

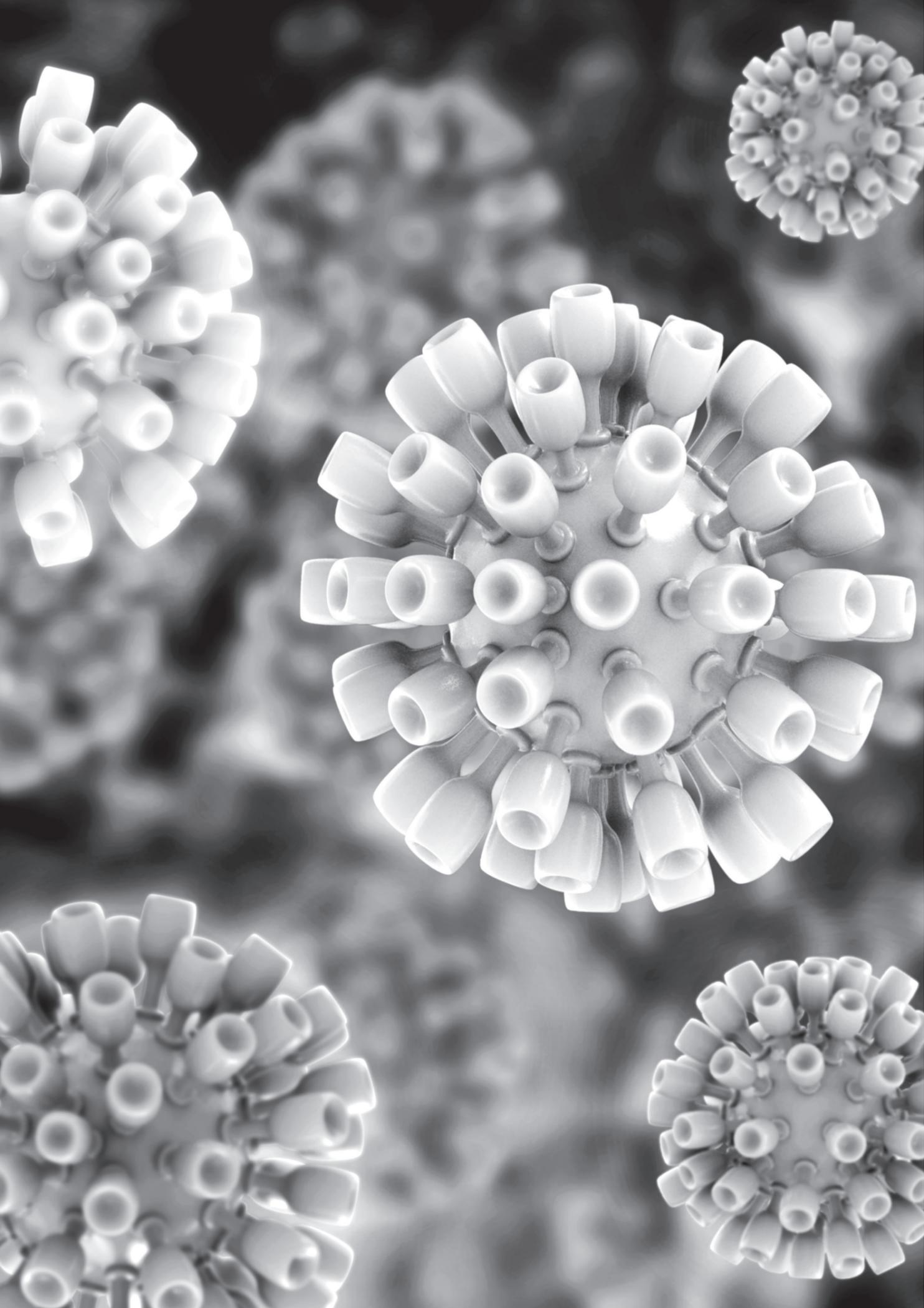
2018

THE HEPATITIS  TRUST

Eliminating Hepatitis C in Scotland: A Call to Action

A summary of evidence from the **Hepatitis C Elimination Inquiry** held by the cross-party **Scottish Hepatitis C Parliamentary Champions** group and **The Hepatitis C Trust**

Report produced by
The Hepatitis C Trust



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Foreword

As committed advocates for the elimination of hepatitis C, we are proud that Scotland has been considered a leader in global efforts to tackle this deadly virus. Successive Scottish Governments have, with cross-party support, ensured that ever-increasing numbers of people in Scotland are tested, diagnosed, treated and cured. With the widespread availability and decreasing cost of all-oral treatments which cure over 95% of people, more people than ever before are accessing hepatitis C care.

Eliminating a public health issue that disproportionately affects some of the poorest and most marginalised groups in our society is an extraordinary and eminently achievable opportunity. However, if Scotland is to achieve elimination of hepatitis C by 2030, in line with our commitment to the World Health Organization (WHO) targets, we must renew our political will.

Through this elimination inquiry we have heard about the challenges to achieving our shared goal of elimination. Large numbers of people are still undiagnosed, and only a small percentage of those infected receive treatment each year. With the benefits of reduced timelines and simplified delivery of treatment comes the renewed challenge of diagnosing thousands of infected people, many of whom will be more difficult to find.

Overly complex care pathways create barriers to accessing treatment, and fragmented, short-term funding models mean there are still waiting lists for treatment in some areas.

Despite these challenges, we remain optimistic. Across the country, the infrastructure, mechanisms, and enthusiasm to improve awareness, prevention, and treatment already exist. What we need now is bold national leadership to co-ordinate, incentivise, and drive innovative practice in finding, diagnosing, and treating new patients. We hope this report will be a first step.

This report brings together the views of leading clinicians, services, charities and patients who participated in our inquiry. Their contributions have told us how we can begin to realise this extraordinary opportunity. We are united in our belief that a hepatitis C-free Scotland is achievable, and in our commitment to working together to make it a reality.

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Recommendations at a glance

Elimination

1. The Scottish Government to determine what elimination means for Scotland, guided by an ambition to relegate hepatitis C to the status of a rare and unusual disease, with any occasional outbreaks resulting in immediate treatment and containment.
2. The Scottish Government to produce a hepatitis C elimination strategy, containing targets for elimination going beyond the global baseline set out in the World Health Organization's Global Health Sector Strategy on Viral Hepatitis. The strategy should include ambitious targets to decrease national incidence and mortality, building on the World Health Organization's plan, as well as absolute numbers for overall prevalence, prevalence in people who inject drugs, incidence of new infections, incidence of end-stage liver disease and mortality.
3. The Scottish elimination strategy to set out detailed plans on how these targets are to be delivered, what actions should be taken to ensure the necessary prevention, diagnosis and treatment, and who is responsible for those actions.
4. The Scottish Government to develop a monitoring framework and produce regular evaluation reports detailing progress towards elimination, echoing the robust monitoring provisions contained in the Hepatitis C Action Plan (2006-2011).

Awareness

5. The Scottish Government to investigate the feasibility of a national awareness campaign.
6. High-profile public figures to use World Hepatitis Day as an opportunity to speak out, publicly highlighting risk factors, the importance of testing and ease of treatment.
7. Awareness-raising messaging to be targeted at users of image and performance enhancing drugs in gyms, men who have sex with men in sexual health services and South Asian communities in religious and community centres.
8. Additional research and pilot projects to be conducted on how to raise awareness effectively about lesser-known risk factors like unsafe medical and dental care or unsafe tattooing practices.
9. Additional training to be delivered to GPs on hepatitis C awareness, both through in-person training sessions and development of online training.

