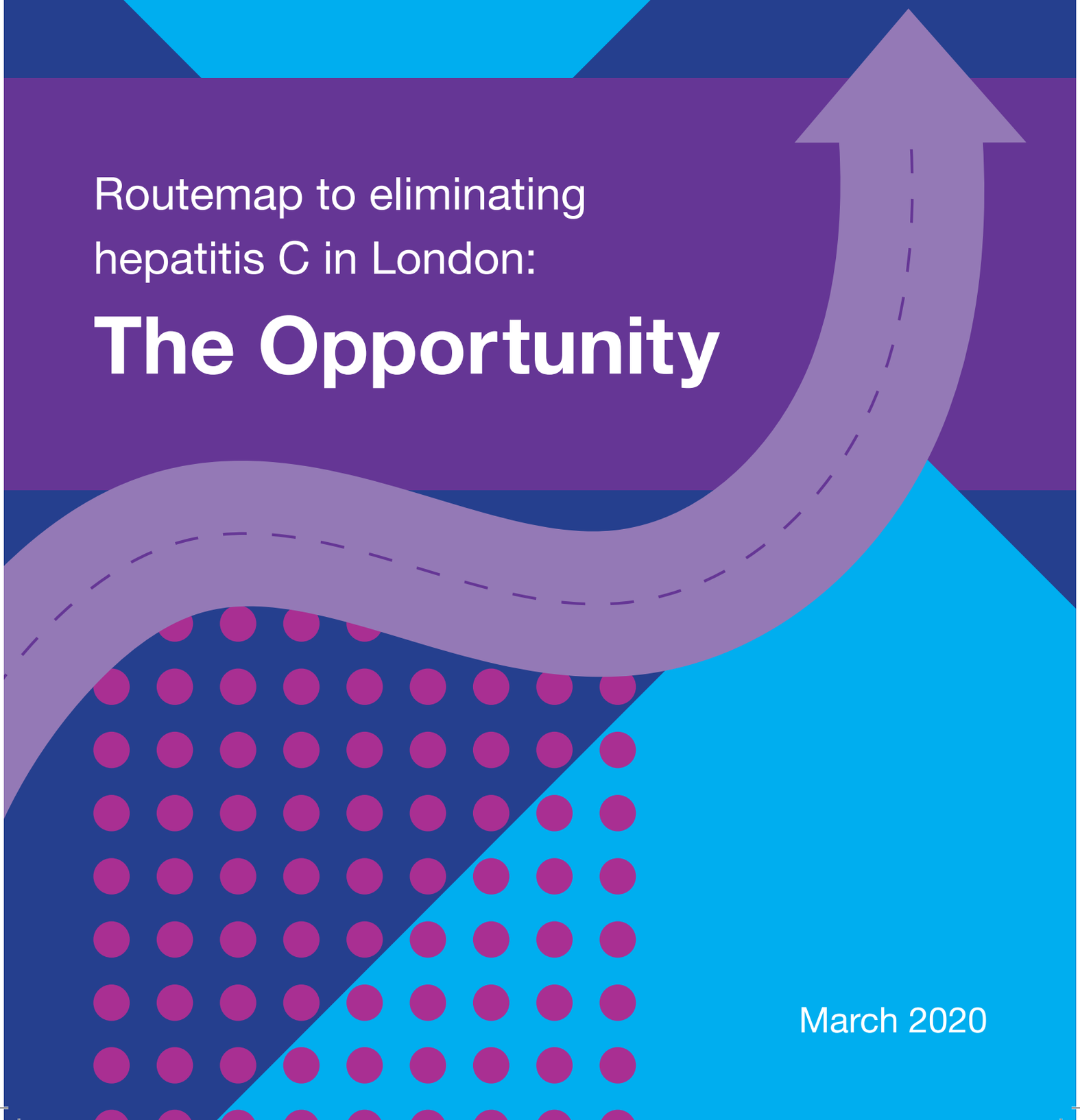
LONDON JOINT WORKING GROUP ON SUBSTANCE USE + HEPATITIS C

SUPPORTED BY MAYOR OF LONDON

THE HEPATITIS C TRUST

Routemap to eliminating hepatitis C in London:

The Opportunity



March 2020

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Introduction

Hepatitis C is an infectious blood-borne virus that can cause cirrhosis, liver cancer and premature death – yet we now have the treatments and care pathways to cure it and effectively eliminate the virus in London. This is an incredible opportunity and one anyone who has any experience of hepatitis C, in a personal or professional capacity, is determined to achieve.

