PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

The London Joint Working Group on Substance Use and Hepatitis C (LJWG)

Dr Kosh Agarwal
David Badcock
Dr Ashley Brown
Janet Catt
Dr Emily Finch
Charles Gore
Dr Magdalena Harris
Dr Michael Kelleher
Prof David Nutt
Prof William Rosenberg
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

Executive summary

• In 2011, the London Joint Working Group on Substance Use and Hepatitis C (LJWG) highlighted a huge unmet need in London in terms of access to hepatitis C testing and treatment for people with a history of injecting drugs. Tackling The Problem Of Hepatitis C, Substance Misuse And Health Inequalities: A Consensus For London set out best practice recommendations for commissioners and service providers.

• Left untreated, the hepatitis C virus (HCV) can lead to cirrhosis, cancer, liver failure and the need for transplantation. The greatest risk factor for hepatitis C is injecting drug use.

• A quarter of all those with hepatitis C in England live in London\(^1\). Public Health England (PHE) estimates that around 41,500 people in London have chronic hepatitis C, of whom around 40% are undiagnosed\(^2\). 90% (37,350) are likely to have a history of injecting drugs. Prevalence in London is higher than anywhere else in England.

• NICE-approved treatments can cure the majority of patients for a fraction of the cost of a liver transplant. In spite of this, only around 1,400 Londoners – 3% of the affected population – received treatment in 2012.

• Since the last LJWG London Consensus in 2011, health and social care services and commissioning responsibilities in England have undergone major change following the Health and Social Care Act 2012.

• New treatments for hepatitis C are becoming available; all-oral regimens with the potential for 90-100% cure rates, fewer side effects and significantly shorter treatment times are likely to be available from 2015. These will make treatment easier for people to manage, and be more suitable for a community setting.

• However, the improved efficacy of new drugs will have only a modest impact on the burden of disease unless they are accompanied by significant improvements in case finding. At existing treatment levels, the long-term disease burden will greatly increase: liver-related mortality will double and hepatocellular carcinoma (HCC) more than double\(^3\). Treating many more patients with better drugs will have a much bigger impact and will make the prospect of eliminating hepatitis C an exciting and real possibility.

• More needs to be done to make services easier to reach: clinics should be run in the community, at suitable times. A lack of knowledge about hepatitis C among some primary healthcare and drug workers is a barrier to screening, diagnosis and referral, and comprehensive information should be made available for health and drug workers, service users, carers, and all service providers who interact with at-risk groups.

• Commissioners should adopt a joined-up approach to pathway development, planning integrated services that make it easier for vulnerable people to access high-quality treatment, care and support. Models of care should be developed that can be delivered by multi-speciality providers both in and out of clinical settings. Consideration should be given to the planning and provision of harm reduction prevention resources, routine screening, diagnosis, referral pathways and comprehensive support to enable people with a history of taking drugs to access high quality care across the capital.

• Ongoing drug or alcohol use is not a contra-indication to hepatitis C treatment, and research shows that people who are actively using drugs can and should be treated for hepatitis C\(^4\). Both national and European treatment guidelines recommend treatment for this population.

• Data collection is a vital element of any effective hepatitis C strategy, in order to accurately assess the public health need, plan and commission services, and assess the effectiveness of treatment strategies.

• Identification and sharing of best practice is needed in the prevention, diagnosis, treatment and support for homeless people with hepatitis C. Many are not registered with a GP, or engaged with any services, so can find it difficult to access specialist care. Antiviral treatment can be challenging even for those with robust support networks.

• The aim of this document is to reinforce the need for urgent leadership from the Department of Health, PHE and NHS England and concerted action from Local Authorities, Health and Wellbeing Boards, Clinical Commissioning Groups (CCGs) and service providers to improve hepatitis C testing and treatment services in London for people with a history of using drugs – the group most affected by chronic hepatitis C – in order to find and treat significantly more people affected by the disease.

• A summary of practical recommendations by sector is included in Part Three.

3. Dore et al J Viral Hep 21: S1 104
Introduction

In 2011, the London Joint Working Group on Substance Use and Hepatitis C (LJWG) highlighted a huge unmet need in London in terms of access to hepatitis C testing and treatment for people with a history of injecting drugs. Tackling The Problem Of Hepatitis C, Substance Misuse And Health Inequalities: A Consensus For London set out best practice recommendations for commissioners and service providers.

Three years on, more effective and better tolerated treatments are becoming available; as treatments improve there is a real opportunity to find and treat more people and begin to eliminate the consequences of hepatitis C infection. New models of care and prevention are urgently needed, in order to save thousands of people from premature death, and millions of pounds in NHS resources from the long-term burden of disease.

The vast majority of people in London with hepatitis C are still not being treated: over 37,000 people in London with a history of using drugs are likely to have hepatitis C yet in 2012 only around 1,400 patients in total received treatment, according to estimates from Public Health England (PHE). Not only are we failing to treat people who have a curable condition, but many London boroughs still have no plans to improve their provision of hepatitis C services.

The aim of this document is to reinforce the need for urgent leadership from the Department of Health, PHE and NHS England and concerted action from Local Authorities, Health and Wellbeing Boards, Clinical Commissioning Groups (CCGs) and service providers to improve hepatitis C testing and treatment services in London for people with a history of using drugs – the group most affected by chronic hepatitis C – in order to find and treat significantly more people affected by the disease.

