MSD

Making Hepatitis C History: A Framework for Elimination

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Thanks

Since the outputs and recommendations of the steering committee members were made, the NHS environment and provider landscape has been significantly impacted by Covid-19 but the overarching principles still apply.

MSD would like to thank the following UK Hepatitis C experts for their participation in guiding and contributing to this publication:

Birmingham Elimination Framework Steering Committee

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Foreword

Professor David Mutimer
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Hepatitis C is one of the most significant public health challenges facing society today, and NHS England's 2025 ambition to eliminate hepatitis C as a public health threat in England by 2025, ahead of the World Health Organisation global goal of 2030, is to be lauded and welcomed.

Challenges exist in reaching the targets of elimination. These include the identification of infection in a disease which is largely asymptomatic. At a local level, the last few years have witnessed a large number of initiatives which increase the rate of diagnosis and help the drive towards elimination.

Indeed, when seeking to achieve elimination, several principles have emerged. Most important are local partnerships and co-operation, and a detailed understanding of the complete patient management pathway. All partners need to agree simple and effective pathways that are patient focused and which result in a rapid journey from diagnosis to treatment and cure.

That is where this Framework comes into play. It is not a 'one-size-fits-all' document but rather a reference point. A guide looking right across the patient pathway to simply encourage and help local stakeholders and decision makers to agree and shape their own elimination goals, targets and strategies.

It is certainly not exhaustive but rather a considered contribution to support delivery of the 2025 elimination ambition. Certain elements will be more, or less, relevant to local stakeholders. That is to be expected.

I was pleased to be invited to join the Framework's expert group and I hope local leaders find it a valuable resource. Wherever you may be on your own elimination journey, this document has been designed to speak to and support you in some way.

Foreword two:

Debbie Porter
Executive Director, Specialty Care, MSD

The UK has a real opportunity to eliminate hepatitis C as a public health threat, within a generation.

It is a brave goal but at MSD we believe that we have never been closer than we are today to realising this ambition. Our commitment to this mission has been at the heart of our work for many years and it is this commitment that led us on the journey which culminates in the publication of this document '*Making Hepatitis C History: A Framework for Elimination*'.

It isn't to say there won't be challenges. Today, two thirds of people living with hepatitis C remain undiagnosed and there is an urgent need to identify, diagnose and treat all people living with hepatitis C.[1] This will require our health and social care systems to think creatively and adopt new ways of working.

But with the combined efforts of all stakeholders – healthcare professionals as well as local authorities and national government, policy makers, advocacy groups, non-governmental organisations (NGOs) and the private sector – elimination is certainly achievable.

This document embodies the experience, expertise and leadership from experts from across Birmingham, an area of the country which has been leading the way in the progress towards micro-elimination. Whilst this document recognises that each area of the UK is different, there are also commonalities that underpin the success of any hepatitis C micro-elimination strategy. Principles and approaches which, if kept front of mind, will help set us on the right path towards achieving the ambition.

By drawing this expert group together, we hope to provide a simple, practical document to aid local health leaders across England who are focused on micro-elimination, to navigate potential challenges and forge their own path towards elimination. It aims to support development of local strategies, from identification of those living with undiagnosed hepatitis C to continuing care, measuring impact and evaluation.

MSD would like to thank each Expert Group member for providing their support and insight in the development of this Framework and we look forward to working with the community to make the elimination of hepatitis C within a generation, a reality.

Introduction

Viral hepatitis is a major public health threat globally, estimated as the seventh highest cause of mortality.[2] In England alone, recent estimates suggest that around 89,000 people are chronically infected with hepatitis C,[3] the majority of whom are from marginalised and underserved groups in society, such as people who inject drugs (PWID).[4] In 2015, 10,470 people were estimated to be living with hepatitis C related cirrhosis or liver cancer in England.[5]

Against this backdrop, the NHS is planning for England to be the first country in the world to eliminate hepatitis C. It has committed to meet the target set out in the World Health Assembly Global Health Sector Strategy (GHSS) on viral hepatitis[6] to eliminate hepatitis C as a major public health threat – by 2025[7], five years earlier than the 2030 ambition as set out in the GHSS.