Prevention

- 10.** Adequate provision of sterilised injecting equipment to be made available at community pharmacies and in substance misuse services to meet service users' reported needs.
- 11.** Prevention messages to be targeted at PWID, including via peer-to-peer programmes, delivered through the expansion of existing recovery voluntary programmes in substance misuse services, as well as in prisons.
- 12.** Interventions designed to educate at-risk patients about the dangers of reinfection to be developed and embedded as an integral part of the treatment process.
- 13.** All healthcare workers undertaking exposure-prone procedures who were working before the introduction of mandatory testing in 2007 to be tested for hepatitis C.
- 14.** If research pilots currently being undertaken at NHS Tayside and in Australia investigating a 'treatment as prevention' model prove this to be an effective approach, integrate this model into the national elimination strategy.

Testing and Diagnosis

- 15.** Introduction of opt-out testing for hepatitis C in substance misuse services, with commissioning contracts stipulating clear mechanisms to hold services to account for failures to meet testing targets.
- 16.** The Scottish Government to research and assess cost-effectiveness of innovative approaches to finding undiagnosed patients, such as:
- Screening in needle exchange services and pharmacies providing OST.
 - Screening in GP clinics in areas of high prevalence.
 - Using screening programmes in other disease areas as an opportunity to add hepatitis C screening at low cost.
 - Opt-out screening for any patients with bloods taken in A&E departments.
 - Providing incentives to people to bring peers for testing.
 - Offering testing at the end of peer-to-peer talks.
 - Introducing informatics analysis and algorithms in primary care clinics to identify at-risk individuals.
 - At-home testing kits.
- 17.** National guidance to be issued on effective implementation of opt-out testing in prisons to overcome wide variations in test acceptance.
- 18.** Workforce training on hepatitis C to be part of continued professional development (CPD) for substance misuse workers and community pharmacy staff to ensure they are confident providing key messages and delivering testing.
- 19.** Increased communication of test results between services and the development of a database of diagnosed patients.

Linkage to care

- 20.** Secondary care services to accept direct referrals from substance misuse services, pharmacies and peers, as well as from GPs.
- 21.** Health boards and/or hospitals to undertake look-back work to re-engage those diagnosed but lost to follow-up, and to enrol them into treatment.
- 22.** Peer support to be provided to newly diagnosed individuals to reduce risk of disengagement.

Access to treatment

- 23.** Treatment cost reductions to be reinvested into additional treatments or services to ensure access to treatment is available immediately to all who need it.
- 24.** Money saved on VAT by delivering treatment in the community to be directly reinvested into treatment budgets or services to ensure treatment is available immediately to all who need it.
- 25.** Clinicians to be encouraged to exceed treatment targets, which must not be considered a cap by health boards.
- 26.** Treatment to be delivered in community settings, such as substance misuse services, community pharmacies and primary care centres.
- 27.** Availability of hepatitis C treatments in prison to be increased, and resources made available to ensure prison healthcare staff have capacity to deliver effective hepatitis C care. Appropriate follow-up support to be made available to those released from prison with an untreated infection.

Funding

- 28.** Additional research to be conducted exploring the link between hepatitis C treatment and positive behavioural change such as reduced reoffending or addiction recovery.
- 29.** The Scottish Government to explore alternative treatment funding models offering the opportunity to rapidly increase the number of patients receiving treatment.
- 30.** Targeted additional investment to be made as part of a cost-effective national strategy, resulting in significant cost savings from reduced liver transplants and liver disease, as well as prevention of harmful drug use and other risky behaviours.

Background on hepatitis C in Scotland

Hepatitis C is a blood-borne virus that primarily affects the liver, and can cause fatal cirrhosis and liver cancer if left untreated. Hepatitis C can also have a much broader impact and has been linked to cardiovascular disease, mental health issues, kidney problems, and musculoskeletal pain. It is transmitted through blood-to-blood contact, and disproportionately affects marginalised and disadvantaged groups, such as people who inject drugs (PWID), homeless people, men who have sex with men (MSM), and migrant communities from endemic countries. These groups are not the only ones at risk: significant numbers were infected by the NHS through infected blood and blood products.

People infected with hepatitis C often experience few or no symptoms, which can result in them living with the virus for many years without being diagnosed, increasing the risk of severe liver damage. Crucially, hepatitis C is preventable, treatable and curable for the vast majority of people. New treatments are now available, with short treatment durations, limited side-effects and cure rates upwards of 95%.

Scotland has long been regarded as a world leader in tackling hepatitis C. The Hepatitis C Action Plan (2006-2011) and the current Sexual Health and Blood Borne Virus Framework (2015-2020) are considered to be models of international good practice and have led to significant increases in the numbers of people diagnosed and treated in Scotland over the past decade.

Recent estimates suggest that around 34,500 people are chronically infected with hepatitis C in Scotland, with more than 40% remaining undiagnosed. Of those diagnosed, many are not in touch with services and need to be reconnected to the service pathway. In 2016/17, 1,739 people commenced treatment for hepatitis C, slightly lower than the total for 2015/16¹. Worryingly, the incidence of hepatitis C infections among people who inject drugs in 2015/16 was reported as almost double that of 2011/12².

¹ Scottish Government, 13 Nov 2017.
<<http://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-12382&ResultsPerPage=10>>

² Scottish Government, 11 May 2017.
<<http://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-08842&ResultsPerPage=10>>

Background to the elimination inquiry



In September 2015, the same month that Scotland hosted the inaugural World Hepatitis Summit, the Scottish Government published the Sexual Health and Blood Borne Virus Framework 2015-2020, a strategy that contained an explicit commitment to the elimination of hepatitis C. This commitment marked a watershed moment in Scotland's hepatitis C journey and reinforced the country's status as a global leader in tackling the virus.

In May 2016, the United Kingdom joined 193 other member states in signing up to the World Health Organization Global Health Sector Strategy on Viral Hepatitis, which commits participating countries to the elimination of hepatitis C as a major public health threat by 2030. This commitment included signing up to targets of a 90% reduction in incidence of chronic hepatitis C infections and a 65% reduction in mortality from hepatitis C by 2030. The strategy also contains service coverage targets for 2030, including 80% of those eligible being treated and 300 sterile syringe and needle sets distributed per year to improve harm reduction.

To move towards elimination, the WHO set interim targets of a 30% reduction in infections and a 10% reduction in mortality by 2020. These targets are a global baseline, but many countries and regions have developed bespoke elimination strategies with more ambitious targets to address infection among key populations.

In May 2017, with the support of the cross-party Hepatitis C Parliamentary Champions, The Hepatitis C Trust launched an inquiry to map progress towards the Scottish Government's world-leading commitment to hepatitis C elimination, and develop recommendations to ensure elimination is achieved.

World Health Organization Global Health Sector Strategy on Viral Hepatitis service coverage targets for the elimination of HBV and HCV as public health threats, 2015-2030

Target areas		Baseline 2015	2020 target	2030 target		
Service Coverage	Prevention	1. Three-dose hepatitis B vaccine for infants (coverage %)	82%	90%	90%	
		2. Prevention of mother-to-child transmission of HBV: hepatitis B birth-dose vaccination or other approaches (coverage %)	38%	50%	90%	
		3. Blood and injection safety (coverage %)	Blood safety: donations screened with quality assurance	89%	95%	100%
			Injection safety: use of engineered devices	5%	50%	90%
	4. Harm reduction (sterile syringe/needle set distributed per person per year for people who inject drugs [PWID])	20	200	300		
	Treatment	5a. Diagnosis of HBV and HCV (coverage %)	<5%	30%	90%	
5b. Treatment of HBV and HCV (coverage %)		<1%	5 million (HBV) 3 million (HCV)	80% eligible treated		
Impact leading to elimination	Incidence of chronic HBV and HCV infections		6-10 million	30% reduction	90% reduction	
	Mortality from chronic HBV and HCV infections		1.46 million	10% reduction	65% reduction	

The inquiry consisted of two oral evidence sessions, on 14th and 20th June 2017, that brought together individuals and organisations working across the hepatitis C patient pathway to give evidence to the Hepatitis C Parliamentary Champions. The first session involved individuals working in frontline services and focused on the day-to-day challenges of preventing new infections and testing, diagnosing and treating people with hepatitis C. The second session involved individuals working in more managerial roles, and focused on some of the strategic barriers to eliminating hepatitis C.

