THE HEPATITIS C TRUST

Capital Challenge

Tackling Hepatitis C in London

Contents

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Foreword

Health inequalities are so great in London that there is a 17 year gap between the highest and lowest life expectancy for men[1]. Hepatitis C is arguably one of the most unequal of conditions because of the populations it disproportionately affects and the poor health outcomes of those living with the condition.

More than 50,000 people are living with hepatitis C in London[2], over a quarter of the UK's hepatitis C population[3]. Of those living with the condition in the capital, two thirds of people are current or former injecting drug users, almost 10% are migrants (mostly from South Asian communities) and over 8% are men who have sex with men[4].

Many of these people do not know that they have the condition, and those that do are often lost to follow up. This means that even through hepatitis C can be tackled through prevention, early identification and treatment; it continues to be a major contributor to liver disease and deaths in the capital. Poor service provision is compounded by a failure to take into account the needs of different groups living with hepatitis C by local bodies.

This situation cannot continue; if the Greater London Assembly (GLA) is to deliver against the *London Health Inequalities Strategy,* and NHS and local authorities are to achieve progress against new outcomes measures on liver disease and to abide by the Equality Act 2010, we need action now.

The current reforms to the health service risk destabilising hepatitis C services even more but the changes also represent an opportunity to make sure that we deliver for people with hepatitis C. By prioritising the condition locally, we can contribute to our aim of eradicating the virus within a generation, as well as reducing London's health inequalities.

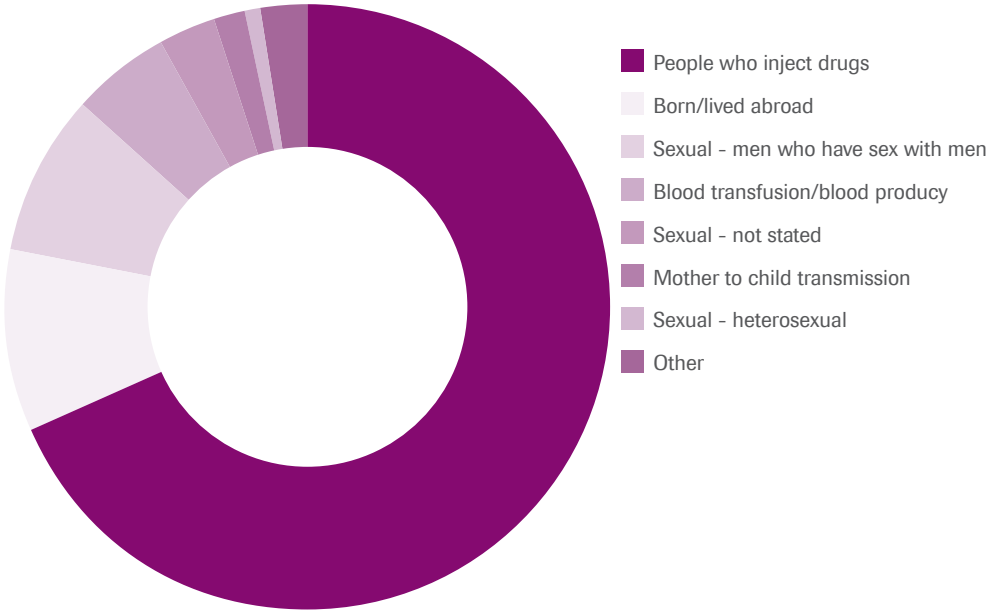
This report sets out the status of hepatitis C in the capital and assesses current service provision at a local authority and NHS commissioner level. We hope it will be a useful starting point for future joint working on tackling hepatitis C in London.

The current state of hepatitis C in London

Over a quarter of people with hepatitis C in the UK live in London – the hepatitis C capital of the UK[5]. There are an estimated 58,000 people living with hepatitis C in the capital and around 40% of them remain undiagnosed[6].