This is to be applauded and warmly welcomed. NHS England's pledge to become the first country to eliminate hepatitis C[7] signals a clear national commitment to lead the global ambition to identify and treat more people living with hepatitis C – and provides a hugely exciting opportunity.

A key step in this journey was the launch of a new strategic elimination tender by NHS England in 2019.[8] This "ground-breaking deal", sees three drug companies working together with the NHS and third sector providers, to proactively identify and treat people who may be unaware they have hepatitis C, including homeless people and those with mental health problems.[8]

Now two years in to the strategic elimination initiative, much progress has been made.[3] But there is more that can be done, and this relies on a coordinated national response which drives change at a local level. Already, much great and vitally important work is being carried out to achieve elimination up and down the country driven by healthcare professionals, national and local policymakers and affected communities. Local implementation plans should be adapted to incorporate new pathways and guidance developed in response to the Covid-19 pandemic.

This Framework, which has been produced by MSD seeks to neither duplicate nor distract from that work. Instead, it aims to further build the thinking underpinning the elements needed for the successful elimination of hepatitis C – both in theoretical and practical terms – looking across identification, referral, treatment, continuing care, and how to measure impact and evaluation. This framework is particularly focused on systems within England but can also be utilised in other regions across the UK.

How to use this document

This document has been designed as a checklist and a reference guide to support you – local government and health leaders – in outlining and understanding some of the key steps and considerations needed to support the development of locally tailored hepatitis C elimination strategies. This document contains guidance for the whole process, from the identification of who is needed around the table, through to unpacking and understanding the local hepatitis C pathway.

No two localities are the same in terms of the populations they serve, resource to hand, and services on the ground. As such, the Framework is deliberately broad in its approach, with simplicity and accessibility at its core.

It is not binding, but supportive. It is a tool to be leveraged as needed and appropriate at the different points in the development of your own hepatitis C elimination strategy, bringing together both the theoretical and practical steps to be worked through.

As you work through the Framework some sections may be of more, or less, relevance to you and your local area. That is to be expected and local health leaders are encouraged to work through the Framework at their own pace.

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Bringing the right team together (Part 1)

Overview: The hepatitis C commissioning and delivery landscape is complex. While different parts of the pathway – including Public Health England, NHS England and social care – are responsible for ensuring the integrated commissioning of hepatitis C services, it is also crucial that these bodies work in collaboration with clinicians, public health agencies and other stakeholders to:

- Simplify referral pathways
- Improve the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings
- Drive innovative approaches to outreach and support for people living with hepatitis C.

Aim of this section: **This part of the toolkit will support you in identifying the right team to bring together to develop your micro elimination strategy, and drive it forward through collaboration, publication and advocacy. This page provides a simple snapshot of those involved in the commissioning and delivery of services, while the next page sets out those you may want to consider forming part of your core steering group.**

Hepatitis C pathway:
Who commissions and who delivers?

Commission and delivery key:

- Health and justice settings
- Primary and secondary services
- Community based services
- Pharmacies
- NHS England and specialised services
- National public health leadership

Awareness-raising
Mayor
Local MPs
Councillors
Patient organisations
Public Health England

Identification (testing)

Commissioned by:
NHS Health and Justice | Local authorities | Clinical Commissioning Groups | NHS Specialised Commissioning

Delivered by:
Prisons | Drug and alcohol services | Sexual health services | Pharmacies | GP surgeries | Hospitals

Referral for diagnosis

Commissioned by:
NHS Health and Justice | Local authorities | Clinical Commissioning Groups | Pharmacies

Delivered by:
Delivered by: Same providers as above *(identification)* to assess for treatment using FibroScan and initiate a follow-up test prior to referring to the ODN to determine the best treatment options