To eliminate hepatitis C in London, we need to find and treat all those living with hepatitis C and to prevent new infections. All parts of the complex health and social care landscape in London – the NHS, Operational Delivery Networks (ODNs), local authority public health commissioners, drugs services, prisons, community outreach and others – must come together in a concerted and coordinated drive to find and treat those infected, to reduce new infections, and to increase awareness and understanding about the virus.

This is what the Routemap aims to do, convened by the London Joint Working Group on Substance Use and Hepatitis C (LJWG), led by a multi-sector stakeholder steering group and supported by the Mayor of London. **With this Routemap we hope to take a major step forwards in the history of disease elimination and make London the first global city to eliminate hepatitis C.**

Background

Hepatitis C is a blood-borne virus, transmitted by blood-to-blood contact. Risk factors therefore include sharing injecting equipment, having a tattoo or piercing in unregistered premises, receiving a blood transfusion or blood products before 1991 when screening for hepatitis C was introduced, having sex where blood is involved, and being born or having medical procedures in a high prevalence country or region (e.g. Egypt, Eastern Europe and South Asia).

Because of these routes of transmission, hepatitis C disproportionately affects many marginalised and vulnerable groups. It is highly prevalent amongst people who are homeless, and over half of people who attend hospital for hepatitis C are from the poorest fifth of society.[i] The Mayor of London is committed to reducing health inequalities and championing the work of the NHS, charities, volunteers and organisations involved in working to eliminate hepatitis C. One of the objectives in the London Health Inequalities Strategy is that people and communities are supported to tackle HIV, TB and other infectious diseases, including addressing the stigma surrounding them.[ii]

Over the past decade hepatitis C treatment has transformed dramatically. NICE approved tablet treatments are now available that can cure the virus in more than 95% of people in a matter of weeks with minimal side effects. The World Health Organization has set a goal of eliminating hepatitis C by 2030, and NHS England and NHS Improvement have set an ambition to eliminate hepatitis C as a public health threat in England by 2025. Last year NHS England and NHS Improvement signed a ground-breaking deal with pharmaceutical companies to reduce drug costs for hospitals and initiate a multitude of projects, as a part of a comprehensive elimination strategy, to find people living with hepatitis C and to support them into treatment.[iii]

Hepatitis C in London

Public Health England (PHE) estimates there are around 113,000 people living with hepatitis C in the UK, with around two-thirds of people undiagnosed.[iv] In London, the estimated number of people living with the virus has recently been revised from 40,000 to 14,200 people due in part to increased and successful efforts to test and treat more people.[v] Many are living with the virus undiagnosed and unaware. The number of people living with hepatitis C varies considerably between London boroughs.

Key statistics

There were more laboratory reports of hepatitis C in London in 2018 than for any other region in England, with **over 2,600 new diagnoses reported.**[vi]

London accounts for **nearly a third (31%)** of new hepatitis C antibody-positive laboratory reports in England.[vii]

A third (33%) of people injecting drugs in London in 2018 reported direct or indirect sharing of drug taking equipment in the last month, the greatest risk factor for transmitting hepatitis C.[ix]

The landscape

In London there are four ODNs, the systems responsible for delivering treatment for hepatitis C; different drug and alcohol treatment services in each of the 33 London boroughs, each offering hepatitis C testing and many of which offering treatment; six prisons offering opt-out BBV testing to all prisoners, over 100 homeless hostels, four mobile outreach vans supporting people experiencing homelessness with hepatitis C and other tests, and peer support teams across both community and prison services. Soon, selected pharmacies will offer hepatitis C testing to at-risk clients as part of a national two-year NHS England and NHS Improvement programme.[x]

There are many examples of dedicated and innovative practice across London, with services working together to offer patient-centred testing and treatment to people with or at risk of hepatitis C. For example, The Hepatitis C Trust's mobile outreach van has partnered with King's College Hospital NHS Foundation Trust to engage people experiencing homelessness in testing and treatment. As well as being a 'one stop shop' for hepatitis C care, the van also runs a needle and syringe programme (NSP) and signposts people to other services.

