SIGNPOSTING THE WAY TO ELIMINATION BY 2025

JULY 2018
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INTRODUCTION

Two years ago, the Government made an important promise. Alongside 193 other countries it pledged to help eliminate the life-threatening Hepatitis C virus (HCV) by 2030. In January, NHS England announced it was going further and would aim to eliminate the virus by 2025, making us the first country in the world to do so.

Some 160,000 people are infected in the UK,1 approximately half of whom remain undiagnosed,2 while a report last year found that only nine countries are set to hit the original 2030 target. Some excellent work has been done. The Government and NHS England’s commitment to tackling the disease is welcome and, thanks to new medicines, we have made significant steps in the right direction. In 2015, the NHS treated virtually every UK patient who developed cirrhosis as a result of HCV and has reversed the growing mortality.

The virus – a liver infection that spreads through blood-to-blood contact – is a global health threat that affects 71 million people around the world.3 We have a responsibility to wipe it out. Hepatitis C could be the UK’s next big public health success story. But if we want to eliminate it by 2025 we need a concerted and coordinated effort to find undiagnosed patients and treat them. The Coalition can play an important role as an enabler in setting the pace for this endeavour.

PROFESSOR STEVE RYDER
Chair of the Hepatitis C Coalition

The Hepatitis C Coalition welcomes the approach that NHS England is taking to identify those living with the virus and our work must be carefully coordinated to ensure no areas lose out. Hepatitis C is a disease of vulnerable people which means testing and treatment must be available where vulnerable people access care, not only GP surgeries but homeless shelters, needle exchanges, sexual health clinics, pharmacies and amongst the prison population. Investment in case-finding, awareness-raising and fighting stigma is critical to the success of this ambition. If people don’t know they are at risk, they won’t get tested or treated risking serious health problems in the future.

With enhanced diagnosis rates and better pathways into treatment, there is now a real opportunity to eliminate the virus. But we all need to play our part. Clinicians like me are on the frontline and have valuable insights that can help ensure the future model is fit for purpose. As the Coalition, our role is to coordinate action and collaborate with everyone across the hepatitis C pathway, to drive us all towards elimination.

PROFESSOR ASHLEY BROWN
Vice Chair of the Hepatitis C Coalition

The launch earlier this year of the “Eliminating Hepatitis C in England” report from the All-Party Parliamentary Group on Liver Health plays a significant role in identifying the opportunities for collaboration. As a natural next step, this document looks in practical terms at how the Coalition and other organisations can take ownership and signpost the way to elimination.

We have an unprecedented opportunity to make sure that this preventable disease is eliminated but we have to work together — the 2025 elimination target is within our grasp.

RACHEL HALFORD
Vice Chair of the Hepatitis C Coalition

1. The Hepatitis C Coalition
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THE HEPATITIS C COALITION

The Hepatitis C Coalition is an umbrella group of leading clinicians, patient organisations, professional groups, industry and other interested parties committed to the reduction of morbidity and mortality associated with hepatitis C (HCV) and its eventual elimination.

We work collaboratively with all parts of the hepatitis C pathway and want to see a more coordinated and effective approach to testing, treating and curing – and a greater emphasis on preventing new infections. We want to see hepatitis C eliminated as a public health threat in the UK.

Chair
PROFESSOR STEVE RYDER
Consultant Hepatologist at Nottingham University Hospitals NHS Trust and Honorary Professor at the University of Nottingham, School of Medicine

Vice-Chair
DR ASHLEY BROWN
Consultant Hepatologist at St Mary’s Hospital

Vice-Chair
RACHEL HALFORD
Chief Executive of The Hepatitis C Trust

The Hepatitis C Coalition receives funding from AbbVie, Gilead Sciences and Merck Sharp & Dohme, and the secretariat is provided by Lexington Communications.

The Department of Health and Social Care, NHS England and Public Health England are observers of the Coalition and able to attend quarterly meetings.