Awareness-raising
Mayor
Local MPs
Councillors
Patient organisations
Public Health England

Treatment

Commissioned by:
NHS Specialised Commissioning provides drugs to relevant providers | NHSE also expects ODNs to coordinate and approve treatment which may be delivered in a number of locations

Delivered by:
Specialist hospitals | Prisons | Local authority outreach centres | Pharmacies

Awareness-raising
Patient organisations

Continuing care

Commissioned by:
NHS Health and Justice | Local authorities | Clinical Commissioning Groups

Delivered by:
Prisons | Drug and alcohol services | GP surgeries | Hospitals

Measuring impact and evaluation

Commissioned and delivered by:
Public Health England | NHS Health and Justice | Local authorities | Clinical Commissioning Groups | Pharmacies

** Pathway adapted from hepatitis C Action Hepatitis C Commissioning Toolkit*

Bringing the right team together (Part 2)

Not every one of these stakeholders will need to be involved in the development of your elimination strategy from inception through to publication and implementation. However, garnering their insights and collaboration during the process will be important in designing a unified, universal and integrated pathway.

Core steering group: The core group that should be involved in the development of the strategy are the 'decision-making authorities' and 'hepatitis C testing or treatment service providers'. The individuals that form part of these groups are outlined below.

Nonetheless, the unique composition of each region will dictate the additional stakeholders that may form part of the core group. For some regions a representative from homelessness services could be indispensable if outreach is a key part of the strategy, while for others, a Sustainability and Transformation Partnership lead may be integral.

Patients and impacted communities should always be considered as stakeholders in the development of any strategy. It is also worth noting that hepatitis C services in secondary care are delivered through Operational Delivery Networks, usually referred to as ODNs.

Co-opted members: Within each of the sub-strategies; identification (page 16), referral (page 20), treatment (page 23), continuing care (page 26) and measuring impact and evaluation (page 29) it would be desirable to co-opt representatives from other stakeholder groups. Indicated on each page are the stakeholders it would be beneficial to include in these discussions, and the development of these sub-strategies.

Following the discussion of the expert group the following decision makers and responsibilities were identified as the most appropriate stakeholders in the process toward hepatitis C elimination.

Decision-making authority (core steering group members)[9]

1. **Director(s) of Public Health (local authority):** Responsible for **commissioning testing** for hepatitis C in drug services and sexual health services, needle exchange programmes in pharmacies, local awareness-raising campaigns around hepatitis C[10]

2. **CCG(s) representative (NHS):** Responsible for **commissioning testing** for hepatitis C by GPs and in hospitals, **monitoring of treatment** if overseen in a hospital, **treatment costs for some associated health complications** arising from hepatitis C infection, ensuring appropriate levels of **hepatitis C knowledge among relevant staff** such as GPs

3. **Health and justice commissioner(s) (NHS England):** Responsible for **implementing opt-out testing for hepatitis C in prisons** and ensuring **access to treatment** pathways for those who are diagnosed with hepatitis C in secure settings

4. **Operational Delivery Network (ODN) clinical lead(s) and managers (NHS):** In each ODN a multi-disciplinary team makes prescribing decisions **on which people living with hepatitis C in their area should receive treatment.** People living with hepatitis C in each ODN area are referred to the MDT for review by local services, including primary and secondary care services and prisons

Hepatitis C testing service provider (core steering group members)

5. **Drug and alcohol services (local authority):** Via a clinician or a nurse, responsible for the **delivery of hepatitis C testing** and **referring** those who are positive into treatment

6. **Sexual health services (local authority):** Via a clinician or a nurse, responsible for the **delivery of hepatitis C testing** and **referring** those who are positive into treatment

7. **The Hepatitis C Trust (Third sector):** The Hepatitis C Trust's peer-to-peer support work involves staff and volunteer peers with lived experience of hepatitis C providing support to those at risk of and living with hepatitis C, raising awareness and **supporting access to testing and referral treatment**.[11]

   NB: GPs and pharmacists – who also provide testing – are considered under 'clinical service provider'

Changes during the COVID-19 Pandemic

During the COVID-19 pandemic, alternative funding and planning mechanisms have been used in some parts of the NHS but the requirement for teamwork and collaboration across stakeholder groups in healthcare and public health remains a critical success factor for successful hepatitis C services.