And yet still more will need to be done if we are to successfully eliminate hepatitis C according to WHO's definition: an 80% reduction in new infections from 2015 levels, 80% of those eligible being treated, and a 65% reduction in mortality from hepatitis compared with 2015 levels.[xi]

A priority in achieving elimination must be to reduce new infections. Two in five people injecting drugs do not have enough needles and syringes for a clean set of works for each injecting event.[xii] A study of over 400 people who inject drugs in London published in 2018 found that 65% of those who had injected in the previous year had reused needles or syringes during that time.[xiii] NSPs will be crucial to maintaining elimination going forward.

What more needs to be done

To reduce stigma and encourage testing we will need to raise awareness of hepatitis C both among those at risk and those who work with them, such as professionals across London working at substance use services, prisons, and homeless services. In addition, we need to raise awareness with people who are not engaged with the above services. These may be people who injected drugs many years ago and who are no longer in touch with any drugs services, or people who are from a high-prevalence country.

The potential of GPs to find people who are not yet aware they have hepatitis C has also so far not been fully realised, although there are pockets of dedicated work going on which can be built on across London.

Even once people have been diagnosed, many fall off the patient pathway, an issue which could be mitigated by the widespread adoption of one-step reflex testing and more person-centric pathways that blend what are currently siloed disease-specific pathways into efficient and synergistic ones.

In addition, initiatives to drive down HIV transmission have much to teach us, and there is potential to work closely with HIV professionals to reduce the significant co-infection rates of the two viruses.

Finally, we will never achieve elimination unless we prevent new transmissions. This means ensuring harm reduction services are well resourced and available to all those who need them.

In creating this Routemap, the LJWG and partners, supported by the Mayor of London, will spotlight issues and focus efforts in areas where coordination and synergies are needed, building on the partnerships and initiatives already taking place.

About the Routemap to hepatitis C elimination in London

The Routemap to hepatitis C elimination in London sets the direction of travel to bring key stakeholders together and make elimination a reality in London.

We are coming together to develop a pan-London approach to preventing new infections, increasing access to testing for people at risk, and improving pathways to treatment for those infected. We also aim to make pathways seamless and synergistic with the efforts aimed at tackling HIV and other blood-borne viruses.

The concept of the Routemap to elimination in London started at a meeting of leaders in the hepatitis C field from across NHS England and NHS Improvement, local government, PHE, the ODNs, local authority public health teams, outreach projects, and the third sector in June 2019, convened by the GLA and LJWG. There was unanimous agreement that a coordinated and concerted approach to eliminating hepatitis C in the capital was needed.

Since then a steering group has been formed with representatives from each health or care area and a broader consultative meeting was held with key sector representatives in November 2019.

The steering group have identified five main opportunity areas that will be a focus for progress as part of the Routemap.

Work is ongoing and we encourage everyone to get involved. Please contact **info@ljwg.org.uk** to find out how you can contribute to the work.