BACKGROUND

Hepatitis C is a viral infection which damages the liver. Left untreated, it can cause liver scarring (cirrhosis), leading to liver disease, liver failure and liver cancer (hepatocellular carcinoma). Hepatitis C is one of the three main causes of liver disease, the only one of the five “big killers” in the UK where mortality rates are rising.4 Until recently, treatments were difficult to take with many side effects, lasted a long time and were not effective in everyone. The revolution in treatment has changed that, now 8-16 weeks of pills with very few side effects offer cure rates of around 95%.5

Last year the Hepatitis C Coalition met with Steve Brine MP, Minister for Public Health and Primary Care, to discuss the issues surrounding hepatitis C in England. Claire Foreman from NHS England and Dr Sema Mandal from Public Health England (PHE) were also in attendance.

We laid out the relevant facts surrounding hepatitis C in the UK and the World Health Organization (WHO) Global Health Sector Strategy (GHSS) targets on viral hepatitis, which included a commitment to eliminate hepatitis C by 2030. The Minister asked the Coalition to write up a short document setting out how a joined-up approach to eliminating hepatitis C in England might look, which was the starting point for this document.

Since this meeting, the landscape has moved on further. In January 2018, NHS England announced that it was now aiming to make England the first country in the world to eliminate hepatitis C by 2025, five years ahead of the WHO target. “Elimination”, for the purposes of NHS England, refers to the WHO aim to reduce hepatitis C virus infections by 80% from its baseline level in 2015 in order to achieve elimination of HCV as a public health threat. But achieving this ambitious elimination target requires everyone involved in the complex patient pathway of hepatitis C to play their part. For example, NHS England will be working with industry on a procurement strategy for the medicines which will also enable case-finding and will form the basis of the aim for elimination. This document sets out, in concise, practical terms, ways in which the Coalition proposes to help, and suggests ways in which others might do so too.

The All-Party Parliamentary Group (APPG) on Liver Health has produced its seminal report ‘Eliminating Hepatitis C in England’6 which was launched in Parliament on 20th March 2018. That same month, PHE also published its ‘Hepatitis C in England: 2018 Report’.7 Our document is intended to draw on the findings in both of these and to highlight areas where additional impact can be obtained in order to drive momentum on elimination immediately.

THESE AREAS ARE AS FOLLOWS:

» Sharing knowledge and information
» Awareness
» Testing, treatment and engagement
» Prisons and the justice system
» Better data and evidence-based informatics

Finally, we have also included a regional case study to highlight best practice. We have chosen the Greater Manchester area, detailed by Dr Andrew Ustianowski, a leading Infectious Diseases consultant in the area.
Context

Hepatitis C services are delivered in England via 22 operational delivery networks (ODNs). NHS England set out its requirements for ODNs in its service specification, published in April 2015. This document introduced operational delivery networks, with “centres that manage treatment decisions and prescribing but have a dispersed delivery model that will support partnership working and local access for patients in England. Network leadership will be provided through specialist centres with proven expertise in managing HCV, and prescribing decisions will be made through MDT meetings.”

There is already a wealth of resources available about services, both for healthcare practitioners and for patients, produced by organisations and individuals involved in the fight against hepatitis C. However, the hepatitis C pathway is complex and sometimes commissioning services can be fragmented. The NHS reforms of April 2013 saw the division of responsibilities for hepatitis C services between a number of different organisations:

- NHS England health and justice – responsible for costs within prison services

Given the different points of entry to hepatitis C service pathways, the split between commissioners can be problematic. The below diagram seeks to demonstrate the different commissioners and providers involved in different hepatitis C service pathways.

In order to help commissioners, providers and patients navigate the system more easily, more needs to be done to help all parts of the pathway to understand how it works, by sharing this knowledge and information.

There are already some service pathway maps in existence. Each operational ODN should have one, as well as other groups such as the British Association for the Study of the Liver (BASL), the British Viral Hepatitis Group (BVHG), and the London Joint Working Group on Substance Use and Hepatitis C (LJWG) – but it would be very valuable to draw together what resources we have from there, to work to identify gaps.

Actions for the Coalition

The Coalition will work with our member organisations, their networks, and other stakeholders to signpost to helpful resources on the testing and treatment of hepatitis C. We will collate relevant materials in one central location for immediate ease of reference by ODN leads, clinicians, and other interested parties.

This information can then be hosted on HCV Action’s website. HCV Action is the voice of the hepatitis C professional community, so will be easily accessible for healthcare professionals in this field. This will help ensure uniformity of care, promote problem-solving and enable the sharing of best practice.