“Many Londoners are not receiving the services and treatment they deserve and need to beat hepatitis C. Health and Wellbeing Boards, Clinical Commissioning Groups and service providers can, and must, work together more effectively to deliver better outcomes for individuals, their families and all our communities”
Councillor Victoria Borwick, Deputy Mayor of London

“We need to find new ways of doing things or quality will suffer.”
Sir Bruce Keogh, National Clinical Director, NHS England

PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

Part One: hepatitis C service provision in London

1. About hepatitis C
1.1. Left untreated, the hepatitis C virus (HCV) can lead to cirrhosis, cancer, liver failure and the need for transplantation. 2014 figures estimate that 160,000 people in England are living with hepatitis C. Around 40% are undiagnosed, since the disease can remain asymptomatic or may be mis-diagnosed for many years. Although NICE-approved antiviral treatments can cure hepatitis C in the majority of cases, only 3% of the estimated chronically-infected population in England received treatment in 2012.

1.2. Reducing mortality from liver disease is a stated aim of the Public Health Outcomes Framework 2013-16, yet liver disease remains the fifth most common cause of death. Liver-related mortality rates in England are rising, in contrast to many other European countries; liver disease is a major cause of death among younger people. The cost to the NHS in England is already at least £500m a year, and is rising by 10% annually.

1.3. 15-20% of people with hepatitis C will develop cirrhosis within 20 years. Up to 5% of those with cirrhosis will develop liver cancer each year. Hepatitis C is the commonest indication for liver transplantation. Deaths from end-stage liver disease and liver cancer related to hepatitis C have quadrupled since 1996. Because liver damage develops slowly, the number of people affected will continue to increase, even though rates of infection are predicted to fall.

1.4 Total healthcare costs at current treatment levels of 3% a year, including treatment and care for advanced liver disease and its complications, have been estimated at £4.6 billion over the next 30 years. The future healthcare burden significantly outweighs the cost of treating now.

“Of the main causes of liver disease – alcohol, obesity, and viral hepatitis – hepatitis C is the one bit that is actually solvable in a reasonable amount of time. We could all but eradicate hepatitis C in England within the next 30 years, and make a huge dent in the prevalence in a reasonably short time, if there are clear directions to local NHS on how to go about it in a way that is easy to action.”
The Hepatitis C Trust

3. Hepatitis in the UK, 2014 PHE
4. Harris et al, Increased uptake and new therapies are needed to avert rising hepatitis C-related end stage liver disease in England: modelling the predicted impact of treatment under different scenarios. J Hepatol. 2014
6. PHE statistics for 2010-2011 (quoted in briefing for councillors, 2013)
8. Harris et al, Increased uptake and new therapies are needed to avert rising hepatitis C-related end stage liver disease in England: modelling the predicted impact of treatment under different scenarios. J Hepatol. 2014
2. New treatments, new opportunities
2.1. New treatments are becoming available with shorter treatment duration, higher cure rates and fewer side effects than current standard of care. However, the improved efficacy of new drugs will have only a modest impact on the burden of disease unless they are accompanied by significant improvements in case finding. At existing treatment levels, prevalence will decline to around 83,700 cases of hepatitis C in England by 2030. The long-term disease burden, however, will greatly increase: cases of decompensated cirrhosis will increase by over 60%; liver-related mortality will double; and hepatocellular carcinoma (HCC) more than double. Treating many more patients with better drugs will have a much bigger impact and will make the prospect of eliminating hepatitis C an exciting and real possibility.

3. People with a history of using drugs
3.1. The greatest risk factor for hepatitis C is injecting drug use. Where the risk factor was reported in data collected by PHE, injecting drugs was recorded in over 90% of hepatitis C diagnoses in England between 1996 and 2003. Similarly, English data from the 2013 Unlinked Anonymous Monitoring (UAM) survey suggests that as many as 50% of people who inject drugs (PWID) have hepatitis C. This represents a large pool of people who may be completely unaware they have the virus and can unwittingly spread it to others.

3.2. Sharing needles and other injecting paraphernalia is most commonly associated with the transmission of blood-borne viruses (BBV) including hepatitis C, although they can also be spread by sharing cocaine straws and crack pipes.

3.3. Marginalised and vulnerable groups, such as people who use drugs (PWUD), are often stigmatised and can find it difficult to navigate traditional referral pathways. More needs to be done to integrate health, social care, drug treatment and other services to provide the care and support they need.

3.4. There is an argument that treating hepatitis C in people who actively inject drugs is an effective form of prevention. Modelling from Bristol University shows that, with relatively modest levels of treatment, hepatitis C prevalence in this population could be substantially reduced, even taking into account the risk of re-infection. Antiviral treatment of people who inject could play a significant role in reducing the burden of hepatitis C – both in public health and economic terms.

3.5. Outcome models published in 2014 suggest that if treatment rates in England were increased from the current 3% to 14% by 2018, it would be possible to eliminate the virus by 2030.

10. Dore et al J Viral Hep 21: S1 104
11. Hepatitis C in the UK 2014, PHE
12. Hepatitis C in the UK 2014, PHE
4. Hepatitis C in London
4.1. London is the largest city in the European Union, with a population of 8.4 million in 2013. It is one of the most ethnically diverse cities in the world; 40% of the London population is classified as non-white and many migrants come from parts of the world with a high prevalence of hepatitis C.