Steering group membership

Constituency	Name	Title
Drug services and chair	Dr Emily Finch	Consultant Addiction Psychiatrist at the South London and Maudsley NHS Foundation Trust
GLA and deputy chair	Vicky Hobart	Head of Health, Communities and Intelligence Directorate, Greater London Authority
ODNs	Dr Kosh Agarwal	ODN Co-Lead South Thames, Consultant Hepatologist and Transplant Physician at the Institute of Liver Studies, King's College Hospital, London
ODNs	Prof Ashley Brown	ODN Lead West London, Consultant Hepatologist at St. Mary's and Hammersmith Hospitals in London and honorary senior lecturer at Imperial College London
ODNs	Dr Dan Forton	ODN Co-Lead South Thames, Consultant Gastroenterologist, St George's University Hospital
Local authorities	Andy Brown	Head of Substance Misuse / ONWL Sub Regional Lead, Community and Well Being, Brent Council
CCGs	Prof Sam Everington	Chair, Tower Hamlets CCG, GP, Bromley by Bow Partnership
Patient representatives	Rachel Halford	Chief Executive, The Hepatitis C Trust
STPs	Simon Hall	Director of Transformation, East London Health and Care Partnership
NHS England and NHS Improvement	Amanda Heeralall	Regional Programme of Care Manager Blood and Infection (London) Specialised Commissioning
PHE	Alison Keating	Head of Alcohol, Drugs and Tobacco
Association of Directors of Public Health (ADPH) and Directors of Public Health	Dr Nicole Klynman	Consultant in Public Health, London Borough of Hackney and City of London
Sexual health	Jonathan O' Sullivan	Director of Sexual Health for London
LJWG	Dee Cunniffe	Project Manager, London Routemap

Steering group deputy and co-opted members

PHE (London)	Emma Burke	Programme Manager, Alcohol, Drugs and Tobacco
Local authorities	Sarah Hart	Senior Public Health Commissioner, London Borough of Haringey
CCGs	Dr Werner Leber	NIHC Clinical Lecturer in Primary Care & Clinical Co-lead, Clinical Effectiveness Group, Queen Mary University London
ADPH	Iona Lidington	Director of Public Health, Royal Borough of Kingston upon Thames
NHS England and NHS Improvement	Dr Jacqueline Lindo	Lead Consultant in Public Health Medicine, Specialised Commissioning, NHS England and NHS Improvement (London)
Drug services	Jody Lombardini	Director of Addictions Services, Central and North West London NHS Foundation Trust
GLA	Alison Pearce	Senior Policy and Programmes Officer
Patient representatives	Stuart Smith	Director of Community Services, The Hepatitis C Trust
London Council (Co-opted member)	Clive Grimshaw	Strategic Lead for Health and Social Care

Opportunity area 1

Promoting the conversation: Reducing stigma and raising awareness

We know we have work to do to end the stigma surrounding hepatitis C, to raise awareness of what the virus is and the availability of curative treatments, and to promote testing to all the many and varied people living in London who may have been at risk.

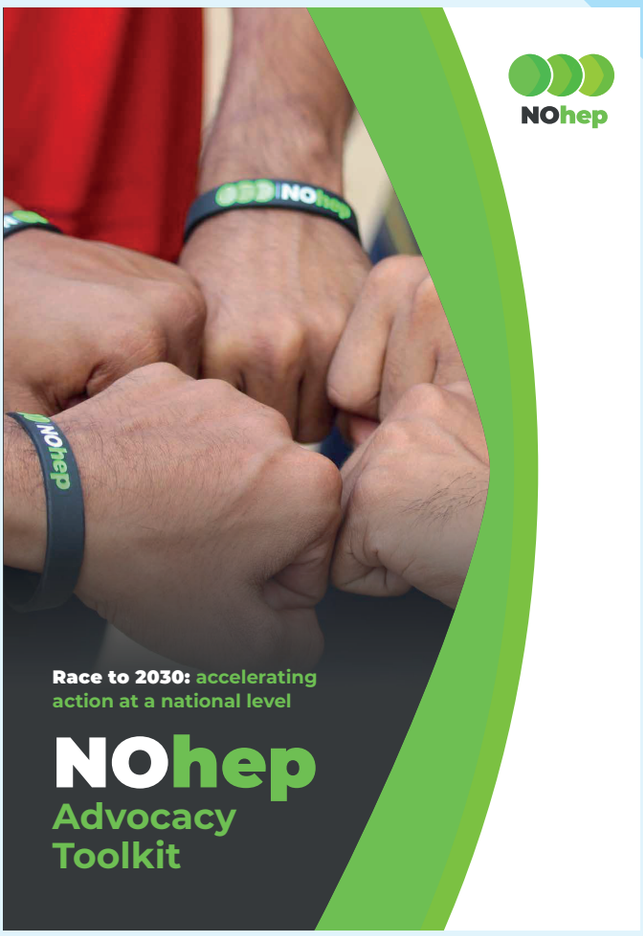
Awareness of what hepatitis C is, and the highly effective treatments that are now available, is poor. For example, the LJWG's pharmacy hepatitis C testing pilot showed that 57% of people tested did not know that interferon-free treatments were now available.