The Coalition will link to this resource on our own website, include links to it in patient-facing materials, and promote this on social media to ensure coordination and widespread reach.

The Coalition will work with PHE and HCV Action to signpost to best practice guidelines and to identify gaps. Where gaps in information do exist, we will work with our member organisations to address them. For example, producing infographics to show different pathways for different types of patients, or diagrams that show funding flows within the different bodies.

Actions for others

The key action for other organisations is coordination. To make the most of everyone’s work and to guard against duplication, we would encourage anyone who has worked to produce these sorts of resources – commissioning guidance, tools, best practice case studies, or maps – to put them forward to the Coalition to be included on the signposting page and/or the HCV Action page.

Anyone with anything to share should contact the Coalition by emailing hepccoalition@lexcomm.co.uk or calling 020 7025 2300.
Context
Finding the undiagnosed, and reconnecting with patients who have been diagnosed but remain untreated, is a key priority for achieving elimination. According to the APPG report, “while awareness of hepatitis C among health professionals has been increasing with the advent of new treatments, misinformation about risk factors, symptoms, and treatment options among GPs is still common. Stigma also exists within the healthcare profession, with people who inject drugs (PWID) or others with chaotic, unstable lives sometimes perceived as ‘undeserving’ of expensive treatments and not being appropriately informed of testing and treatment opportunities as a result.”

In every area, health service leaders should collaborate to destigmatise and demystify hepatitis C in order to reach the undiagnosed who are unaware of their condition, or who would be ashamed of their condition if it were known. The APPG report recommends that we “take the HIV awareness ads from the 1980s as inspiration for hepatitis C.”

Steps are being taken on the ground to reach those who have been tested, but are not in contact with treatment services. PHE is looking at additional ways to reach those patients who have been diagnosed but have not accessed treatment. This presents a significant opportunity, but it is estimated that there are around 40,000-50,000 people who have been diagnosed but remain untreated, so a campaign to find those people and re-engage them with services will be crucial.

Hepatitis C is often known as the ‘silent killer’ because its effects can go undetected for years. People who have not been treated themselves could be in danger of developing cirrhosis or hepatocellular carcinoma themselves, but also pose a transmission risk to others. Finding the diagnosed but untreated population is therefore key not just to reducing the numbers of those infected, but also in preventing further infection. This is fundamental to elimination.

Actions for the Coalition
» The Coalition will work closely with PHE and the Department of Health and Social Care (DHSC) to support ODNs in re-engaging the diagnosed but untreated population, in order to get as many of them as possible treated and cured
» The Coalition will launch a social media campaign around finding the 40,000-50,000 diagnosed patients. This could be conducted in partnership with other health organisations or foundations with a view to maximising its coverage and being as targeted and efficient as possible so as to maximise available resources
» The Coalition will utilise social media to build momentum and, as advised by the APPG report, look to find a high profile celebrity backer or spokesperson who will help to bring awareness of hepatitis C to a wider audience and to break down stigma and embarrassment around the condition.

Actions for others
» Clinicians and other healthcare professionals should take every opportunity to encourage awareness of hepatitis C among primary care practitioners and local commissioners
» To engage and share widely the campaign materials around retesting so that it reaches as far and wide an audience as possible.

AS WELL AS FINDING THOSE WITH AN UNDIAGNOSED INFECTION OF HEPATITIS C, IT IS ABSOLUTELY VITAL THAT WE TREAT THE ROUGHLY 50,000 PEOPLE WHO HAVE PREVIOUSLY BEEN DIAGNOSED BUT NEVER TREATED. THE HEPATITIS C TRUST BELIEVES THAT A DEDICATED NATIONAL AWARENESS CAMPAIGN SHOULD BE LAUNCHED TO ENCOURAGE THESE INDIVIDUALS TO ACCESS TREATMENT AND GET CURED BEFORE THEY DEVELOP SERIOUS HEALTH COMPLICATIONS.