4.2. A quarter of all those with hepatitis C in England live in London. PHE estimates that around 41,500 people in London have chronic hepatitis C, of whom around 40% are undiagnosed. 90% (37,350) of those are likely to have a history of injecting drugs. This prevalence is higher than anywhere else in England, and although diagnosis rates are higher (60% compared to 20-40% elsewhere in England), these do not translate into higher rates of treatment. In 2012 only around 1,400 people were treated, and hepatitis C was the primary indication for just under a quarter of first liver transplants.

4.3. Injecting drugs is the most significant risk factor for hepatitis C. According to the National Drug Treatment Monitoring System nearly 29,000 people accessed structured treatment for problem drug use in the London region in 2013-14.

4.4. London houses over 7,000 prisoners and young offenders, and the prevalence of hepatitis C is known to be considerably higher in the prison population (14%) than in the general population (3%).

4.5. Half of England’s rough sleepers are in London. Many use drugs and alcohol, as well as having other mental or physical health problems, and these are associated with poor outcomes: a homeless PWUD admitted to hospital is seven times more likely to die over the next five years than a housed PWUD admitted with the same medical problem.

4.6. In its 2013 briefing to councillors, the London Drug and Alcohol Policy Forum pointed out that hepatitis C affects some of the most marginalised groups in London. In addition to PWUD, almost 10% of people with hepatitis C in London are migrants from high prevalence countries, and over 8% are men who have sex with men. Between 2010 and 2011, almost half of patients admitted to London hospitals with a diagnosis of chronic hepatitis C were from the most deprived fifth of society.

% Share of the total amount of hospital admission of patients with chronic hepatitis C in London

Fig 2: The percentage of patients with chronic hepatitis C in London admitted to London hospitals (across the 32 NHS CCGs) from each NHS Deprivation quintile, 2010-2011.

---

15. London.gov.uk
16. 2011 Census
22. Standards for commissioners and service providers, Faculty for Homeless Health, May 2011
5. Service provision and policy in London

5.1. London faces particular challenges due to the size, diversity and often transient nature of its population, as well as the disjointed nature of existing service provision. However, hepatitis C remains a low priority – a 2014 report by the Hepatitis C Trust found that 13 out of 33 London boroughs made no mention at all of hepatitis C in their Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies

5.2. There is no overall policy underpinning hepatitis C services throughout London and the quality of care can vary greatly. London’s network of hepatitis C services is complex, currently comprising:
- 33 Local Authorities
- 32 Clinical Commissioning Group (CCGs)
- 33 Health & Wellbeing Boards
- 16 Acute Trusts
- 3 Mental Health Trusts
- 2 Community Trusts
- 19 NHS Foundation Trusts GPs
- 8 prisons
- 7 major hepatitis C treatment units
- 33 Local Healthwatch Organisations
- 40+ drug treatment services
- Many smaller local treatment centres

See page 19 for a map of health bodies in London.

“\textbf{The lack of joined-up service provision across primary and secondary care is causing a lack of adequate treatment, with patients bouncing from service to service.}”

Linda Greenslade, Royal Free Hospital

5.3. Service configuration in London causes difficulties in planning integrated care pathways. In April 2014, LJWG and a coalition of partners called on the Department of Health, NHS England and PHE to work together to make hepatitis C a priority, clarify commissioning responsibilities in London and appoint an official with responsibility for hepatitis C in London. An announcement regarding this post is yet to be made.

5.4. Borough leads need to jointly commission services between public health and CCGs. CCGs are currently responsible for the costs of long-term liver disease.

5.5. There are examples of good practice in London but there are also inconsistencies and gaps. The LJWG’s Public Health Report on the Commissioning of HCV Services in London for PWUD revealed a significant variation in practice among London boroughs, and even between services within the same borough. Only one in three boroughs had a testing-to-treatment pathway in place, but even where one did exist, not all services along the pathway were aware of it. Critics of the Health and Social Care Act 2012 have observed that its focus on localism can encourage fragmentation of services. Others point to examples of services in London, such as cancer and HIV, that clearly benefit from pan-London commissioning and robust clinical networks.

5.6. LJWG has provided evidence to the London Health Commission (LHC), and called for leadership and a London-wide strategy. Disappointingly, the LHC report, published in October 2014, made no mention of hepatitis C. There is a recommendation to appoint a London Health Commissioner, which LJWG would support.

6. National Policy Framework

6.1. NHS England’s Five Year Forward View calls for innovative service design in order to achieve quality outcomes. Proposals include multi-specialty models of care, such as those that are known to be effective in hepatitis C care, and which LJWG recommends should be adopted in London.

6.2. The Public Health and NHS Outcomes Frameworks (2013-16) target liver mortality and preventable communicable disease, and challenge service providers (including drug treatment services) to improve health quality and length of life, although there are no hepatitis C-specific targets.

6.3. The reorganisation of the NHS in England following the Health and Social Care Act 2012 has resulted in major changes to commissioning responsibilities. Funding for prevention, testing, assessment, treatment and drugs for hepatitis C may be provided by different authorities. The services patients may interact with along the care pathway can be commissioned by NHS England, PHE, Local Authorities, CCGs or Offender Health, depending on their location or referral pathway. The complexity of the commissioning landscape means that the system can be disjointed and difficult for patients to navigate. However, as the Hepatitis C Trust pointed out in its 2013 audit of services during the transition to the new structure, NHS reforms may also present an opportunity for improvement.