This workstream will:

- Identify what communications work is happening across London, highlight needs, and develop plans to meet those needs.
- Consider different target audiences and the messages and channels best suited for those audiences, working with people with lived experience of hepatitis C every step of the way.
- Work closely with Fast Track Cities and the HIV community to better understand and address stigma with the aim of eliminating stigma and normalizing testing and treatment.

Mayor of London Sadiq Khan visited a testing van at a homeless hostel on World Hepatitis Day, 27th July 2019, to promote hepatitis C testing and to get a test himself.

#HepCULater is an awareness campaign run by the NHS Substance Misuse Provider Alliance.



#NOHep is the global hepatitis awareness campaign run by the World Hepatitis Alliance.

Opportunity area 2

Engaging people who are under-served by traditional health systems

Some disadvantaged and vulnerable groups are at risk of hepatitis C, such as people who are homeless, people who inject drugs but are not in touch with treatment services, undocumented migrants and sex workers. These groups are likely to have complex health needs and are unlikely to be diagnosed and treated in a hospital setting.

- Average life expectancy for those who are homeless is 44 years.
- The number of rough sleepers in London has more than doubled in the last 10 years.
- Only 10 local authorities in London reported there was any current collaborative work with Clinical Commissioning Groups (CCGs) to address hepatitis C in homeless populations (PHE survey 2019).

This workstream will:

- Work with partners, including the third sector, to explore the feasibility of introducing a health check process in homeless assessment centres / staging posts which would also conduct hepatitis C and HIV testing.
- Bring together the range of outreach and find-and-treat homeless initiatives in London to achieve better coordination and efficiencies to make sure resources are always deployed where they are most effective and needed.
- Link the work around the development of the hepatitis C pathway with the Mayor's wider Life off the Street's programme, both through his commissioned services such as NSNO, and CHAIN but also strategically through the work of the Life off the Streets taskforce.
- Consider messaging and information and support needs for vulnerable groups of people.
- Work closely with the roll out of the national NHS England and NHS Improvement-funded pharmacy testing programme across London to ensure the opportunity this presents is maximised for these groups.
- Consider further work to engage with under-served groups.

Opportunity area 3

Working with GPs to find the undiagnosed

GPs can help find people who are not yet aware that they have hepatitis C, particularly those who contracted the virus many years ago and people who are from high prevalence countries. This workstream will closely work with ODNs, CCGs and GP practices to update GPs on availability of new treatments, spread good practice and encourage a proactive approach to case finding, leveraging the possibilities opened by the use of electronic health records.

NICE guidance on hepatitis B and C testing for primary care (PH43)[xiv]

- GPs and practice nurses should offer testing for hepatitis B and C to people at increased risk of infection, particularly migrants from medium- or high-prevalence countries and people who inject or have injected drugs.
- GPs and practice nurses should offer testing for hepatitis B and C to people who are newly registered with the practice and belong to a group at increased risk of infection.
- GPs and practice nurses should ask newly registered adults if they have ever injected drugs, including image and performance enhancement substances at their first consultation.
- GPs and practice nurses should offer annual testing for hepatitis C to people who test negative for hepatitis C but remain at increased risk of infection.

Screening for new registrations

Tower Hamlets have rolled out a multiple infection screening programme in general practice for new registrants, looking for HIV, hepatitis B, syphilis, latent TB and hepatitis C. This could be promoted to be considered by other boroughs across London.

Supporting GPs to case find with new software

A case finding software tool for GPs has been developed as part of the NHS England and NHS Improvement deal with industry and will be available later from April 2020. This will allow GP practices to search through their records for people who have READ codes indicating past infection with hepatitis C (people who were diagnosed many years ago many not have been offered treatment), and other risk factors. The people identified can then be contacted by their GP and offered a test.