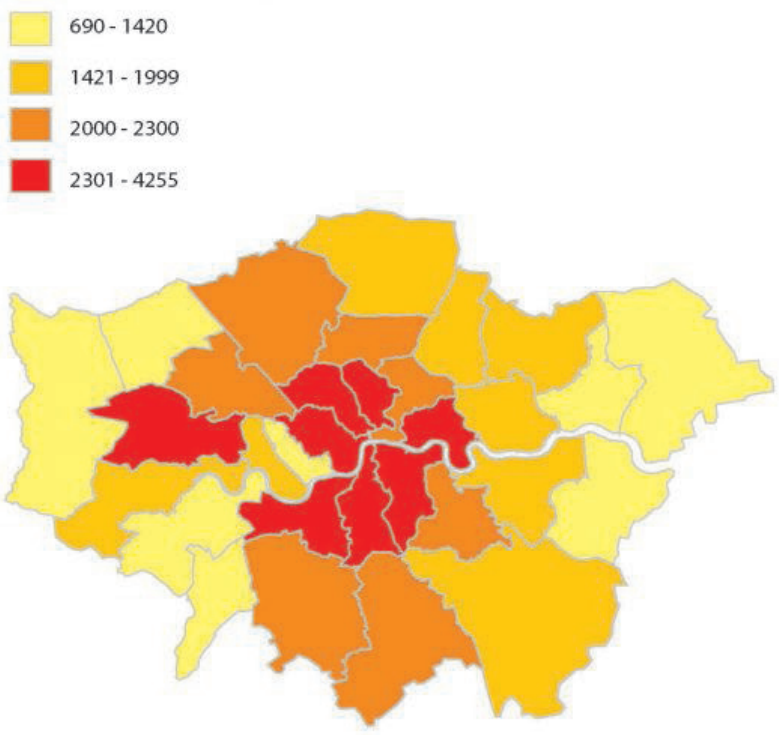
Hepatitis C predominantly affects injecting drug users but other at risk groups include people from South Asian communities and men who have sex with men[7]. The full breakdown is set out in Figure 1.

Figure 1 – Risk factors among people diagnosed with hepatitis C in London



There is a seven-fold variation in the number of people diagnosed with hepatitis C across London, as can be seen in Figure 2.

Figure 2 – Estimated number of patients with hepatitis C by London NHS area, 2010[8]



Around 40% of people living with hepatitis C in London are undiagnosed as the condition can go undetected for years due to the generic nature of its symptoms, or lack of them[9]. This means that a significant proportion of people with the virus in London could be unknowingly spreading hepatitis C to others. The transitory nature of many of the people affected by hepatitis C, particularly injecting drug users and migrants who may have insecure immigration status only increases the problem. A recent study found that failure to detect the virus among injecting drug users means that each person with hepatitis C spreads the virus to 20 others – ten of these in the first two years[10].

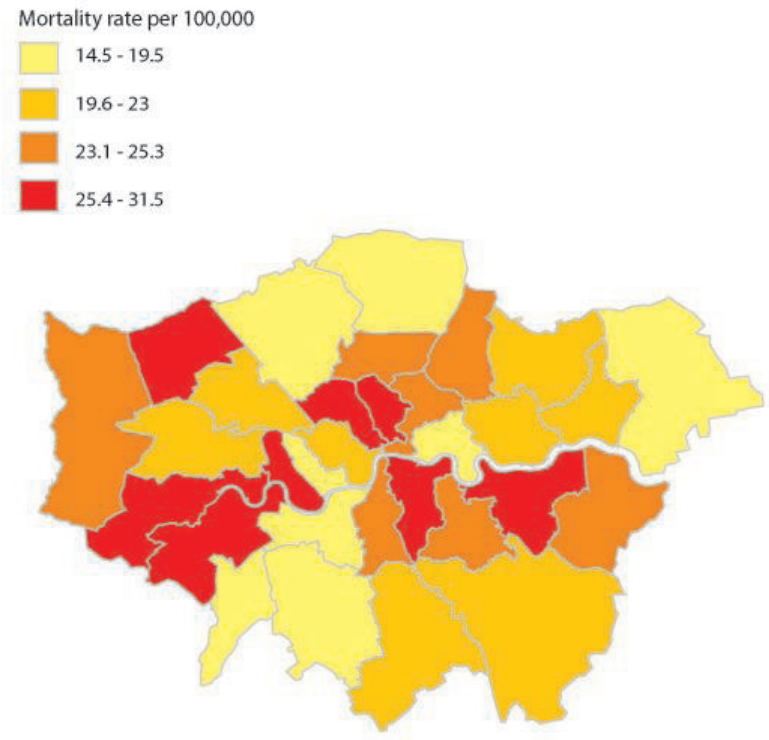
Failure to identify and treat hepatitis C can cause cirrhosis, liver cancer, liver failure, or even death[11]. The increasing pool of people with hepatitis C in London will result in significant costs in terms of morbidity and mortality due to chronic disease and financial cost due to the treatment of late complications of the virus. In London, the estimated cost of treating those already identified is £29 million and current annual treatment costs are estimated to be £5.7 million[12].