See page 20 for maps of commissioning and funding responsibilities in England since 2013.

“The Health and Social Care Act 2012 is a turning point for the NHS. With the correct action, it can also be a turning point for hepatitis C.”

The Hepatitis C Trust

6.4. The Government has failed to deliver the Liver Strategy that was promised in 2011; however, NHS England’s Commissioning Intentions 2015/16 for Prescribed Specialised Services plan does include the requirement for providers of hepatitis C treatment to report a minimum data set (treatment provided, genotype and sustained virological response (SVR)). The document also flags up the planned increase in BBV testing for offenders, which commissioners should take into account.

6.5. NHS England is in the process of drafting a hepatitis C service specification, which will set out standards for providers that ensure consistent high quality care for all people with hepatitis C across the country.

6.6. NHS England and PHE are working together to produce a national improvement framework for hepatitis C. This will seek to co-ordinate the actions of different commissioners and healthcare providers to tackle the virus, with a view to substantial improvements for patients. Encouragingly, in correspondence with the Hepatitis C Coalition, the Under Secretary of State for Public Health commented that “PHE and NHS England had joint ownership and leadership of the plan, but the Department [of Health] had a strong interest and role in supporting this work. The Minister’s involvement could also be used to add impetus, to resolve arising problems and to become directly involved on the advice of PHE”.

6.7. Department of Health, PHE and the Local Government Association are in the early stages of planning a joint hepatitis C and TB summit to explore how to bring together local health systems and local authorities to control hepatitis C and TB rates.

6.8. Funding remains a key challenge. New all-oral antiviral drug regimens will make treatment easier, but come at a cost. Health services need to weigh up affordability against long-term cost-effectiveness. At the time of writing, discussions are ongoing over budget responsibilities for hepatitis C treatment and the long-term costs of liver disease.

6.9. The Commissioning for Quality and Innovation (CQUIN) payment framework provides an opportunity to link funding to achievement of local quality improvement goals. NHS England and CCGs could consider using CQUINs to measure and reward effective implementation of the LJWG care pathway. Targets for screening, diagnosis and successful treatment of hepatitis C could be developed and agreed at a Local Authority level. A CQUIN scheme in the East Midlands
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

that ran from 2009 to 2013 rewarded local hospitals for sharing data on adherence and SVR\(^30\).

6.10. The Health Premium Incentive Scheme for Local Authorities is also currently in development. Indicators in the Public Health Outcomes Framework are being considered for inclusion in the scheme, and recommendations will be made, including payment structures for 2015.

6.11. The 2011 LJWG London Consensus called for opt-out testing in prisons, where the prevalence of hepatitis C is considerably higher (14%) than in the general population (3%)\(^31\). A partnership between the National Offender Management Service, NHS England and PHE has set out plans for an opt-out policy for BBV testing in prisons, with care pathways to be developed for those found to be hepatitis C positive. The intention is for prisons to introduce the new policy during 2014/15.

6.12. PHE published Liver Disease Profiles in October 2014, comparing each region and borough in England for the first time\(^32\). The dataset includes three indicators for hepatitis C, providing the means for London boroughs to benchmark their performance.

7. Hard to reach?

7.1. Marginalised groups such as people with a history of using drugs can find it hard to access testing and treatment for hepatitis C. Service user focused qualitative research from the London School of Hygiene and Tropical Medicine identifies many barriers, including stigma, complex referral and appointment systems, long waiting times, rigid non-attendance policies, as well as discrimination and a lack of understanding of the complex health and social needs of the service user. Service users interviewed as part of the PREVENT study reported that having poor venous access put them off BBV testing, and they expressed a strong preference for dried blood spot (DBS) testing.

7.2. Other barriers to testing and treatment include a lack of knowledge among health workers, which means they may be reluctant to initiate discussions about hepatitis C, and a lack of clearly signposted networks and referral pathways.

8. Find more, treat more, save more

8.1. The current standard of care using cost-effective, NICE-approved treatments\(^33,34,35\) can cure 40-70% of infected individuals for a fraction of the cost of a liver transplant. In spite of this, only around 1,400 Londoners\(^36\) receive treatment each year.

8.2. Until recently, standard treatment consisted of pegylated interferon injections and ribavirin tablets for 24 – 48 weeks. Both drugs commonly cause side effects. Protease inhibitors boceprevir and telaprevir, the first of the direct acting antivirals (DAAs), were introduced in 2011. These drugs are used in combination with ribavirin and interferon. This combination, known as triple therapy, improved cure rates and shortened treatment times for some genotypes.

"We need to find more, treat more, save more.”
Professor Matthew Cramp

---

33. Peginterferon alfa and ribavirin for the treatment of chronic hepatitis C (TA 20)\(^0\)
34. Telaprevir for the treatment of genotype 1 chronic hepatitis C (TA252)
35. Boceprevir for the treatment of genotype 1 chronic hepatitis C (TA253)
36. PHE Hepatitis C in London 2014 (2012 data)
8.3. Further advances in DAA therapies have led to the development of interferon-free and ribavirin-free treatment options, although these are not yet widely available. New medical treatments, with the potential for 90-100% cure rates, all-oral regimens, fewer side effects and significantly shorter treatment times are likely to be available from 2015.