Opportunity area 4

Reducing pathway attrition

Pathways from testing into treatment need to be as simple and short as possible so that people do not fall out of the pathway. This workstream will look at care pathways across London to identify how pathways can be simplified and made more patient-centric.

1-step reflex testing across London

One key way to do this is to ensure that people are told if they have active infection (i.e. if they are RNA positive) when they have their test result, not just whether they have ever been infected (i.e. they are antibody positive). The majority of tests are automatically reflex-tested for active infection if antibodies are detected, enabling this full diagnosis to be given to the patient. However, in some areas of London up to 30% of tests are not automatically reflex-tested for active infection, meaning that people will only be told they have been infected in the past and therefore need further blood tests to establish active infection. This adds a layer to the care pathway where people may disengage.

This workstream will bring virologists, commissioners, CCGs, ODNs, PHE and other stakeholders together to ensure 1-step reflex testing is standard across London.

Improving commissioning of testing and pathways into care in drug and alcohol services

Drug and alcohol services are a critical partner in offering testing and pathways into treatment for people who are at risk of infection.

This workstream will support ODNs, which have responsibility for dispensing treatment, as well as local authority commissioners and drug services to identify and implement good practice in testing (including 1-step reflex testing), re-testing, harm reduction, data reporting and pathway development.

Integrating peers into pathways

Peer support enables someone to receive help from another person who has lived through a similar experience. Peers are often uniquely placed to engage with people with complex needs and who are unlikely to engage with traditional health services. For example, The Hepatitis C Trust's peer programme enables peers to work in substance use services, homeless hostels and prisons supporting people into testing and through treatment.

Opportunity area 5

Aligning hepatitis C and HIV public health efforts to begin producing truly person-centred pathways

There are significant synergies in efforts to address HIV and hepatitis C, and good practice in both areas that can be built on. In a meeting of senior leaders from the HIV Fast Track Cities initiative (FTC) and of hepatitis C stakeholders, four key areas of synergy and potential future partnership work were identified as opportunities for accelerating elimination of transmission of HIV and hepatitis C:

1. Promote and scale up testing:

Where possible, efforts to increase testing for HIV or hepatitis C should incorporate both and ideally also include hepatitis B. For example, more can be done to increase testing for HIV in drugs services, building on excellent work in hepatitis C, and more can be done to test for hepatitis C in sexual health services, building on excellent longstanding work on HIV. In addition, testing for HIV, hepatitis C and hepatitis B at A&E departments will be explored by FTC and the Routemap Steering Group.

2. Address stigma

Many people with hepatitis C experience significant stigma in a range of settings. For example, many report discriminatory responses to hepatitis C in healthcare settings and a study in prisons identified stigma as an issue among prison officers.

HIV stigma has been identified by the Fast Track Cities initiative as a key issue to address. All work and plans will be co-designed with individuals and organisations working in London's HIV community, focusing on:

- **Societal stigma:** Reshaping the public perception of HIV to a long-term condition that people can live well with, and which cannot be passed on if the individual is on effective treatment.
- **Stigma in environments / places:** Making the NHS a completely stigma-free organisation in phase 1. Rolling this out to other government services in the next phase.
- **Self-stigma:** Building knowledge, self-confidence and resilience, as well as developing the skills needed to challenge any stigma experienced or witnessed.

By working together and learning from the progress being made in addressing HIV stigma, we can start to actively address hepatitis C stigma.

3. Reduce coinfection

With the treatments available for hepatitis C, coinfection should no longer exist. This workstream will look at how people who are coinfected can be supported into treatment for both their viruses.

4. Defining and maintaining elimination

Elimination of a transmissible virus will only be maintained if a sustainable infrastructure is achieved to sustain testing and swift pathways into treatment for any new infections. We need to start planning for this phase now, alongside our concerted effort to reach effective elimination.

The development and implementation of the Routemap to hepatitis C in London is an ongoing process and we encourage all stakeholders to get involved. Please email **info@ljwg.org.uk** for updates and to get involved.