As well as staging two oral evidence sessions, The Hepatitis C Trust also requested and received written evidence from individuals and organisations interested in providing their perspectives on how the elimination of hepatitis C in Scotland can be achieved.

This report draws together the evidence into a summary of action needed to achieve elimination, looking in detail at:

1. Elimination strategy
2. Awareness
3. Prevention
4. Testing and diagnosis
5. Linkage to care
6. Access to treatment
7. Funding

Summary of evidence and recommendations

Elimination strategy

Scotland has previously been regarded as a world leader in tackling hepatitis C, but contributors felt that a renewed effort is needed if Scotland is to eliminate hepatitis C by 2030. There was general agreement

“Scotland is seen as the leading light across the world in terms of tackling hepatitis C. We have to carry that on.”

that Scotland is not on track to achieve elimination by 2030 based on current testing and treatment rates.

Contributors argued that a dedicated Scottish Government strategy is therefore needed to ensure elimination is achieved, setting out detailed plans to identify, test and treat more patients, with provision for regular monitoring and evaluation of progress. Such a strategy should also quantify levels of prevalence, incidence, and mortality that would constitute elimination in Scotland, with ambitious targets that go beyond the WHO commitments.

A national elimination strategy should aspire to be an international example of good practice to which other nations can look for guidance and inspiration in progressing their own hepatitis C strategies.

The remainder of this report looks in more detail at the steps that need to be taken in relation to prevention, testing, diagnosis and treatment for Scotland to achieve elimination.

Steps towards elimination – recommendations:

1. The Scottish Government to determine what elimination means for Scotland, guided by an ambition to relegate hepatitis C to the status of a rare and unusual disease, with any occasional outbreaks resulting in immediate treatment and containment.
2. The Scottish Government to produce a hepatitis C elimination strategy, containing targets for elimination going beyond the global baseline set out in the World Health Organization’s Global Health Sector Strategy on Viral Hepatitis. The strategy should include ambitious targets to decrease national incidence and mortality, building on the World Health Organization’s plan, as well as absolute numbers for overall prevalence, prevalence in people who inject drugs, incidence of new infections, incidence of end-stage liver disease and mortality.
3. The Scottish elimination strategy to set out detailed plans on how these targets are to be delivered, what actions should be taken to ensure the necessary prevention, diagnosis and treatment, and who is responsible for those actions.
4. The Scottish Government to develop a monitoring framework and produce regular evaluation reports detailing progress towards elimination, echoing the robust monitoring provisions contained in the Hepatitis C Action Plan (2006-2011).

Awareness

Stigma and lack of awareness of hepatitis C remains an ever-present challenge. Contributors agreed that stigma has decreased in the last ten years, but it was reported as being still highly prevalent, and considered more significant among some groups than the stigma attached to HIV. The effect of such stigma can be to prevent individuals from accessing testing for the virus, with some refusing to even consider the idea that they could be infected due to fear of being stigmatised if diagnosed.

One contributor said that patients' perception of stigma is often influenced by the environment in which they access care. In substance misuse services, where there is good availability of testing (often delivered by non-clinical staff), staff have an opportunity to build lasting positive relationships with users and integrate hepatitis C treatment into a broader addiction recovery plan. This serves to increase the take-up of testing, decrease the effects of stigma on the individual, and decrease stigmatising attitudes within the PWID community.

It was recognised that there still remains a low awareness of hepatitis C among GPs, due to the fact that symptoms of hepatitis C are often non-specific and easy to misdiagnose. There can be a reluctance to test patients presenting with possible symptoms due to their vagueness, and it was felt that testing needed to be normalised through greater clinical awareness.

Contributors believed that a targeted awareness campaign towards users of image and performance enhancing drugs was needed, with knowledge of hepatitis C often low among this at-risk group. Providing information in gyms and beauty clinics about the risks of using unsterilised needles, through peer talks and written resources, would likely be an effective way of raising awareness among this group. Likewise, information should be provided in sexual health services to men who have sex with men (MSM) who may be at risk of transmission, with awareness of hepatitis C often lower than awareness of HIV among this group.

Other at-risk groups include the South Asian community, which has a high prevalence of hepatitis C due to widespread re-use of needles and razors in some South Asian countries, and people who receive unsafe medical and dental care or tattoos, often delivered abroad. There was agreement that people at risk in these groups are more diffuse and therefore harder to locate, target for awareness-raising, and test. It was suggested that additional research and evaluated pilot projects be commissioned to investigate how best to raise awareness of hepatitis C in these risk groups.

Awareness campaigns should be carefully crafted with the involvement of service-users to deliver messaging that is empowering and supportive. Contributors relayed that stigma surrounding hepatitis C often overlaps with stigma about injecting drug use, with addiction often still seen as an avoidable personal fault, leading to harmful assumptions regarding peoples' character and circumstances.

It was noted that a national awareness campaign would be desirable, but would need to have Government backing and funding attached to make a measurable impact. Contributors recalled the national HIV/AIDS public education campaigns of the 1980s, which included highly recognisable branding in adverts and leaflets distributed nationally. This campaign was seen to be highly effective and a significant contributing factor to the reduction in prevalence and incidence of HIV over the last few decades. The cost-effectiveness of such a campaign would need to be assessed. Cost considerations should take into account that such a campaign could also contribute to implementing the single recommendation of the Penrose Report into contaminated blood: "That the Scottish Government takes all reasonable steps to offer an HCV test to everyone in Scotland who had a blood transfusion before September 1991 and who has not been tested for HCV"³.

An estimated 800 people in Scotland are living with HIV and unaware of their status, compared with over 15,000 people who are estimated to be unaware of their hepatitis C-positive status⁴. It was felt that Scotland should aspire to at least an equivalently low number of people living with an undiagnosed infection of hepatitis C, and that strong national awareness campaigns would be a powerful contributor to achieving this goal.

Awareness - conclusion and recommendations:

Combating stigma and increasing awareness of hepatitis C across the population should be a continual endeavour. Particular attention should be given to raising awareness within groups where the risk factors may be lesser-known, and communities less networked. We must also recognise that awareness can still be low among clinicians, and ensure they have the necessary information to pro-actively test and treat patients.

5. The Scottish Government to investigate the feasibility of a national awareness campaign.
6. High-profile public figures to use World Hepatitis Day as an opportunity to speak out, publicly highlighting risk factors, the importance of testing and ease of treatment.
7. Awareness-raising messaging to be targeted at users of image and performance enhancing drugs in gyms, men who have sex with men in sexual health services and South Asian communities in religious and community centres.
8. Additional research and pilot projects to be conducted on how to raise awareness effectively about lesser-known risk factors like unsafe medical and dental care or unsafe tattooing practices.
9. Additional training to be delivered to GPs on hepatitis C awareness, both through in-person training sessions and development of online training.