8.4. Models show that the introduction of more effective treatments will reduce morbidity and mortality by around 10-20%. However, if the number of people treated was also increased to 14% by 2018, then the effect would be an 85% reduction in mortality and a 90% reduction in decompensated cirrhosis by 2030, making the elimination of hepatitis C a real possibility.

8.5. The combination of better drugs and improved uptake will have a significant impact on outcomes, and this should be done hand-in-hand with better harm reduction measures. Results from Scotland show a rapid decline in the incidence of hepatitis C among people who inject drugs was associated with a national scale-up of harm reduction interventions. A combination of needle exchange, opioid substitution therapy (OST) and a shift away from injecting meant that between 2008 and 2012, 1,000 fewer Scottish injectors contracted hepatitis C.

8.6. Information on currently licensed medical treatments for hepatitis C can be found at www.medicines.org.uk. There are many new treatment regimens on the horizon and readers should refer to NHS Horizon Scanning, NICE and SMC for details of products that are anticipated to be approved for use in the UK.

37. Strategies to manage hepatitis C virus (HCV) disease burden, H. Wedemeyer et al Journal of Viral Hepatitis, 2014, 21, (Suppl. 1), 60–89
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

Part Two: Making London hepatitis C services easier to access

“We need to consider: are the groups at risk from hepatitis C ‘hard to reach’ or are our services ‘difficult to access’?”
Dr Helen Harris, Public Health England

1. Diagnostic and treatment services must be easy to access. Outreach services are more convenient and less challenging for many service users than hospital clinics. Hepatitis C treatment services should be sited in drug treatment or primary care services, and have flexible opening hours and appropriately trained staff.

2. Clinics should be run at convenient times, for example in the afternoon; appointments should be easy to book, and clearly communicated to patients and carers. Reminders by phone, text or email should be provided. The introduction of interferon-free treatment regimens will make community-based services more feasible.

Service development in Scotland has focused on making it easier for the at-risk community to access testing and treatment. Managed Care Networks (MCNs) have been developed to facilitate communication between primary and secondary care. DBS testing has been rolled out and many drug workers, prison nurses, midwives, social workers, and homeless workers trained in its use. Open referral systems mean that people can be referred, by these workers, direct to a hepatologist on the basis of a positive test. Nurse-led and outreach clinics have been established, and shown to be effective. Rates of testing, diagnosis and treatment have increased significantly. Treatment numbers in Scotland have increased by 120% since the start of the Scottish Action Plan (2006-11).

3. There is a need for training and education

3.1. A lack of knowledge about hepatitis C among some primary healthcare and drug workers is a barrier to screening, diagnosis and referral40. The 2013 LJWG pilot project showed that staff confidence can be boosted by formal training in a number of key areas, including disease transmission and prevention, disease progression, symptoms and testing, treatment and specialist care, and data collection and reporting.

LJWG Pilot project
In 2013, LJWG set up pilots in four London boroughs (Croydon, Haringey, Islington and Lambeth) to assess the practical impact of its recommendations on testing and referrals. The Hepatitis C Trust provided training, as well as testing in partnership with Find and Treat, a specialist outreach team tackling TB among homeless people. Training had a positive impact on the confidence of key workers to talk about hepatitis C with their clients, and the project showed that existing statutory reporting processes and systems don’t necessarily capture all the relevant data along the care pathway.

Pathway & outcome findings

<table>
<thead>
<tr>
<th>PCDAS Referral to BBV Nurse for Harm Reduction &amp; Testing (N=91)</th>
<th>Results (N=81)</th>
<th>Referred to Treatment Services (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>81 (99%) tested</td>
<td>22 (27%) Ab &amp; RNA positive</td>
<td>5/22 (22%) offered treatment.</td>
</tr>
<tr>
<td>1 refusal</td>
<td>3 Ab positive but RNA negative</td>
<td>4 recently referred</td>
</tr>
<tr>
<td>9 known Ab and RNA negative</td>
<td>1 Waiting result</td>
<td>5 DNAs</td>
</tr>
<tr>
<td></td>
<td>55 Ab &amp; RNA negative.</td>
<td>1 refused treatment</td>
</tr>
</tbody>
</table>

Assessed for Treatment (N=15)

1/3 of patients referred did not attend their hospital appointments...

FIG 5: Islington pilot data, showing data collection along the care pathway

3.2. The Hepatitis C Trust provides training for drug service staff, prison staff, GPs and other relevant health and social care professionals. The Royal College of General Practitioners (RCGP) has developed a training module, the first part of which can be done online41.

3.3. Patient education leaflets about hepatitis C and its treatment should be developed and provided in appropriate language to support and empower people in making decisions about treatment. Information resources should be objective and factual, and address common misconceptions (e.g. hepatitis C can’t be cured, people who use drugs are not entitled to treatment, everyone will need to have a liver biopsy etc).

4. Commissioners should adopt a joined-up approach to pathway development, planning integrated services that make it easier for vulnerable people to access high quality treatment, care and support. Models of care should be developed that can be delivered by multi-speciality providers both in and out of clinical settings.

4.1. Antiviral treatment is a major undertaking, but done at the right time and with the right support, people can successfully complete their treatment and clear the virus. Buddying, support groups and peer education can be very useful to help people cope with diagnosis and treatment, and a targeted and intensive approach, including motivational interviewing and contingency management are helpful for people who currently use drugs or alcohol, or have mental health problems42.