Research from a public health survey commissioned by the London Joint Working Group for substance misuse and hepatitis C (LJWG) found that treatment of mild, moderate and cirrhotic disease were all found to be cost-effective[13].

Hepatitis B and hepatitis C are the second most common cause of liver disease in the UK, after alcohol misuse[14]. Hospital admissions and deaths from hepatitis C related liver disease and liver cancer have risen three-fold in the UK since 1998[15]. In addition, overall liver mortality has increased; a trend which is in stark contrast to the rest of Europe where deaths from liver disease are decreasing[16].

Figure 3 shows the variation in liver disease mortality across London – NHS Greenwich has the highest death rate, which is more than double that in NHS Wandsworth[17]. This variation cannot be explained by the number of people affected in a particular area as it is not always the areas with the highest prevalence that have the highest mortality rates. This suggests that there may be inequalities in how liver disease is treated across the city.

Figure 3 – Chronic liver disease mortality 3 year average per 100,000 population[18]



Problems with hepatitis C commissioning in London

Successive reports have identified problems with the commissioning of hepatitis C services as one of the major contributing factors to poor outcomes in the UK[19,20,21].

There have been some improvements in London in recent years. For example, more testing has taken place, particularly in primary care. There has also been a decrease in the sharing of needles as a result of needle exchange schemes[22]. However, as highlighted by the LJWG:

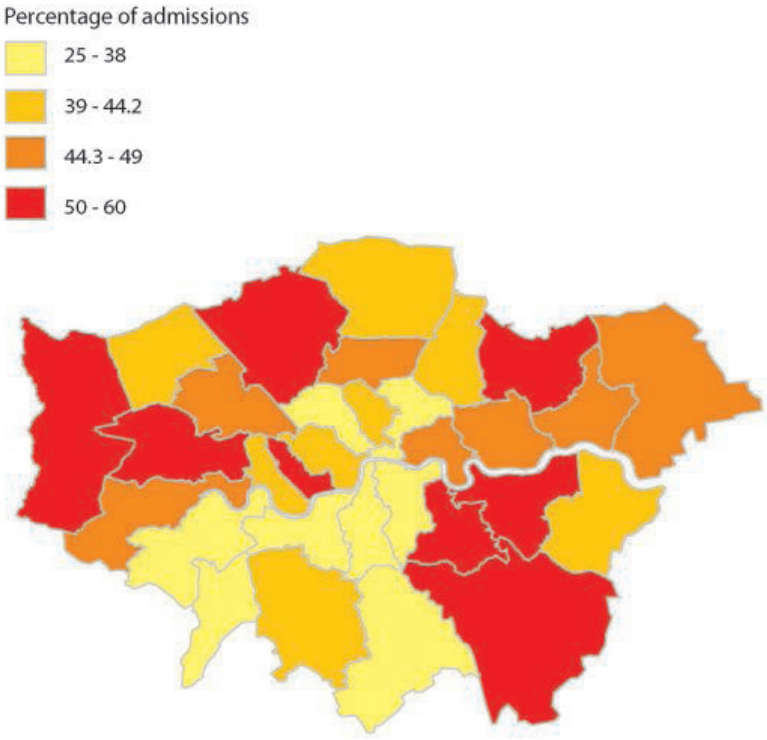
"Current service provision is disjointed and patchy, so much so that even where individual services are performing well, gaps in the wider provision needed to treat drug users with hepatitis C continue to undermine their progress"[23].

It can be difficult to identify patients and refer appropriately for treatment and support. However, only half of NHS commissioners in London were reported as having a treatment care pathway for people with hepatitis C[24]. People at risk of, or diagnosed with, hepatitis C require additional support to access appropriate care. Having no care pathway in place raises questions about how the local NHS is able to accommodate the varied needs of people affected by the condition. It also appears that prisons are failing to identify and support people at risk of hepatitis C in the capital[25].