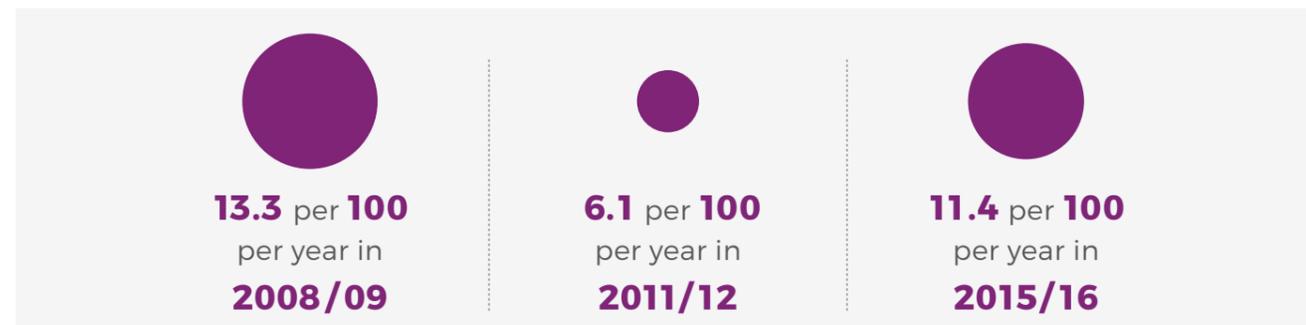
³ The Penrose Inquiry Final Report, March 2015, <http://www.penroseinquiry.org.uk/finalreport/pdf/penrose_inquiry_final_report.pdf>

⁴ Health Protection Scotland, November 2017, <http://www.hps.scot.nhs.uk/ewr/article.aspx?id=76467&wrttype=2>

Prevention

For Scotland to achieve the elimination of hepatitis C by 2030 (or sooner), it is essential that new infections are prevented. There is a lack of reliable estimates of new hepatitis C infections in the general population, and additional investment in surveillance and modelling is necessary. Health Protection Scotland reports that following a decline in hepatitis C incidence among PWID from 13.3 per 100 per year in 2008/09 to 6.1 per 100 per year in 2011/12, rates have now increased again to 11.4 per 100 per year in 2015/16⁵, a concerning development.

Infections among PWID



Most new hepatitis C infections are the result of the sharing of injecting equipment among people who inject drugs (PWID). Contributors to the oral evidence sessions felt the most desirable way of preventing new hepatitis C infections is preventing people taking drugs in the first place. Problem drug use is a national challenge and a significant driver of many inequalities and poor health outcomes, but a full discussion of policy measures aimed at preventing drug use was beyond the scope of the inquiry. We were told that one immediate and effective way of preventing new infections among PWID is the provision of opioid substitution therapy (OST). Helping service users to transition to OST from injecting drugs removes the risk of hepatitis C transmission through the sharing of injecting equipment.

Another important measure for preventing new infections among PWID is investment in needle and syringe programmes (NSP) that provide other injecting equipment, such as filters, spoons and water, as well as needles and syringes. Such programmes help to reduce the risk of hepatitis C transmission through the sharing of injecting equipment. However, current levels of NSP were reported as being inadequate – a view supported by data from the Needle Exchange Surveillance Initiative, which revealed that PWID reported receiving fewer sterile needles/syringes, filters and spoons in 2015-16 than in 2013-14⁶. Increased provision of injecting equipment was therefore felt to be an important measure to prevent further hepatitis C infections.

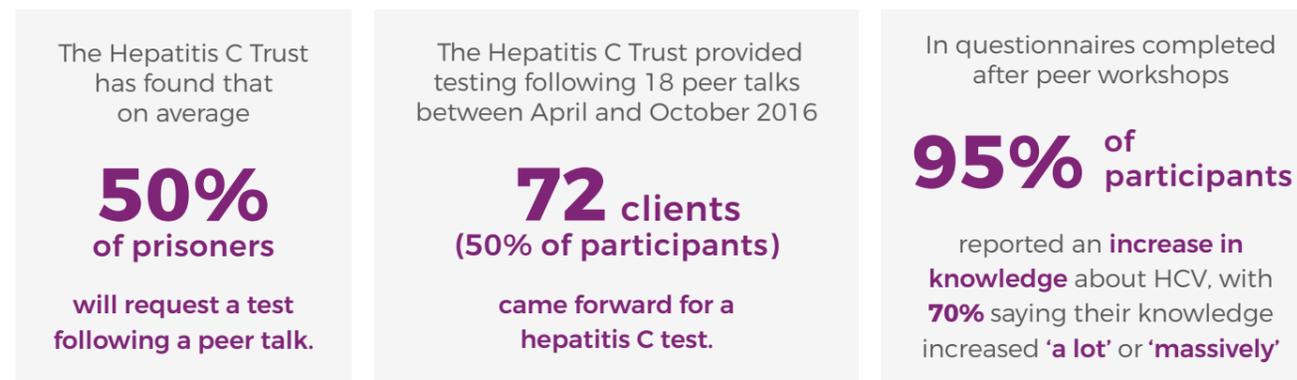
The role of substance misuse services in prevention was widely acknowledged, with such settings regarded as important providers of harm reduction messaging, in addition to the prevention benefits of supporting patients to transition to OST and providing NSP. However, contributors noted that budget cuts are presenting significant challenges to local Alcohol and Drug Partnerships (ADPs). Half of all health board areas reduced budgets for ADPs in 2016/17 compared with 2015/16, with an average decrease of 10%⁷. A further four health board areas kept budgets at the same level, with just two areas

delivering an increase. There was widespread agreement that substance misuse services would need additional resources in order to play an increased role in preventing new infections of hepatitis C.

The recent increase in new hepatitis C infections among PWID was attributed by some inquiry participants to users of new psychoactive substances (NPS), often colloquially referred to as 'legal highs'. The Scottish Government reports that drug related deaths where NPS were present at the time of death have risen from four deaths in 2009 to 112 deaths in 2015⁸. The same report notes that interviewees who were actively injecting NPS reported incidences of equipment sharing and poor injecting technique, and this was echoed in the inquiry, with participants reporting that this new cohort of PWID tends to be less well informed about harm reduction and the risks of hepatitis C. While it was reported that the number of users of NSP is beginning to decline, it is important that information is targeted at this cohort if the increase in new infections is to be reversed.

The use of peers to disseminate key messages around prevention is seen as an effective intervention. This is particularly the case for PWID, with messages often being seen to have greater validity when delivered by someone who has had comparable experiences to the recipient. Existing peer-to-peer projects have had good results, with contributors highlighting a peer-to-peer project by The Hepatitis C Trust and substance misuse charity Addaction called 'Talk and Test', where testing was provided directly following 18 peer talks between April 2016 and October 2016. Following these workshops, 72 clients (50% of participants) came forward for a hepatitis C test. In questionnaires completed after peer workshops facilitated by The Hepatitis C Trust, 95% of participants reported an increase in knowledge about HCV, with 70% saying their knowledge increased 'a lot' or 'massively'⁹.

Knowledge of hepatitis C following The Hepatitis C Trust's peer-to-peer workshops



Peer messaging was also considered to be an effective method of raising awareness among people in prison, where prevalence is extremely high, with 19% of Scottish prisoners found to be hepatitis C-positive in a 2012 study¹⁰. The Hepatitis C Trust has found that on average 50% of prisoners will request a test following a peer talk. Contributors felt that increasing the use of peers to share messages around safe injecting and harm reduction should be a key part of hepatitis C prevention efforts in Scotland, and that funding should therefore be provided to expand peer programmes in substance misuse services and prisons.

⁵ Scottish Government, 11 May 2017. <<http://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-08842&ResultsPerPage=10>>.

⁶ NHS Scotland; Needle Exchange Surveillance Initiative, 2008-09 to 2015-16; March 2017. <<http://www.hps.scot.nhs.uk/resourcedocument.aspx?id=5863>>.

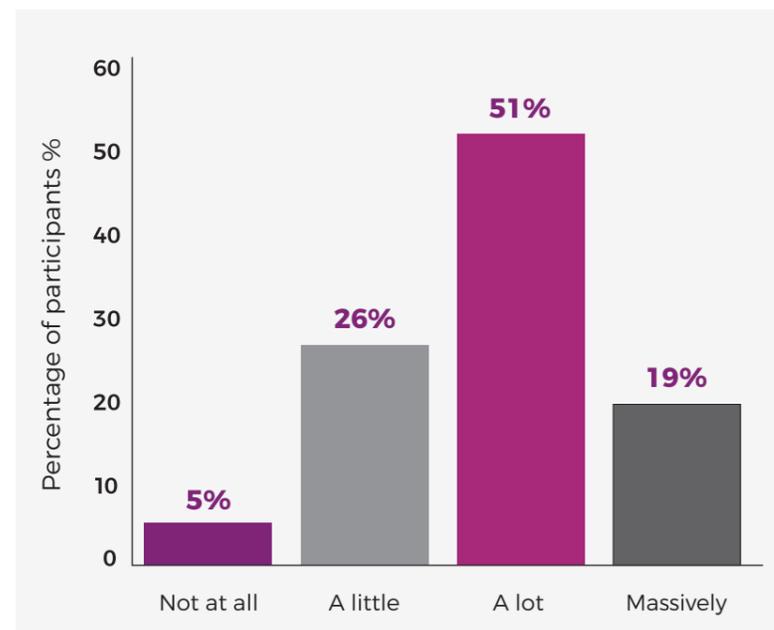
⁷ Scottish Drugs Forum; Drug and Alcohol Services Funding Timeline 2015-17. <<http://www.sdf.org.uk/wp-content/uploads/2017/09/CPC-ADP-Funding-Timeline-2.pdf>>.