4.2. The success of the pathway depends on high levels of awareness among workers, clear guidance on what to do, good communication between services, and effective clinical networks. The move towards integrating health and social care, and the creation of Health and Wellbeing Boards, could pave the way for better hepatitis C care pathways and services in London.

4.3. A multi-disciplinary approach including psychosocial support, psychiatric assessment, treatment for alcohol dependence, support with housing or benefits and appropriate OST should be considered. Ideally, antiviral treatment for hepatitis C should be given in the community. The Addaction Weston-super-Mare treatment service, for example, acts as a successful model of how delivering nurse-led hepatitis C treatment in the community can increase treatment numbers, improve attendance rates, and better meet the needs of under-served groups43.

4.4. Ongoing drug use is not a contraindication, and research shows that people who are actively using drugs can and should be treated for hepatitis C44. Both national and European treatment guidelines recommend treatment for this population45,46. Having treatment for hepatitis C can help people to break with the past and put their drug-taking lifestyle behind them, and data from Australia suggests that OST protects against hepatitis C virus acquisition in people who inject drugs47.

41. elearning.rcgp.org.uk/course
44. Jack K, Varnam M, Thompson B. Br J Gen Pract 2005; 55 515
45. Peginterferon alfa and ribavirin for the treatment of mild chronic hepatitis C. NICE technology appraisal guidance 106
46. EASL hepatitis C treatment guidelines 2014
4.5. Health professionals should bear in mind that if ongoing drug or alcohol use is likely to affect adherence, it may not be the ideal time for the person to have treatment.

4.6. OST is a widely accepted treatment for people with opioid dependency and current evidence supports its use to help stabilise patients before and during antiviral treatment. OST should always be provided in combination with psychological support, to increase the likelihood of a successful outcome. It is important to maintain effective levels of OST during hepatitis C treatment, and so close liaison between drug services and hepatitis treatment services is vital.

4.7. Many people with hepatitis C drink alcohol, which has a synergistic effect in progressing fibrosis; alcohol issues should be addressed at the same time, involving third-party agencies where necessary. While ongoing alcohol use is not an absolute contraindication to treatment, it can affect adherence and make interpretation of surrogate biochemical markers more difficult, thereby compromising the eventual outcome. More importantly, it is illogical to attempt to eradicate one factor while ignoring the other. Treatments for alcohol misuse should be considered; therapies such as acamprosate and naltrexone are recommended by NICE for moderate to severe alcohol dependence. Brief interventions and twelve-step programmes also have a role to play.

4.8. Prevention and harm reduction are important. High levels of awareness in drug treatment services, prison services, needle exchange services, homeless health and other services will help to prevent the spread of hepatitis C. Needle exchange services can be a person’s first point of contact, and these should always have appropriate opening hours that suit service users. Harm reduction messages should be clear and consistent across all services. Information can be found at www.harmreductionworks.org.uk.

5. Routine screening

5.1. Every person attending a drug treatment service in London should be tested for BBVs unless they opt out. If people decline, tests should be offered again in three months. Routine screening in non-specialist healthcare settings, informed by local prevalence data, should be planned and commissioned.

5.2. HIV co-infection should be considered, and all HIV-positive people should be offered a hepatitis C test. Vaccinations for hepatitis A (HAV) and B (HBV) should be given.

5.3. BBV testing at needle exchange services is very effective and should be considered at all needle exchange services, as this may be the patient's first point of contact.

5.4. Testing for antibodies can be carried out by either taking venous blood (using DBS or venepuncture) or with oral fluid testing kits. Blood tests are the gold standard and should be used in preference to oral tests, which have lower sensitivity and specificity than blood tests. Those testing positive for antibodies should have their sample tested for hepatitis C RNA to confirm whether they are currently infected. Laboratory services should be set up to do both tests at the same time.

5.5. CCGs can work with healthcare providers to develop incentives that will encourage screening, for example using the CQUIN payment framework or the Health Premium Incentive Scheme. This may be especially useful to tackle health inequalities in under-resourced areas.

6. Diagnosis

6.1. Results should be given by a health professional. If the result is negative, the discussion should include the recommendation that, if there is a risk of recent exposure to the virus, the person should be re-tested in six months. If positive, information about the disease and treatment options should be given. Consistent harm reduction advice should be reinforced regardless of the test result.

6.2. Non-invasive methods of liver fibrosis assessment (Fibroscan™) should be available during the diagnosis process, and there should be rapid turnaround of viral tests (within a week).

7. Referral and assessment

7.1. Referral systems need to be robust, and relationships established between services to ensure patients do not get lost in the system. Managed Clinical Networks (MCNs) have been successful in Scotland and North London. Cancer networks are another good example.

7.2. Every RNA-positive patient should be referred to a specialist hepatology team who will provide information about hepatitis C and the treatments available so that the patient can make a decision on whether to start antiviral therapy. All patients have the right to high quality care regardless of lifestyle, and ongoing use of drugs or alcohol are not contraindications to treatment.

7.3. The specialist team should assess each patient’s suitability for treatment, as well as their individual support needs, including a mental health assessment. All patients should meet and have a discussion with a clinical nurse specialist (CNS) before starting treatment.