In London, emergency admissions for hepatitis C constitute around 44% of all admissions for hepatitis C. The variation between NHS areas in London is shown in Figure 4 and ranges from 25% in NHS Richmond to 60% in NHS Redbridge[26]. A high proportion of emergency admissions suggest that the local NHS may not be supporting people with hepatitis C effectively, as people who are well supported do not usually end up being admitted as an emergency.

Although Figure 2 shows that the majority of people living with hepatitis C are in the centre of the city, Figure 4 shows that many of the worst areas in terms of admissions are outside the centre. This variation suggests that it is not necessarily the areas with the highest prevalence that struggle to effectively support people with the condition.

Figure 4 – Percentage of emergency admissions for hepatitis C as a percentage of overall hepatitis C admissions in London



Opportunities for improvement

The implementation of the Health and Social Care Act 2012 is a turning point for the NHS and it can be for hepatitis C, if the correct action is taken.

There is a national focus on improving outcomes from liver disease through the NHS Outcomes Framework, and proposed National Liver Strategy. It is the first time that improving outcomes from liver disease has been on the same platform as other major killers such as cancer and cardiovascular disease through its inclusion in Domain 1 of the NHS Outcomes Framework and Domain 4 of the Public Health Outcomes Framework.

In addition, one of the objectives of the Public Health Outcomes Framework is to make improvements against wider factors that affect health and wellbeing, and health inequalities[27]. It makes clear that local bodies will have to work together to make this a reality.

This joint working will be particularly important as the reforms will see responsibility for hepatitis C commissioning transferring from PCTs to local authorities (for the public health elements), clinical commissioning groups and to the NHS Commissioning Board (for specialised types of hepatitis C treatment). These bodies will have to work together if hepatitis C is to be tackled effectively.

This should be used as an opportunity to renew momentum on hepatitis C. New NHS commissioners and local authorities have the chance to strive for excellence in hepatitis C services, learn from the mistakes of the past, and to show that new structures can work together to improve outcomes in hepatitis C.

The *London Health Inequalities Strategy* recognised the complex reasons for health inequalities in the capital and set out objectives for reducing health inequalities. The focus on regional and local leadership and ensuring measures on health inequalities are embedded in healthcare strategies is welcome. Delivering improvements for hepatitis C will help the GLA to deliver on its objectives on health inequalities.

Translating policy into action

The Hepatitis C Trust has identified four focus areas that, if tackled, could improve hepatitis C outcomes and save lives in London:

1. Prevention
2. Testing
3. Engagement in services
4. Treatment and support

Given the nature of hepatitis C and the people that it affects, there are specific issues around hard to reach groups that should be taken into account. For example, a testing campaign for injecting drug users would not necessarily help to identify people with hepatitis C from South Asian communities or men who have sex with men, thus missing out on almost 20% of the hepatitis C population in London.

Information from our audit of local authorities and NHS commissioners, coupled with knowledge that we have developed through our relationships with providers of hepatitis C services in London, gives us a good idea of what action is currently being undertaken on these issues in London. It also allows us to identify where additional steps should be taken to tackle hepatitis C and specific issues around hard to reach groups.

1. Prevention

Awareness campaigns and targeted prevention measures should form the core of local authority public health services and all areas should be assessing hepatitis C needs so that prevention measures can be planned accordingly. Prevention measures need to focus on making people aware of how hepatitis C is spread, to educate people to protect themselves and others.

Our audit of NHS commissioners and local authorities showed that:

- More than half of NHS commissioners and a quarter of local authorities in London that responded to our audit have not undertaken an assessment of current or future health needs in relation to hepatitis C, calling into question their ability to assess the need for and target prevention measures effectively
- Only a quarter of local authorities in London have run awareness campaigns for hepatitis C
- More than 70% of local authorities in London have no targeted measures in place to prevent hepatitis C transmission among at risk groups

In areas where measures are in place, they tend to be focused on injecting drug users and those using harm reduction services. It is, however, not only injecting drug users who are at increased risk of contracting hepatitis C. Although welcome, existing prevention activities should be broadened to target all at-risk groups, including those from South Asian communities and former injecting drug users.