⁸ Scottish Government: Understanding the patterns of use, motives, and harms of new psychoactive substances in Scotland; Nov 2016. <<https://beta.gov.scot/publications/understanding-patterns-use-motives-harms-new-psychoactive-substances-scotland/pages/16/>>.

⁹ HCV Action: Good Practice Case Study: South West HCV Peer-to-Peer Education; April 2017. <<http://www.hcvaction.org.uk/resource/good-practice-case-study-south-west-peer-peer-education>>

¹⁰ University of Bristol, University of the West of Scotland, and NHS Scotland; Hepatitis C Prevalence and Incidence among Scottish Prisoners and Staff Views of its Management; May 2012. <<http://www.hcvaction.org.uk/resource/hepatitis-c-prevalence-and-incidence-among-scottish-prisoners-and-staff-views-its>>

Reported increase in knowledge of HCV after peer workshops



Whilst the vast majority of hepatitis C transmission is through the sharing of equipment for injecting drugs, it was also recognised by contributors that prevention measures are needed for other potential transmission routes.

An additional recommendation was to extend mandatory testing to all healthcare workers undertaking exposure-prone procedures, including those who were working before the introduction of mandatory testing in 2007. Given the nature of such work, these individuals are more likely than others to have come into contact with the virus and could then be transmitting it to other patients. Treating any workers who are found to be hepatitis C-positive would be an important method of prevention.

More broadly, the most effective method of preventing new infections is to treat people already carrying the virus, particularly those most likely to transmit to others, namely PWID. The 'treatment as prevention' approach is therefore an essential element of an effective elimination strategy, and will be outlined in further detail in the 'treatment' section.

Prevention – conclusion and recommendations:

Prevention measures are a crucial element of any elimination strategy. In order to prevent new infections and reinfection, messaging around reducing the risk of transmission must be targeted at key groups. In addition, programmes aiding prevention, such as the provision of injecting drug equipment, must be adequately resourced.

- 10.** Adequate provision of sterilised injecting equipment to be made available at community pharmacies and in substance misuse services to meet service users' reported needs.
- 11.** Prevention messages to be targeted at PWID, including via peer-to-peer programmes, delivered through the expansion of existing recovery voluntary programmes in substance misuse services, as well as in prisons.
- 12.** Interventions designed to educate at-risk patients about the dangers of reinfection to be developed and embedded as an integral part of the treatment process.
- 13.** All healthcare workers undertaking exposure-prone procedures who were working before the introduction of mandatory testing in 2007 to be tested for hepatitis C.
- 14.** If research pilots currently being undertaken at NHS Tayside and in Australia investigating a 'treatment as prevention' model prove this to be an effective approach, integrate this model into the national elimination strategy.

Testing and diagnosis

Increasing testing among at-risk groups

While testing rates have increased in recent years, the number of patients diagnosed has decreased in both 2015 and 2016 compared with the previous year, suggesting efforts to find undiagnosed patients may be stalling.

Sustained targeting of at-risk groups for testing was considered vital by our witnesses, with repeat testing in substance misuse services and needle exchange services mentioned as an important way of identifying new cases. Widespread testing in these settings was also felt to be important from a public health perspective, with PWID being an important group to diagnose and treat, due to the increased likelihood of onward transmission. Contributors suggested that substance misuse services should be mandated to carry out hepatitis C testing on an opt-out basis, with commissioning contracts stipulating clear mechanisms to hold services to account for failures to test sufficient numbers of clients.

Witnesses highlighted NHS Tayside's project offering repeat testing to PWID as an example of good practice in implementing and normalising sustained testing. 1,866 individuals have been tested as part of the project, with a considerable proportion of individuals returning for repeat testing (around 40% of previous hepatitis C-negative patients returned for additional tests). A critical factor in the success of the project is the work of NSP providers in testing service users, reaching a key at-risk group who may not be accessing other services (see case study 1).

Despite the Government committing to the implementation of opt-out testing in Scottish prisons in 2015, prison testing rates were reported as being sub-optimal and highly variable. In data on testing in prisons collected via Freedom of Information requests, a significant increase in tests conducted in prisons following the opt-out policy was evident in some health boards, but not in others. Additionally, even in health boards where testing has increased, the number of people initiated into treatment has not risen accordingly, suggesting a lack of linkage into the care pathway. Contributors felt this was attributable to low levels of understanding of how testing should be offered among some prison staff members, with further guidance for staff recommended. This failure to properly implement opt-out testing was regarded as a missed opportunity, given the high prevalence of hepatitis C among the prison population and the opportunity to treat an often difficult-to-reach population while they are in touch with services.

Contributors also emphasised the need to widen testing to people who are not accessing substance misuse services because their drug use is historic (some may have only injected once or twice many years ago). As these individuals are more likely to have been carrying the virus for a long time, and are consequently more likely to have developed severe liver damage, it is crucial that they are diagnosed. With primary care the most likely setting to diagnose this cohort, increasing awareness of hepatitis C among GPs (as well as among those at risk) is vital.

In order to target testing most effectively, it was recommended that analysis should be conducted into the areas of highest prevalence, with screening to be introduced in GP clinics in those areas. One contributor suggested that such work could be combined with NHS Health Scotland's 'Keep Well' programme, which targets healthcare at individuals aged between 40 and 64 living in areas of high deprivation, as such areas often have higher rates of hepatitis C infection. Whilst central funding for 'Keep Well' has recently been withdrawn, some health boards are continuing the campaign locally.

In addition to GP clinics, contributors identified other settings where screening programmes could



be introduced. Community pharmacies were identified as an important location to increase testing, with screening recommended for those accessing pharmacies for NSP or to receive OST. As this group is particularly at risk of having contracted hepatitis C, introducing screening is likely to be a cost-effective approach to diagnosing more patients.

Targeted opt-out testing of routine blood samples in A&E departments was also mentioned as an innovative way to test large sections of the population. A ground-breaking 2015 campaign called 'Going Viral' offered routine testing in nine UK emergency departments (including one in Glasgow) for one week. Of 7,800 patients who had bloods taken across the emergency departments, 2,118 people were tested, an uptake of 27%. Of those tested, 3% were infected with hepatitis C, with 71 infections found over the course of the week¹¹. While some of these may have been people who had previously tested positive, this was also seen as an effective way to re-engage people who were previously diagnosed but lost to follow-up.

¹¹ Quality in Care, 'Going Viral': Hepatitis C/B/HIV testing in 9 Emergency Departments, 2015: http://www.qualityincare.org/hepatitis-c/case_studies/going_viral_hepatitis_c_b_hiv_testing_in_9_emergency_departments

Case study 1: NHS Tayside diagnosis rates

NHS Tayside has had a whole-systems approach to the elimination of hepatitis C since 2008, when Phase II of the Hepatitis C Action Plan for Scotland was published. It is estimated that over 80% of the infected population in the Tayside region has been diagnosed.