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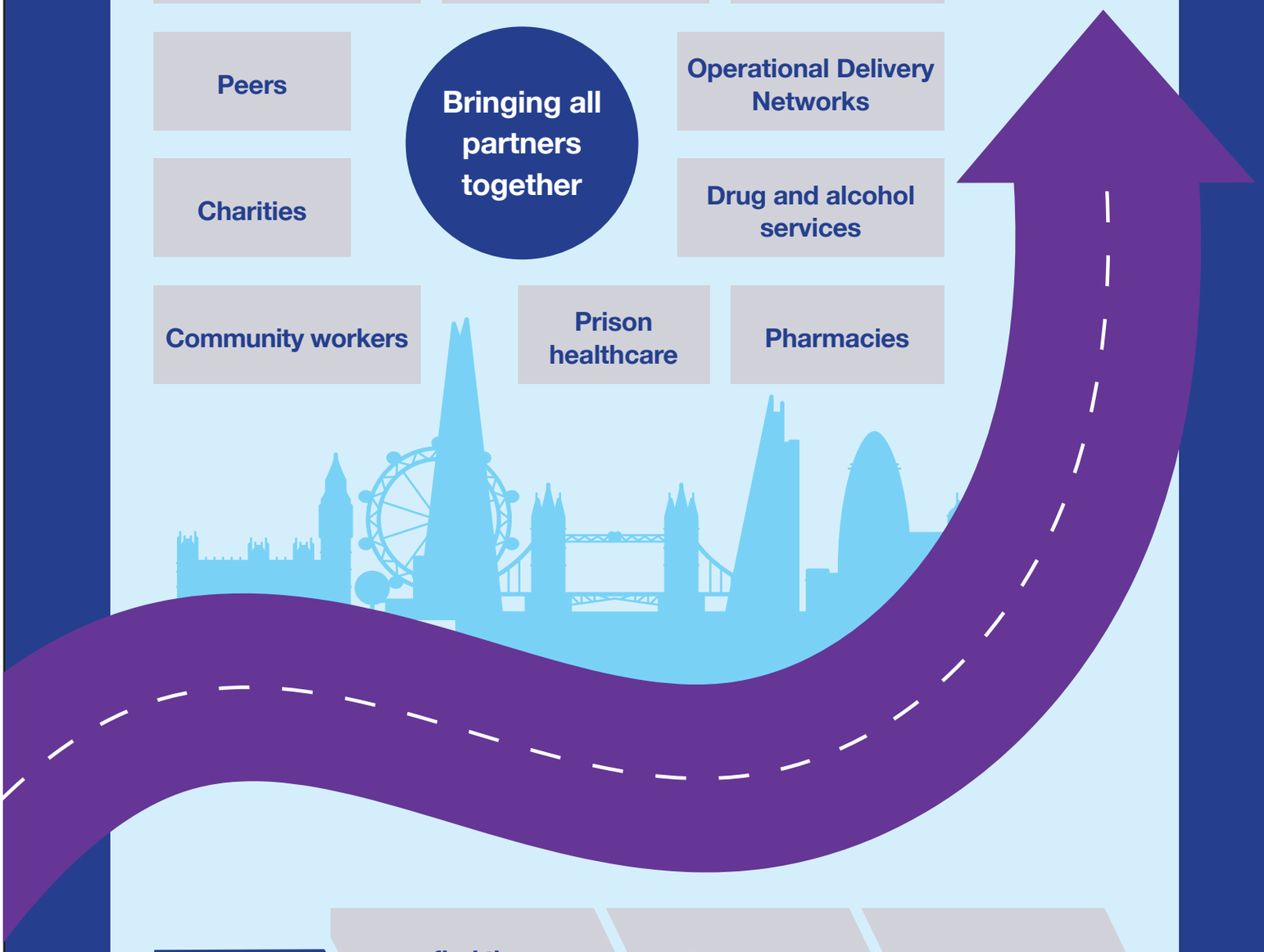
Routemap to eliminating hepatitis C in London



To drive forward work to:

- find the undiagnosed
- make treatment easy to access
- prevent new infections
- raise awareness
- remove stigma
- **eliminate hepatitis C in London**