Through undertaking a thorough assessment of local hepatitis C needs, local authorities will be able to target prevention measures at different at-risk groups affected in their area.

Haringey Council programme on hepatitis C

Haringey Council has a prevention programme for infectious diseases, covering tuberculosis, hepatitis B and hepatitis C. The programme was developed due to the high prevalence and incidence of infectious diseases in the area.

The programme plans to tackle hepatitis C by:

- Raising awareness to increase reporting and detection amongst populations at increased risk such as South Asian communities
- Developing a local hepatitis C action plan to support strengthened commissioning, integrated and robust pathways and take measures to increase testing
- Ensuring the a broad range of prevention services are maintained, going beyond needle and syringe exchange
- Improving information provided by hospitals on the number of people with hepatitis C who are referred, seen and treated for hepatitis C and their clinical outcome

Further information can be found at: http://www.haringey.gov.uk/index/social_care_and_health/health/jsna/jsna-adults-and-older-people/jsna-infectious-diseases.htm

2. Testing

As part of health promotion efforts, local organisations should be developing hepatitis C awareness and testing campaigns to increase the uptake of testing. It is only through wider testing programmes that the huge numbers of undiagnosed people will be identified and can be supported to manage their condition and, where appropriate, receive treatment.

Our audit of NHS commissioners and local authorities showed that:

- Around half of local authorities in London stated that they have data on the number of people tested for hepatitis C in their area, although this is often restricted to data from drug treatment agencies so would not cover everyone at risk of hepatitis C
- Only 17% of NHS commissioners in London have data on the number of people tested for hepatitis C
- Less than one third of local authorities in London have worked with the NHS to develop local testing campaigns
- 17% of NHS commissioners in London have measures in place to encourage testing in GP practices

These results show that testing for hepatitis C in London is patchy. Data on the number of people tested for hepatitis C are not universally collected and local testing campaigns are generally restricted to injecting drug users who access drug treatment services. In 2010, national testing rates dropped for the first time in several years, this is thought to be because people from the 'easy to reach' groups have already been tested and identified[28].

In order to identify people who are living with hepatitis C but are unaware that they are, it will be necessary for the NHS and public health services to work together and find other ways of reaching people who might be unknowingly living with the virus. Given the prevalence of hepatitis C in London, health and wellbeing boards should prioritise this issue and identify other ways to improve testing and the monitoring of testing.

The National Institute for Health and Clinical Excellence (NICE) has developed public health guidance on ways to promote and offer testing for hepatitis B and hepatitis C. This guidance includes specific reference on how to reach the hard to reach and sets out suggested testing activities[29].

The Royal College of General Practitioners (RCGPs) has an online learning tool for the detection, diagnosis and management of hepatitis B and hepatitis C. The online course forms the first activity for a RCGP qualification or can be a standalone course[30]. Participation should be encouraged among GPs, particularly those in high prevalence areas in London.

The Hepatitis C Trust has taken its testing van to mosques in London to target people from South Asian communities. There was significant interest and a number of people were tested as a result of the activity[31]. We hope to undertake more of this work in the near future.

3. Engagement in services

Due to the chaotic lifestyles of some people with hepatitis C, long-term engagement in health services can be difficult and people are often lost to follow up. Identifying mechanisms to support these people would help to ensure that they receive appropriate advice about managing their symptoms and receiving treatment.

Our audit of NHS commissioners and local authorities showed that:

- More than 60% of NHS commissioners in London have no estimate of number of hepatitis C patients who access NHS services in its area
- Not one NHS commissioner in London has undertaken an audit of the quality of hepatitis C services
- More than 60% of local authorities in London have measures in place to ensure coordination on hepatitis C

Failure to monitor who is accessing services suggests that no mechanisms are in place to prevent people living with hepatitis C from becoming lost to follow up. This mirrors findings from the HPA that show that less than half of NHS commissioners in London have a treatment care pathway in place for hepatitis C[32].

Local authorities and NHS commissioners should work together and be flexible in the way that they deliver hepatitis C services. The transfer of responsibility for the commissioning of some treatment to the NHS Commissioning Board will also require greater planning and coordination to help to keep people in the system and ensure they receive any psychological or emotional support alongside their treatment.