7.4. Pre-treatment discussions should include the length and likely outcome of treatment depending on genotype, potential side effects and their management, information about the natural progression of hepatitis C and factors that affect it, and advice on preventing transmission to others. Planning a suitable start date should take into account any family, social, housing or employment issues. Safe storage and disposal of medications and equipment need to be discussed. Storage may be a particular issue for people who are homeless.

8. Patient-centred treatment

8.1. Individualised, patient-centred care should be provided by a multi-disciplinary team linking appropriate resources such as psychiatric assessment, psycho-social support, treatment for alcohol dependence, housing support and OST. Treatment should take place in a convenient community location such as a drug treatment service.

8.2. Appointments for antiviral therapy should be coordinated with OST appointments, and phone, email or text reminder messages used.

8.3. Patients should have a regular review during treatment, to have side-effects monitored, and have the opportunity to discuss any problems.

8.4. Ongoing peer support and education should be aimed at encouraging and supporting patients to live healthy lives and reduce harmful behaviours. Signposting should be provided to support groups, as well as peer education and volunteering opportunities.

8.5. Every effort should be made to ensure that prisoners continue their treatment uninterrupted, and that provision is made for continuity of care on release or transfer to another prison.

9. Long-term care

9.1. Aftercare and ongoing support should be in place to manage any residual effects after antiviral treatment. Patients who have an SVR should be referred to their GP or drug treatment service for the management of any ongoing side effects of treatment. GPs may be unaware of potential post-antiviral treatment effects, some of which can be significantly debilitating.

9.2. Patients who do not have an SVR should be monitored on a regular basis by the hepatitis treatment service and offered re-treatment or new therapies as appropriate. It is imperative not to lose contact with these patients. Patients with evidence of cirrhosis should continue with long-term follow up for liver cancer (HCC) surveillance.

LJWG SMARTPHONE APP

LJWG was awarded a Gilead UK and Ireland Fellowship to evaluate the potential role of smartphone app technology in improving communication between services, with a view to improving rates of attendance at specialist hepatitis treatment services. The i-Count HCV app allows health professionals in different services to share information securely. The aim is that by facilitating rapid information and communication between the referring drug treatment service and the specialist hepatitis team, the app will support integrated patient care.
10. **Data collection is a vital element** of any effective hepatitis C strategy, in order to accurately assess the public health need, plan and commission services, and assess the effectiveness of treatment strategies. The following information should be collected:

i. Tests offered
ii. Tests performed
iii. Positive results
iv. Patients referred to specialist care
v. Patients offered treatment
vi. Patients starting treatment
vii. Patients completing treatment
viii. SVR
ix. The reasons patients decline testing or treatment should be noted

Additional data might include patient experience measures, genotypes and sub-types, numbers of patients attending specialist clinics after being referred and the reasons patients discontinue treatment.

From April 2015, providers of hepatitis C treatments will be required by NHS England to report a minimum data set, including treatment, genotype and outcome\(^50\).

11. **Homeless health**

11.1. **Identification and sharing of best practice** is needed in prevention, diagnosis, treatment and support for homeless people with hepatitis C. Many are not registered with a GP, or engaged with drug treatment or other support services, so can find it difficult to access specialist care. Antiviral treatment can be challenging even for those with robust support networks. Safe storage of interferon injections can be an issue, and the prospect of all-oral treatment regimens brings opportunities to expand treatment in this important population.

11.2. **Information should be provided to the homeless community** about hepatitis C, including the implications of having the condition, harm reduction messages, and the location of testing facilities and treatment options. This can be done verbally, as part of homeless outreach projects, or through literature distributed in homeless shelters, drug treatment services, OST clinics and soup kitchens.

11.3. **A multi-specialty approach to healthcare for the homeless** can ensure being homeless is not a barrier to receiving high quality treatment, care and support.

11.4. **Clinicians and commissioners should work with homeless charities** and services to ensure that all relevant staff (for example in shelters) are aware of hepatitis C and are trained to deliver simple procedures like administering a DBS test. Clinicians should work with the local authority and Health and Wellbeing Board.

11.5. **There are opportunities for multi-morbidity testing.** Testing at the same time for hepatitis A, B and C, TB and HIV avoids the duplication of effort and NHS resources. Mobile units can provide targeted health services to people on the streets. Find & Treat uses a mobile X-ray unit to screen almost 10,000 people a year, primarily for TB but also for other conditions. The screening is done in hostels, drug treatment services, street projects, day centres, detention centres and prisons\(^51\). Rapid and point-of-care testing can be used effectively in these environments\(^52\).

**LJWG toolkit**

The LJWG has collated a number of policy, commissioning and educational resources on its website (ljwg.org.uk/ljwg-toolkit). These include fact sheets for patients and information for service providers, not only on hepatitis C but also on topics such as how to improve attendance at clinics, as well as major reports, example of good practice and tools and links to resources for commissioners. If you know of any resources we should include to please contact info@ljwg.org.uk

---

51. NIIS National Infection & Inequality System June 2014
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

FIG 6: London Hepatitis C integrated care pathway for people who use drugs
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

Part Three: How can you help? A summary of recommendations by sector

**Drug treatment services**
- Every patient attending a drug treatment service in London should:
  - tested for BBVs unless they opt out.
  - repeat tested every 6 months, if negative.
  - vaccinated against hepatitis A and B.
- Every hepatitis C RNA-positive patient should be referred to a specialist treatment service for assessment, and provided with support to attend if required. Current substance use is not a contraindication.
- Every drug worker should have a basic knowledge of hepatitis C, (through completing the RCGP Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care, or an equivalent qualification).
- Consistent harm reduction advice should be provided through all services working with drug users, including all needle exchange services.
- Every local drug service should have a nominated person responsible for liaising with hepatitis treatment centres, prisons and primary care.