In order to achieve this, NHS Tayside used peers to engage with at-risk groups and implemented dry blood spot testing in all key community settings, including needle exchanges, substance misuse services and prisons, finding the greatest uptake in services providing needle and syringe programmes. An ongoing development in efforts to diagnose patients is roll-out of testing in community pharmacies for those receiving opioid substitution therapy. Most testing is undertaken by trained non-clinical service workers, many working for third sector organisations. NHS Tayside see training third-sector workers as crucial to reaching at-risk populations who may not have links to the NHS but have established relationships with community services.

NHS Tayside has also implemented a programme of proactive case-finding in general practice, initiated by a group of engaged GPs who thought more could be done to link general practice and specialist services. Every practice has performed a data reconciliation exercise, comparing practice-level information with data on hepatitis C testing and diagnosis held in the specialist services database. Any individuals who were previously tested but were lost to follow-up or unaware of their status were contacted and recalled.

GPs also agreed to review their entire practice populations to identify individuals at high risk based on their past medical history, and invited them in for testing. A pilot of universal testing for all new patients in Dundee City had a very high participation rate, and was subsequently rolled out to Angus.

NHS Tayside has also engaged in significant outreach to ethnic minority groups in an attempt to reach the South Asian community, in which there is a high prevalence of hepatitis C. Starting in 2009 and sustained over several years, a concerted effort was made to reach out to three mosques in the region, and a strong relationship established with the local imam. A lead clinician spoke multiple times on Radio Ramadan to raise awareness of risk factors. Outreach testing sessions implemented in all three mosques were met with enthusiasm, with an estimated 90% of the Pakistani population in the region having now been tested.

Overcoming barriers to testing

It was noted that there are often insufficient levels of testing in non-clinical settings. Staff in these services often have strong personal relationships with their clients and are therefore best placed to engage them in testing and, if they test positive, support them into care. However, testing in substance misuse services is still at sub-optimal levels, partly due to funding challenges, but also due to a lack of staff championing the importance of testing for hepatitis C. For example, one contributor noted that many substance misuse service workers have backgrounds in social care rather than healthcare, which can mean that the health needs of clients are not given sufficient priority.

Contributors therefore highlighted the importance of training non-clinical staff, including key workers in substance misuse services and community pharmacy staff, to provide information and deliver testing. An effective way to ensure staff training for on-site hepatitis C testing is fully embedded into substance misuse services is for local authorities to include training and testing outcomes in service commissioning contracts. This would ensure that testing in the community was prioritised, and would allow services to plan for and request the resources necessary to deliver training and testing targets.

There was recognition from witnesses that hepatitis C may not be an obvious priority for people accessing substance misuse services, who are often living with other significant challenges, such as mental health issues and homelessness, as well as their drug use. However, these people may be living with hepatitis C which could have progressed to cirrhosis or liver cancer without their knowledge. The

“We are often dealing with very vulnerable people leading quite transitory lives. If treatment isn’t available at the point of diagnosis then we very often lose them. It’s quite simple. These people have a million other issues in their life that take precedence, so we have to treat them while they’re engaged, even if it’s for a very narrow window. If you miss that window, they’re gone.”

their lives, such as substance misuse and mental health issues. Taking the first step towards addressing health and wellbeing issues can provide the confidence and motivation to begin to deal with other problematic areas. It is important that substance misuse staff are aware that addressing hepatitis C can be part of the wider rehabilitation process, and are able to convey this to service users and to commissioners.

Contributors noted that one of the main barriers to people engaging in testing is lack of access to treatment (with treatment budgets restricting the number of patients able to access treatment). One contributor noted that some individuals, particularly those living chaotic lives, can be put off accessing testing if they believe there will be significant delays in being enrolled into treatment should they be diagnosed as positive. Another witness noted the increase in the number of people accessing testing for HIV after treatment for managing the condition became available. Expanding the availability of treatment for hepatitis C could therefore have the additional benefit of increasing the number of people accessing testing.

importance of staff feeling confident in advocating for, and carrying out, testing for hepatitis C was therefore felt to be significant, with workforce training key to securing this.

In addition to the direct physical health benefits, treatment for hepatitis C often allows patients to address other problematic aspects of

Communication of test results

We were told that there are often problems around the communication of test results, which can prevent patients from being informed of their diagnosis. A lack of communication between prisons, substance misuse services and GPs can result in patients falling out of the care pathway when they move between services. This can also lead to duplication of testing, with anecdotal information suggesting that people who serve frequent short prison sentences are often repeatedly tested, with no database to record who has received a test and who tested positive. An elimination strategy must therefore include measures to improve communication of test results between prisons, substance misuse services and GPs, with an integrated database to register those tested and/or diagnosed proposed.

Testing and diagnosis – conclusion and recommendations:

Testing rates must increase in order to diagnose and treat more patients. Measures to increase testing should include requirements in commissioning contracts for substance misuse services to test clients on an opt-out basis, and the distribution of Government advice on effectively implementing opt-out testing in prisons. In addition, new and innovative approaches to increasing testing are required, with research needed into the most cost-effective schemes to diagnose more patients.

15. Introduction of opt-out testing for hepatitis C in substance misuse services, with commissioning contracts stipulating clear mechanisms to hold services to account for failures to meet testing targets.

16. The Scottish Government to research and assess cost-effectiveness of innovative approaches to finding undiagnosed patients, such as:

- Screening in needle exchange services and pharmacies providing OST.
- Screening in GP clinics in areas of high prevalence.
- Using screening programmes in other disease areas as an opportunity to add hepatitis C screening at low cost.
- Opt-out screening for any patients with bloods taken in A&E departments.
- Providing incentives to people to bring peers for testing.
- Offering testing at the end of peer-to-peer talks.
- Introducing informatics analysis and algorithms in primary care clinics to identify at-risk individuals.
- At-home testing kits.

17. National guidance to be issued on effective implementation of opt-out testing in prisons to overcome wide variations in test acceptance.

18. Workforce training on hepatitis C to be part of continued professional development (CPD) for substance misuse workers and community pharmacy staff to ensure they are confident providing key messages and delivering testing.

19. Increased communication of test results between services and the development of a database of diagnosed patients.

Linkage to care

Once patients have been diagnosed, it is vital that they are referred and supported into care quickly, to ensure they go on to receive treatment and cure. However, a number of issues with linkage to care following diagnosis were reported by participants in the inquiry.

One example raised by contributors was some secondary care services only accepting referrals from GPs, with patients diagnosed in other settings (such as substance misuse services, pharmacies, or by peers trained to deliver testing in the community) having to go through a GP before being accepted for

“I have 60 or 70 on my waiting list, but actually there’s about 700 people I could treat due to the number of people diagnosed but not treated. They’ve come in, been diagnosed, but I couldn’t give them treatment there and then and so they’ve fallen away and become lost to follow-up.”

treatment in secondary care. This can cause unnecessary delays in enrolling patients into treatment, and creates more opportunities for the recently diagnosed to drop out of care. Contributors emphasised the importance of health boards accepting referrals from a range of services to avoid this problem.

The referral pathway can be shortened in other ways, for instance, by removing the requirement for patients to receive an ultrasound or fibroscan test before beginning treatment. While exact treatment

regimen or length of treatment currently depend on whether or not an individual has cirrhosis, simple blood tests can determine the likelihood of cirrhosis sufficiently well to greatly reduce numbers of people requiring a more exact test like a fibroscan.

Finding individuals who have been diagnosed but lost to follow-up was identified as a huge challenge by contributors. The need for a comprehensive database of diagnosed patients was repeatedly highlighted. It was suggested that a look-back study of GP records is required, and contact made with those who were previously engaged in treatment but did not achieve a sustained virological response (SVR) or who were diagnosed but disengaged from services. Such a task would require additional resources (or at least the reallocation of resources) but would be an effective way of re-engaging those no longer in contact with services and linking them into care.