RACHEL HALFORD, CHIEF EXECUTIVE, THE HEPATITIS C TRUST
TESTING, TREATMENT AND ENGAGEMENT

Context

Testing and treatment is the cornerstone of achieving elimination, and engagement is the practical action that needs to follow on from awareness-raising. Feedback from clinicians and ODN managers during the Coalition’s meetings throughout 2017 suggested that there was widespread support for making a case not just for testing in community settings, but for linking testing into treatment in community settings.

The APPG report focuses on both testing and keeping those tested in contact with services, while the new PHE report recommends that the potential for a phased move of hepatitis C care from specialist settings into the community should be explored. The role of community care settings has therefore been broadly identified as having a great potential for delivering elimination. The new direct acting antiviral medicines (DAAs) are oral medicines which are straightforward to take. Pharmacists also come into contact with patients on a regular basis for other issues, so from an economic perspective this approach will streamline the patient pathway and design services so that they make sense to patients.

For example, testing for hepatitis C could be incorporated into existing screening programmes to maximise coverage and value. Patients would be less likely to drop out of treatment if they do not have the expense and inconvenience of travelling to multiple appointments. Moving testing and treatment into community settings is a development that already has support from both NHS England and PHE.10

Strides are already being made on this in London by the London Joint Working Group on Substance Use and Hepatitis C (LJWG) who has undertaken the first phase of the project, which will involve utilising point of care HCV RNA testing in NSP pharmacies with integrated IT referral pathways and enhanced peer support as well as assessing the feasibility of this model to other cities (Birmingham and Manchester) and exploring the potential to treat HCV in the NSP setting.

The NICE approved antiviral treatments with virological cure rates of 95% provide a great opportunity to eliminate HCV as a public health threat and mitigate the development of HCV associated life-threatening complications. However, whilst these tools exist, more innovative approaches are necessary to engage patients into testing and treatment, especially those that account for 90% of all new cases and have the highest risk of contracting and transmitting HCV – namely people who inject drugs (PWID).

More novel, patient-centred, holistic approaches are required to increase rates of diagnosis and support through hepatitis C treatment for this vulnerable, young, socially marginalized population. Their engagement with healthcare services is at best sporadic, hence utilisation of their unique, trusted relationship with needle and syringe programme (NSP) community pharmacists provides a golden opportunity to provide testing and potentially life-saving treatment to people who would otherwise miss out.

Following the success of our pharmacy testing pilot can build on this further as engaging with the Royal Pharmaceutical Society to identify barriers to develop NSP community pharmacy HCV testing into a sustainable patient-centred pathway into HCV treatment.

Priming findings showed that during the first six weeks, half of the patients tested positive for hepatitis C antibodies.11 In May 2018, the LJWG Pharmacy Testing for HCV in needle exchanges report (Phase 1)12 was published. They found that half of those tested (53%) had hepatitis C antibodies and 78% of those who engaged with specialist services had hepatitis C viral particles detectable in their blood. Testament to the importance of awareness-raising and education is the finding that more than half of people tested (57%) did not know that hepatitis C treatment had moved on from the previous interferon-based treatment. People are being treated and cured of hepatitis C as a result. The pilot also laid the groundwork for future extension of the project with a potential to offer treatment alongside testing, with 84% of participants reporting that they would like to receive any required treatment at their community pharmacy.

The LJWG is now embarking on Phase 2 of the project, which will involve utilising point of care HCV RNA testing in NSP pharmacies with integrated IT referral pathways and enhanced peer support as well as assessing the transferability of this model to other cities (Birmingham and Manchester) and exploring the potential to treat HCV in the NSP setting.

Actions for the Coalition

» The Coalition will support calls for normalising testing in all settings, including pharmacies. There was already support among community and specialist pharmacists for dry blood spot testing (DBST) and administering treatment; the LJWG pilot can build on this further

» The Coalition will leverage its diverse membership to arrange meetings with key pharmacy bodies, sexual health providers and substance use providers in order to support the broadening of these services to community settings.

» The Coalition will work with the LJWG, PHE and the PSNC – the body that represents community pharmacy and works with the DH on pharmacy services including public health campaigns – to discuss how we can deliver public health campaign material to be used in community pharmacies, which will help raise awareness amongst the public.