**Specialist hepatitis treatment services**
- Every hepatitis C treatment centre should have a nominated person responsible for liaising with local drug services, prisons and primary care.
- Everyone referred to specialist services should be assessed for treatment. Current substance use is not a contraindication to treatment, though other factors will influence the decision to initiate treatment. These factors should be recorded to inform improvements in services and patient support.
- Alternatives to treatment in the hospital setting should be formally assessed, and nurse-led outreach services should be established wherever possible.
- Data should be collected on an ongoing basis to capture:
  - Total number of drug users and non-drug users referred for assessment.
  - Total number of drug users and non-drug users offered treatment.

- Barriers to treatment (where treatment is assessed as inappropriate at present or is declined by the patient).
- Adherence and outcomes
- Patients should have access to mental health support before and during hepatitis C treatment.

**Health and Wellbeing Boards**
- Health and Wellbeing Boards should set strategic objectives for hepatitis C which can delivered through the system steered by the Directors of Public Health.
- Joint Strategic Needs Assessments (JSNA) should include robust plans for integrated hepatitis C care pathways
- Health and Wellbeing Boards and local public health teams should work with CCGs to implement effective hepatitis C testing and treatment strategies in their local area.

**Directors of Public Health**
- Every public health area should have a multi-specialty working group responsible for ensuring people who use drugs have access to a robust pathway, from testing to specialist treatment services. The group should include specialists in public health, viral hepatitis, substance use and mental health as well as GPs and support workers.
- The use of DBS (dry blood spot) testing or Point of Care (Rapid) Testing should be available in as many relevant services as possible.
- Data on prevalence and incidence – among both drug users and non-drug users – should be collected on an ongoing basis.

**Clinical Commissioning Groups and primary care**
- Every CCG should have a nominated lead for hepatitis C and substance use.
- Every CCG should draw up a list of service providers and make sure each GP is aware of the local referral pathway.
- Every hepatitis C RNA-positive patient should be referred to a specialist treatment service for assessment, and provided with support to attend if required. Current substance use is not a contraindication to treatment.
At least one GP in every practice should have a basic knowledge of hepatitis C, (through completing the RCGP Certificate in the Detection, Diagnosis and Management of Hepatitis B and C in Primary Care, or an equivalent qualification).

GP practices should implement strategies to search patient records for indications of substance use and invite all those indentified to be screened for BBVs.

**Prisons**

- Every prisoner in London should be:
  - tested for BBVs at their initial health assessment unless they opt out
  - vaccinated against hepatitis A and B
- Every hepatitis C-RNA positive patient should be referred to a specialist treatment service for assessment, and provided with support to attend if required. Current substance use is not a contraindication to treatment.
- Patients on antiviral treatment should not have their therapy interrupted due to incarceration, transfer or release from prison. Health records should move with the prisoner and maintenance of hepatitis treatment and/or OST planned in advance with receiving services.
- Every prison officer should be provided with sufficient training to ensure a clear, basic knowledge of hepatitis C.
- Consistent harm reduction advice and education should be provided through all services working with prisoners, including harm reduction advice after release.
- Every prison should have a nominated staff member responsible for liaising with primary care, public health, drug services and hepatitis treatment centres.

**Further information**

- PHE Commissioning template for estimated HCV prevalence and numbers eligible for treatment by Drug Action Team Area. Produced by Public Health England to help Local Authorities (LA) and Health and Wellbeing Boards estimate the prevalence of hepatitis C virus (HCV) infection in their local population, and the likely disease burden and associated treatment costs.
  www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317140844602

- PHE Liver Profiles
  Published October 2014; provide liver disease data across England
  http://fingertips.phe.org.uk/profile/liverdisease/data#gid/8000063/pat/6/atl/102/page/0/par/E12000007/are/E09000002

- HCV Action Commissioning Toolkit
  www.hcvaction.org.uk/resource/hepatitis-c-adult-services-commissioning-toolkit
FIG 7: Principal formal relationships between health bodies in London. Courtesy of The King’s Fund.
PRACTICAL STEPS TO ELIMINATING HEPATITIS C: A CONSENSUS FOR LONDON

FIG 8: Commissioning of services since April 2013. Courtesy of the King’s Fund.

FIG 9: Budget responsibilities. Courtesy of the King’s Fund.
Thanks to the following for their contributions to producing this document

Natalie Bennett
Nicola Brett
Emma Burke
Robin Cohen
Neil Cowan
Dr Martin Cullen
Dee Cunniffe
Jane Daniel
Grace Everest
Dr Chris Ford
Ellie Gordon
Rebecca Hayden
Andy Jones
Martin McCusker
David Mackintosh
Claire Munro
Antonis Papasolomontos
Sharon Preston
Laura Pritchard
Dr Murad Ruf
Sarah Wise

The LJWG receives funding from: AbbVie, Bristol-Myers Squibb, Gilead Sciences, Janssen and MSD. The content of this document was written by LJWG.