A person-centred approach should be followed and health and wellbeing boards should help to facilitate this. GPs should play a role in ensuring that those at risk are tested but also that they are referred for follow-up.

London Joint Working Group (LJWG) on substance misuse and hepatitis C pilots

The LJWG has identified five areas in London (Croydon, Islington, Lambeth, Lewisham and Haringey) to pilot the group's consensus document which sets out models for ensuring injecting drug users living with hepatitis C are identified, diagnosed, referred and supported through treatment. Through adopting a whole-person approach to hepatitis C among this group, it is hoped that more people with hepatitis C will stay within the system and receive appropriate support.

The pilots will be looking along the full patient pathway. One example of how this should work in practice is that if a person has decided that they would like to consider treatment for hepatitis C, a holistic needs assessment will be undertaken. This will include:

- Social, housing and mental health need
- Key worker support
- Buddying schemes and peer support
- Review of opioid substitution therapy to optimise adherence to HCV treatment

This information should enable local services to support people through treatment more effectively, and to ensure that if someone does not manage to complete treatment, ongoing support is provided.

Further information can be found at: http://www.ljwg.org.uk/pilots

4. Treatment and support

People living with hepatitis C should be given the opportunity to receive treatment. Providers and commissioners should be monitoring uptake as well as treatment outcomes. Treatment can clear the virus in about half of patients[33] and the HPA has predicted that increasing treatment could significantly reduce cases of cirrhosis and liver cancer over the next 10 years[34]. The HPA has also developed modeling to help commissioners to plan treatment services for their populations[35].

Our audit of NHS commissioners and local authorities showed that:

- Around 40% of NHS commissioners in London do have some measures in place to help increase treatment rates

- Less than 20% of NHS commissioners in London have an estimate of the number of people initiated on treatment for hepatitis C and even fewer know how much money they have spent on hepatitis C treatment

The fact that so few NHS commissioners are keeping track of the number of people initiated on treatment, or how much is spent on it, is concerning. This raises questions about how NHS commissioners would monitor the success of measures to help improve treatment.

An audit from the All-Party Parliamentary Hepatology Group (APPHG) identified significant discrimination in relation to treatment among injecting drug users. Its survey of hospitals found that although some hospitals treated everyone with hepatitis C, a number of hospitals had policies in place to either

prevent, or restrict treatment among injecting drug users[36]. This kind of approach is discriminatory and unacceptable, especially as there is positive guidance from NICE on hepatitis C treatments[37].

Under the health reforms, commissioning of treatment for genotype 1 will be the responsibility of the NHS Commissioning Board. The Hepatitis C Trust is keen to ensure that that capacity is planned effectively and that more people receive treatment as a result of the changes in commissioning. This should include a more flexible approach to delivering treatment for injecting drug users and targeted support for other groups.

The Hepatitis C Trust is committed to working in partnership with stakeholders in London to tackle hepatitis C, ensuring that all people at risk of hepatitis C are tested, and if diagnosed, effectively supported through treatment.

By focusing on the areas identified in this report and ensuring that measures are in place to target hard to reach groups, we will be able to deliver improved outcomes for people with hepatitis C – meeting outcome measures in the NHS reforms and helping to achieve the objectives set out in the *London Health Inequalities Strategy.*

In order to achieve this, we need to work together:

- The Greater London Assembly (GLA) should convene a working group that will spearhead the development of a pan-London hepatitis C action plan
- Health and wellbeing boards should support new CCGs and local authorities to prioritise hepatitis C and work together to tackle the condition among all people affected
- The NHS Commissioning Board should consider establishing clinical liver networks to support coordination across specialised, local NHS and public health services, and ensure appropriate clinical input in commissioning decisions
- Public Health England should take a lead on improving the data collection and publication on hepatitis C to enable measurement of all parts of the hepatitis C care pathway. Wherever possible, these data should be disaggregated by each hard-to-reach group
- Charities such as The Hepatitis C Trust should share their expertise and insights where possible and continue to undertake targeted activity with hard-to-reach groups in London
- Elected representatives should support their constituents in holding the NHS and local authorities to account on hepatitis C, ensuring that all people with hepatitis C are supported by public health and NHS services

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