Participants also highlighted the need to support those who have been referred into care, to prevent them from disengaging. This is particularly the case for vulnerable patients who may have trouble accessing services for treatment. Peers were mentioned as a crucial source of support in this regard, with individuals who have been through treatment themselves supporting others to attend appointments and to stay engaged in the care pathway. This support can be both practical (such as ensuring a patient remembers to attend appointments and has transport to get there) and emotional (listening to concerns and sharing their own experience of the benefits of being cured).



Linkage to care - conclusion and recommendations:

Simplifying and improving linkage to care is important to avoid individuals disengaging from treatment. Inexpensive and easily implementable changes in approach can help to remove barriers to referral and reduce delay. Support should be provided for individuals following referral for treatment, particularly through the use of peers. New initiatives should also be undertaken to find people who have previously disengaged from care following diagnosis and refer them for treatment.

- 20.** Secondary care services to accept direct referrals from substance misuse services, pharmacies and peers, as well as from GPs.
- 21.** Health boards and/or hospitals to undertake look-back work to re-engage those diagnosed but lost to follow-up, and to enrol them into treatment.
- 22.** Peer support to be provided to newly diagnosed individuals to reduce risk of disengagement.

Access to treatment

Background

The recent arrival of new direct acting antiviral (DAA) treatments has revolutionised treatment for hepatitis C, with cure rates higher than 95% and increased accessibility and tolerability for patients compared with the old treatments.

The number of patients being treated for hepatitis C has increased in recent years, rising from around 1,000 patients a year between 2012 and 2014 to over 1,700 in 2016/17¹². However, with treatment numbers only just outstripping new diagnoses and concerns about lack of access to treatment in some health boards, there will need to be large increases in the number of people being treated if Scotland is to achieve elimination by 2030.

Current approach

Contributors agreed that widening access to treatment is necessary if elimination is to be achieved. Currently, Scotland is pursuing a clinical approach (treating those with the most advanced health problems) rather than a public health approach (treating those most likely to spread the virus). Witnesses agreed that the sickest must continue to receive treatment, but felt that a combination of the two approaches is required to achieve elimination.

A targeted strategy of treating PWID was also considered to be vital from a public health perspective, with this group of patients the most likely to transmit the virus to others. Evidence submitted highlighted that 90% of new hepatitis C transmissions in Scotland are a result of risky behaviour associated with injecting drugs. Contributors expressed concern about some health boards restricting access to direct acting antiviral (DAA) treatments based on patients' drug and alcohol use. Such restrictions were regarded as incompatible with elimination.

It was reported that restrictions on access to treatment for hepatitis C remain, and that access varies across health boards. Contributors told us that these restrictions are a result of the current treatment

“If we are to eliminate hepatitis C, we have to incorporate a public health approach to treatment. You're never going to eliminate hepatitis C unless you treat all-comers, particularly those who are actively spreading the virus.”

budget being insufficient to cover the number of people waiting for treatment. As a result, those with cirrhosis or fibrosis are prioritised for treatment, with restrictions – disproportionately affecting the most vulnerable – in place for other patients.

Concern was also raised about clinicians in some health boards being asked to slow down the number of people being treated, due to concerns over costs. Contributors were aware of clinicians being asked to treat patients in line with targets, rather than in line with the allocated budget (with treatment cost reductions not resulting in increased access). It was judged that this approach is incompatible with a commitment to elimination.

“As clinicians, we have two hats on. One that says ‘this person has severe liver disease and I need to treat them’, and another that says ‘I need to treat the people that are spreading the virus’. Really, in an ideal scenario, we could wear these two hats simultaneously and just treat everyone!”

Treatment targets were regarded by witnesses as helpful for securing an adequate budget from the health board for hepatitis C care. However, it was felt to be important that health boards do not treat the

target as a cap, with one contributor saying that clinicians should be “expected to treat more” than the target number. One written submission of evidence drew attention to the fact that a similar number of patients commenced treatment in 2016/17 as were diagnosed in 2015. With the number of patients treated being very similar to the number of new diagnoses, Scotland must increase or rapidly exceed its treatment targets if hepatitis C is to be eliminated, rather than simply managed.

Case study 2: Waverley Care – Prison Link Project

A prison link project launched in Autumn 2016 by the charity Waverley Care supports prisoners diagnosed with hepatitis C with their transition and continued treatment upon release. The pilot project is currently taking place with prisoners from HMP Barlinnie.

Prisoners who have been diagnosed with hepatitis C can often access treatment while in prison. However, many former prisoners fall out of contact with healthcare services upon their release. This presents particular challenges for prisoners who transition back into the community during treatment, and those who may not have commenced treatment in the first place due to their imminent release.

Waverley Care works with prisoners who have been diagnosed with hepatitis C and provides them with a holistic programme of support before, during, and after their release. A dedicated Prison Link Worker helps prisoners to plan for liberation, making sure the right support is in place to address the practical issues, like accommodation, benefits and access to recovery services, the lack of which may prevent people from following through with their treatment. Following release, service users are also linked in to Waverley Care's community services to provide continued support.

In the first half of 2017, the project has worked with 24 individuals at different stages of their journey. Following release, over 90% of service users have remained in contact with the Prison Link Worker with many of them now preparing for or commencing treatment.

¹² Scottish Government, 13 Nov 2016.
<<http://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-12382&ResultsPerPage=10>>



Widening access to treatment

The changing nature of treatments for hepatitis C was highlighted by contributors as an opportunity to widen access to treatment. The availability of new pan-genotypic treatments means there is less need for patients to see specialists as fewer tests are required, which offers the opportunity to simplify the care pathway. It was noted that this provides an opportunity to provide screening, diagnosis and treatment in a single community location, such as primary care, community pharmacies or substance misuse services. This was widely felt to be a positive prospect, although resources may need to be redirected to ensure the opportunity is not missed. PWID, in particular, are often less likely to attend hospital appointments (with stigma a significant factor) and transport and distance often act as a barrier to engagement for patients in rural locations. Delivering treatment in community settings would likely improve attendance and thus increase the proportion of patients treated.

A significant benefit of treating patients in the community is that treatments are not subject to VAT - as they are when treatment is delivered in secondary care - and are therefore 20% less expensive. It was noted, however, that this money goes back into the health board's general medicines budget, rather than being ring-fenced for use by hepatitis C services. Ensuring this money is reinvested in hepatitis C services would offer the opportunity to treat a higher number of patients.

Contributors also highlighted the fall in treatment prices in recent years, due to increased competition in the market. It was suggested that health boards take advantage of the resultant savings on treatment costs by reinvesting in hepatitis C services to treat more patients, which could contribute to achieving elimination.

Peer messaging was regarded as an effective method of spreading information about the new treatments and dispelling outdated views, based on experiences of older treatments. It was felt that both group sessions (where a peer shares their experience of hepatitis C treatment in a group setting) or one-to-one 'buddying' (where a peer accompanies an individual to appointments) can be highly effective at supporting patients into treatment and along the care pathway.

Treatment in prisons

Contributors told us that increasing the number of people in prison receiving treatment is also particularly important. While there was recognition that there are many competing priorities in prisons, increased provision of treatment is justified by the wide benefits to patients of being cured of hepatitis C. As noted above, in addition to the specific health benefits, being cured also often allows patients to address other challenging issues in their life, such as offending, substance misuse and mental health issues. As with those accessing substance misuse services, being cured of hepatitis C can therefore be a significant factor in prisoners' rehabilitation.

We were told that it is particularly important that prisoners with hepatitis C released part-way through treatment, or before starting treatment, are referred to appropriate services. The charity Waverley Care's Prison Link project does exemplary work in this area (see case study 2). We also received evidence that suggested including treatment for hepatitis C in community payback orders where appropriate (as already happens with treatment for mental health, alcohol and drug issues), to ensure that low-level offenders are also engaged in care.

Some witnesses felt that prison health services are under-resourced, and that an increased number of prison healthcare staff is necessary to ensure an appropriate focus on hepatitis C. We were told that some staff who are supposed to work predominantly on blood-borne viruses (BBVs) often spend a considerable amount of their time working on general healthcare issues unrelated to BBVs, due to a lack of capacity. It was suggested that funding for BBV healthcare in prisons should be ring-fenced in order to ensure that there are sufficient resources for hepatitis C treatment.