» The Coalition will support the LJWG, PHE and others to deliver media materials and coverage as appropriate

Actions for others

» Industry can play a key part in supporting practical testing workshops and roadshows, given their expertise in how treatments should be administered.

» All parts of the hepatitis C pathway should work to ensure a favourable legal and policy landscape for treatment to be made possible in community settings. This should include substance and alcohol treatment facilities, sexual health clinics and pharmacies.

» The Department of Health and Social Care should work with the Ministry of Justice and indeed the Crown Prosecution Service (CPS) and others, if necessary, to determine if any legal change is necessary to facilitate this.

Dr Sunam Verma - Co-chair and pharmacy pilot Lead LJWG
As the commissioner of healthcare provision across the prison estate and other secure settings, NHS England is fully committed to the elimination of Hepatitis C by 2025. Our current programme of work in addition to opt-out testing for blood-borne viruses includes a comparative review of testing methodologies to speed up diagnosis, England-wide testing promotion initiatives, the roll-out of peer programmes and targeted pathway development programmes to support testing and treatment and the development of case management systems to ensure continuity of care from custody to community.

From a medication perspective, NHS England Health & Justice will seek to address the complexity of prison-based care through advocating for the most rapid commencement of treatment possible, considering both virus genotype / sub-type.

Context
People who inject drugs are frequently incarcerated and therefore, as PHE data confirms, Hepatitis C affects a larger proportion of people in prison and other detention centres than the wider population. While opt-out testing has been rolled out across England, there is still broad variation in terms of practice and uptake.

The National AIDS Trust (NAT), which is a member of the Coalition, published an important report ‘Tackling Blood Borne Viruses: A Framework for Prisons in the UK’ in 2017. This document works as a best practice guide to how blood borne viruses, including hepatitis C and HIV, should be dealt with in prisons and secure settings. However, as acknowledged by both PHE’s Health and Justice team and NHS England, there are various points of attrition in the system that prevent this best practice from being uniformly put into action. There are many cases but the variation in engagement and commitment of prison governors presents a serious institutional barrier, as do operational concerns such as prisoners being able to be accompanied to see an in-reach nurse.

When inmates leave prison, there is also nothing to ensure that they will be registered with a GP, and passing on medical records can present information governance issues (see section below). But prisons still present a key opportunity to treating a section of the population with exceptionally high prevalence, and it is vital that not only is opt-out testing implemented across the board, but that linkage into treatment is also enacted successfully.

Actions for the Coalition
- The Coalition will work closely with the Health and Justice team at PHE, along with NHS England and other stakeholders to engage key individuals involved with the pathway for hepatitis C patients in prisons.
- The Coalition will hold a parliamentary roundtable later in 2018, bringing together as many relevant health and justice stakeholders together as possible including representatives from individual prisons and Community Rehabilitation Companies. This will be aimed at pinpointing the specific barriers to effective testing and linkage into care in prisons and help determine how to overcome these barriers to ensure continuity of treatment.
- The Coalition will produce a short briefing following the roundtable, which will then be used to gather support from prison governors and health practitioners in prisons, and to highlight solutions identified during the roundtable.

Actions for others
- There are many organisations involved in prison health, both nationally and locally. While there is a great deal of goodwill involved to make the system work, there is often resistance from prison governors. Political levers are already being explored to engage prison governors, but more must be done to convince them of the benefit to their institution and to public health, if rates of hepatitis C are brought down. According to Professor Graham Foster, ODNs are being incentivised to work with prisons, so there is now a real impetus for collaborative working that must be supported and encouraged.
- Community Rehabilitation Companies (CRCs), which handle probation and parole, will also need to play a role in enabling released inmates who are being treated for Hepatitis C to register with a GP and ensure there is no gap in their treatment. Prisons go through an exit planning process when they are due to be released; there needs to be a joined-up approach to making sure that continuity of care continues once a patient leaves prison.
Better data and evidence-based informatics

Context

Data on hepatitis C is vital to helping us understand the current context of a problem and how we can solve it. The first issue is around the availability of data, such as ODNs being aware of the number of diagnosed but untreated patients in their area. PHE is looking at additional ways to reach those patients who have been diagnosed but have not accessed treatment. Efficient gathering and sharing of data between the different parts of the patient pathway would significantly reduce the number of patients losing touch with treatment services.

