a series of awareness campaigns in the first half of 2019 would be well-timed to capitalise on a window of opportunity to raise attention to hepatitis C.

Low knowledge and awareness of hepatitis C is not just an issue among the general public, with myths and outdated messages still often 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.

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. Peer-to-peer support involves people who have themselves had experience of hepatitis C delivering awareness-raising talks to people with backgrounds similar to their own, as well as encouraging and supporting people to access testing and/or treatment. Expanding the use of peers in Wales would be an effective way of increasing knowledge and awareness of hepatitis C among at-risk groups.

Low knowledge and awareness among some health professionals is also an ongoing issue. During interviews and focus groups The Hepatitis C Trust conducted with patients prior to the publication of our *Hepatitis C in Wales: Perspectives, challenges and solutions* report, we were told that they often encountered low levels of knowledge of hepatitis C among 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.

Many patients told us 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.

There have been various initiatives to improve this situation, with Public Health Wales carrying out valuable work to improve professional awareness, HCV Action (coordinated by The Hepatitis C Trust) holding a hepatitis C good practice roadshow for healthcare professionals in Cardiff, and the British Liver Trust running a Liver Disease Event for GPs. However, there is a need for GPs and other primary care workers to be provided with regular information about hepatitis C and presented with opportunities to undertake training on hepatitis C as part of continued professional development to ensure increased levels of awareness and knowledge.

Scope to increase community-based activity

As referred to above, a range of community outreach activity has already been rolled out in Wales, particularly in relation to testing. However, there is a need for increased community-based activity to ensure the 2030 elimination target is met.

For example, 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. 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. The Hepatitis C Trust would also encourage more frequent testing in other community-based settings, including pharmacies, homeless hostels, and mosques.

With the simplicity of the DAA treatments for hepatitis C making them highly suitable for delivery in the community, there should be a move towards treatment being made available in any setting where testing takes place. Making treatment available in settings which patients access regularly and removing the need for referral to secondary care is likely to increase treatment uptake. If elimination is to be achieved by 2030, it is essential that Local Health Boards support community outreach work by funding appropriate staffing to support the delivery of treatment in a range of community settings. Welsh Government support is also likely to be required to facilitate the delivery of treatment in certain community settings, such as pharmacies, where there are unresolved issues regarding how treatments are funded.

An increase in community-based activity can also be supported by making use of peers. Peers are well placed to deliver testing and treatment in community settings and to provide the support and encouragement needed to help patients through the care pathway. For example, between October 2017 and December 2018, The Hepatitis C Trust's Peer Support Lead in South East London made contact with 44 hepatitis C positive patients considered 'hard to reach'. Of the 44 individuals, 42 were successfully supported to engage with treatment (95%). Peer support programmes should be commissioned to take place in a range of community services to ensure this support is in place.

Long-term viability of treatment programmes

The Hepatitis C Trust welcomes the Welsh Government's commitment to providing access to DAA treatments for hepatitis C for all who need them. This approach contrasted favourably with the approach adopted in England, whereby restrictions were placed on the number of patients able to access treatment, which initially resulted in waiting lists in some areas.

However, with treatment targets not being met despite this approach, more must be done to support patients to access treatment. With the cost of DAA treatments having reduced significantly since they came onto the market, it is important that these savings are reinvested back into hepatitis C care. The Hepatitis C 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.

It is also vital that Local Health Boards understand that the national hepatitis C treatment targets are a minimum which they should be aiming to exceed. Anecdotally, The Hepatitis C Trust has heard of Local Health Board Finance Directors discouraging hepatology teams

from exceeding the treatment target due to financial concerns. The Welsh Government must make it clear to Local Health Boards that this approach will result in greater financial costs to Local Health Boards in the long run and is not compatible with Wales achieving elimination by 2030. Indeed, even if the current target of 900 patients being treated per year was being met – which it is not currently – the elimination target would be missed by 18 months. At the current rate of treatment, the elimination target will be missed by a substantial distance. It is therefore essential that Local Health Boards adopt an ambitious approach to treatment, with encouragement from the Welsh Government.

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 funding 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. There would therefore be considerable benefits to Wales in considering such an approach.

Key recommendations

- The Welsh Government to produce 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.
- The Welsh Government to work with other key stakeholders to develop a nationally coordinated series of local awareness-raising campaigns for hepatitis C.
- Peer support programmes to be commissioned in community services.
- GPs and other primary care workers to be provided with regular information about hepatitis C and presented with opportunities to undertake training on hepatitis C as part of continued professional development to ensure increased levels of awareness and knowledge.
- The opt-out blood borne virus testing policy in substance misuse services to be backed with adequate resource to ensure sustainability.
- The Welsh Government to work with all relevant stakeholders to facilitate the delivery of treatment in community settings, including pharmacies.
- Local Health Boards to reinvest money saved on treatment cost reductions into case finding and funding for staff personnel and/or peers to support the delivery of testing and treatment in community services.
- The Welsh Government to write to Local Health Board Finance Directors and Chief Executives to emphasise that treatment targets should be considered a minimum to

be exceeded, rather than a cap not to be exceeded.

- The Welsh Government to consider developing a new funding arrangement for hepatitis C treatment, which allows for a longer-term, strategic approach and incentivises case finding.

Further reading

- The Hepatitis C Trust, [*Hepatitis C in Wales: Perspectives, challenges & solutions*](#), October 2016.
- HCV Action, [*Summary report: Hepatitis C good practice roadshow, Cardiff*](#), December 2017.
- All-Party Parliamentary Group on Liver Health, [*Eliminating Hepatitis C in England*](#), March 2018 [focused on England but has many recommendations also applicable to Wales].