Access to treatment - conclusion and recommendations:

With the cost of hepatitis C treatments having reduced markedly since the introduction of all-oral treatments, savings must be reinvested in services to increase treatment numbers. In addition, increasing the provision of treatment in community settings and prisons will have the benefit of widening access for patients, and contribute to achieving elimination.

23. Treatment cost reductions to be reinvested into additional treatments or services to ensure access to treatment is available immediately to all who need it.

24. Money saved on VAT by delivering treatment in the community to be directly reinvested into treatment budgets or services to ensure treatment is available immediately to all who need it.

25. Clinicians to be encouraged to exceed treatment targets, which must not be considered a cap by health boards.

26. Treatment to be delivered in community settings, such as substance misuse services, community pharmacies and primary care centres.

27. Availability of hepatitis C treatments in prison to be increased, and resources made available to ensure prison healthcare staff have capacity to deliver effective hepatitis C care. Appropriate follow-up support to be made available to those released from prison with an untreated infection.

Funding

Elimination of hepatitis C will not necessarily require significant additional financial investment. However, it will certainly require more innovative funding models and re-investment of allocated funds. Concerns were raised about the way hepatitis C treatments are currently funded and treatment targets determined. As discussed above, the current funding model results in insufficient budgets for treatment and waiting lists for treatment in some areas.

Currently, funding and treatment targets are set by fiscal year, preventing NHS Scotland from long-term planning. Additionally, funding is allocated at health board level, rather than through a central funding mechanism, which can lead to variation in the service available to patients. It was noted that health board treatment targets appear to be based on old prevalence data. For example, recent data suggests that Glasgow may have a higher prevalence than the previous estimate of 14,000, upon which the current treatment targets are based.

One possible approach would be to secure a national funding agreement with pharmaceutical companies, allowing for unrestricted access to treatment, as successfully adopted in Australia. This 'treatment for all' approach allows for long-term budget certainty, whilst also removing any restrictions on access to treatment and restoring clinical freedom to clinicians. It incentivises the diagnosis of patients and means that, once a certain threshold has been passed, treatment can be delivered at no additional cost to the Government. This approach has been highly successful in Australia, where it is estimated that over 80% of the infected population has been diagnosed, and treatment is universally available both in clinical settings and in the community. It was felt that such a deal could be agreed in Scotland without greatly increasing the current spend on hepatitis C treatment.

Contributors highlighted that bold ambition will be needed if Scotland is to agree a similar deal, as

pharmaceutical companies will likely negotiate the price based on the number of people expected to be treated. It is reasonable to expect that pharmaceutical companies will only be interested in agreeing a deal if substantial numbers of patients will be treated. One contributor noted that an 'Australia-style' deal will be harder to strike if Scotland is only treating around 1,800 patients a year, as at present. More ambitious treatment targets would result in a lower per-person treatment cost under a block funding agreement, delivering greater value for the Government and health benefits to the increased numbers of people treated.

Contributions to the inquiry from pharmaceutical companies emphasised a willingness to explore innovative funding models. It was noted that a deal between the Scottish Government and industry could go beyond treatment and encompass risk-sharing joint funding approaches to non-treatment related aspects of care, such as diagnosis, service capacity and peer-to-peer support.

The long-term cost-effectiveness of eliminating hepatitis C was emphasised, with one evidence session featuring a discussion on NHS Tayside's estimated costs of achieving elimination. This exploratory work found that the costs, excluding the price of drugs, would amount to £176,000 per annum, which witnesses noted is a tiny figure when compared with the long-term savings of treating people for hepatitis C (a full breakdown of NHS Tayside's estimated costs was submitted to the inquiry and is detailed in Figure 1). It is estimated that this figure would allow for NHS Tayside to treat 480 individuals per year (compared with 170 in 2016/17), should Scotland secure a procurement arrangement that reduces the cost of treatments. These treatment rates would enable NHS Tayside to achieve elimination in four years, rather than the currently estimated six to eleven years. While this figure is specific to NHS Tayside, where testing, case finding and community-delivery are already well developed, the cost-effective nature of investing for elimination is apparent, even allowing for higher costs in other health boards.

It was highlighted that any additional investment should be seen as part of a whole-systems approach to public health. If lack of funding leads to substance misuse or sexual health services being unable to deliver effective behavioural intervention, care, and support, direct investment in medication will be undermined by high reinfection rates. Curing vulnerable people of hepatitis C can also contribute to additional behavioural change and recovery journeys, including reducing harmful drug use and reoffending. Data on these outcomes is currently scant, but contributors felt that additional research to corroborate this conviction based on their experiences would be highly beneficial.

Figure 1 – NHS Tayside estimated financial costs of achieving hepatitis C elimination

(costs for treating 480 patients/year, excluding drug costs):

Associated annual cost

Fees for testing and treatment in community pharmacy	£66,000
Additional nursing hours (0.80-1.00 WTE Band 6)	£40,000
Additional capacity and coordination to support case finding (1 WTE Band 6)	£40,000
GP testing and case finding Service Level Agreement	£30,000
Total	£176,000

NOTE: The cost estimates do not take account of additional funding required for laboratory testing. It is anticipated that the increased costs of more dried blood spot (DBS) tests will be partially offset by using fewer tests in routine treatment monitoring, with bloods only being tested at the outset and on completion of treatment. It is estimated that the savings in treatment monitoring tests for every patient would pay for diagnostic testing for another 2.5 individuals.

Funding – conclusion and recommendations:

In order to deliver universal treatment and effective care, alternative funding models for treatment must be considered. A number of innovative options have been suggested by our contributors, including a long-term, national funding deal with pharmaceutical companies, and targeted additional investment resulting in long-term savings. Additional investigation of more flexible, long-term funding models will be required.

28. Additional research to be conducted exploring the link between hepatitis C treatment and positive behavioural change such as reduced reoffending or addiction recovery.

29. The Scottish Government to explore alternative treatment funding models which offer the opportunity to rapidly increase the number of patients receiving treatment.

30. Targeted additional investment to be made as part of a cost-effective national strategy, resulting in significant cost savings from reduced liver transplants and liver disease, as well as prevention of harmful drug use and other risky behaviours.

Conclusion

For Scotland to deliver its world-leading commitment to hepatitis C elimination, additional effort, innovation, and leadership is necessary. Based on current testing and treatment rates, Scotland will not meet the WHO targets for elimination by 2030.

Improvements in prevention, testing and diagnosis, linkage to care and treatment delivery must be made. In some cases, additional staff resource and funding may be necessary to allow health boards to do more to find those previously undiagnosed and engage them into care. However, there are many

other improvements that can be made simply through improved coordination, more effective guidance and regulation, increased enthusiasm, and bold leadership.

“Not eliminating hepatitis C is quite clearly more expensive in the long term. Eliminating it saves lives but it also saves money. It’s a no-brainer.”

With the decreasing cost of treatments, there should be a national ambition to markedly increase the number of patients treated in the coming years. Given the ease of delivery and short duration of the all-oral treatment, increased testing and treatment

in community and prison settings should be prioritised in order to reach patients who would previously have had difficulty accessing services. Better linkage between services, development of peer programmes, and targeted awareness campaigns are crucial to supporting increased treatment numbers and preventing onward transmission.

To ensure that tackling hepatitis C remains a national priority, we urge the Scottish Government to produce a national hepatitis C elimination strategy with ambitious targets designed to meet or exceed the WHO commitment of elimination by 2030.

The current landscape surrounding hepatitis C provides an extraordinary opportunity to cure thousands of marginalised people of a potentially deadly virus, and eliminate hepatitis C as a public health concern. It is time for a renewed commitment to make a Scotland free from hepatitis C a reality.

Contributors

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