The second issue is around building a greater evidence base around specific interventions; to determine if there is a case for investing in them. For example, data that shows the added benefits of hepatitis C interventions on reduction in crime, or research into the efficacy of peer to peer work, can help determine the best course of action for eliminating hepatitis C. The APPG report calls for innovative peer programmes encouraging attendance at clinical appointments to be supported and expanded, but there’s little to no evidence about how well these work, only anecdotal evidence. This also ties in with the report’s call for improved monitoring of innovative initiatives and approaches to hepatitis C care to allow successful models to be easily identified and upscaled. The APPG report also identifies that there is a lack of data on injection kit provision. This forms a key part of their section on prevention. To eliminate hepatitis C, a solid evidence base will be necessary.

Actions for the Coalition

- The Coalition will explore options for highlighting the barriers to services caused by information governance issues. For example, we could consult Caldicott Guardians to discuss how information governance impacts patients’ linkage into care and ways in which this can be overcome.
- The Coalition will work with the Let’s End Hep C initiative to compare data from England with EU countries, to gather intelligence on best practice and compare policy success in real time which will help show where England is against its elimination targets and to evaluate what is working and what is not from a policy and practice perspective.
- The Coalition will work with the Drugs, Alcohol and Justice Cross Party Parliamentary Group to push for research into the safety and efficacy of needle exchanges and other harm reduction measures to make a case for their role in reducing transmission. This could be done in conjunction with the National Institute for Health Research. Coalition members such as Blenheim and Addaction will be able to help drive this.
- The Coalition will work with PHE on the data they gather and discuss how it can be optimised and leveraged.

Actions for others

- NHS England and PHE should ensure timely communication with ODNs in relation to gathering patient data.
- Drug and alcohol treatment providers should contact the Coalition’s secretariat to propose areas for research.

Dr Ahmed Elsharkawy, Consultant Transplant Hepatologist, Queen Elizabeth Hospital Birmingham and Chairman of the British Viral Hepatitis Group

Hepatitis C elimination is now a public health priority. In order to achieve this it is critical that we engage the disengaged and diagnose the undiagnosed. A crucial enabler of this will be to have central registries of patients who have been tested for HCV; this is because patients are often tested in disparate locations by multiple providers. We need national agreements on suitable information governance arrangements that would allow this.

Whilst many hepatitis C treaters have anecdotal evidence of the transformative effects of hepatitis C treatment on individual patients’ lives, there is a lack of systematic data to demonstrate that hepatitis C cure has an impact on return to drug use, employment or reoffending rates. If such an impact can be demonstrated then hepatitis C elimination will have an impact outside the narrow field of healthcare.
The five pillars comprise:

1. **COMMUNITY PHARMACY TESTING AND TREATMENT**
   The whole pathway being completed by the pharmacist (testing, treatment and test of cure) with no need ordinarily to directly involve other professionals. 60-80 community pharmacies will engage in this programme from around Greater Manchester, largely utilising DBST but also some locations exploring the utility of point of care tests (POCT).

2. **NETWORK TESTING AND TREATING**
   Incentivising diagnosed individuals to bring their network along for testing – thereby aiding case finding – and then treating the identified network at the same time so that those who continue risk behaviour do so within a clean or cleaner network (and therefore have a reduced chance of re-infection).

3. **INTERROGATION OF PRIMARY CARE AND OTHER RECORDS**
   For markers of infection or risk of infection, and thereby identifying individuals to bring up for testing and treatment.

4. **RAPID TESTING AND TREATMENT IN PRISONS**
   Offer all individuals (as a strict opt-out) POCT/similar testing at reception to prison or the following day (dependent on prison), and those positive will commence treatment within 72 hours. It is also hoped that by thus creating a ‘virus-free’ prison new infections in the prison setting will be prevented.

5. **TESTING A&E ATTENDEES AND NEW REGISTRANTS WITHIN PRIMARY CARE**
   A reserve pillar being scoped but without a current plan to commence (pending the performance of the bedrock and other pillars).
REFERENCES

5. NHS Choices, Hepatitis C – Treatment: http://www.nhs.uk/Conditions/Hepatitis-C/Pages/Treatment.aspx