Clinical (service) provider

Consultant hepatologist: Part of the ODN multidisciplinary team, responsible for **treatment initiation** and **monitoring** (or Infectious disease specialists in some areas).

Hepatitis nurse specialist: Responsible for the **management and treatment** of hepatitis C. In some cases, nurses support consultant hepatitis C clinics, run nurse-led clinics hospitals and prisons, work in the community with drug and alcohol services and run community clinics across a region.

GP: Responsible for the **delivery of hepatitis C testing and referral** to hospital for further tests, consultation and care. Often the first point of contact *(may be represented on the steering group through the CCG).*

Community pharmacist: Responsible for the **delivery of hepatitis C testing and referral** to hospital for further tests, consultation and care.

Hub pharmacist/hospital pharmacist: Also responsible for the **hepatitis C referral** to hospital for further tests, consultation and care.

Advisory role

Public Health England: Responsible for **researching, collecting and analysing data** to improve understanding of hepatitis and other public health challenges.

NHS England regional lead for specialised commissioning: Responsible for providing **professional leadership** on specialised commissioning.

NHS England Regional Programme of Care (POC) Manager (Blood and Infection): In collaboration with the NHSE Commercial directorate, set the direction of the strategic plan for HCV that resulted in the Elimination Initiative and tender in line with the commissioning principles of Specialised Commissioning and the NHS.

NHS England regional lead, Infectious Diseases Clinical Reference Group: Responsible for the **delivery of the 'products' of commissioning.** These are the tools used by the ten Hub Commissioning Teams to contract services on an annual basis.[12]

Other relevant service providers

Homelessness services: People experiencing homelessness are thought to be 50 times more likely to be chronically infected with the hepatitis C virus,[13] yet only three per cent will receive treatment; there is an opportunity to **raise awareness** and **signpost** individuals to appropriate services for testing.

Mental health services: The prevalence of chronic hepatitis C virus infection is among the highest in people who have a severe underlying mental illness;[14] there is an opportunity to **raise awareness** and **signpost** individuals to appropriate services for testing.[15]

Awareness-raising and advocacy

Mayor (where applicable): The devolved powers vary across the combined authorities but some directly-elected Mayors – and combined authorities – have greater **responsibility for health budgets** in their region.

Local Members of Parliament (MPs): An MPs role is to **protect, advocate and promote the interests of their constituency and their constituents** at a local and national level.

Cabinet Member for Health and Care* (local authority): Main **decision-maker for public health and care** in a local authority; **responsible for leading the improvement of their population's health**, supported by the Director for Public Health. Often Chairs the Health and Wellbeing Board.

Health and Wellbeing Board (local authority): Responsible for promoting integration and partnership between the NHS, Public Health England and local government. They have a statutory duty, with clinical commissioning groups (CCGs), to **produce a joint strategic needs assessment** and a **joint health and wellbeing strategy** for their local population.

Chair, Health Scrutiny Committee* (local authority): Can influence the policies and decisions made by the council and other organisations involved in delivering public services; **issues can be raised for work programming** in the coming year.

Patient organisation(s): The Hepatitis C trust is the leading patient organisation playing a key role nationally in delivering much needed testing and peer support outreach services, advocacy efforts, research, representation, patient support and information, and raising public awareness.

**Specific title may vary*

Other relevant stakeholders

Prison Governor*: Has overall responsibility for the management of the prison, security, standards and budgets in addition to supporting vulnerable prisoners.

Police and Crime Commissioner: Partners with Health and Wellbeing Boards and plays a role in reducing the health inequalities which exist among offenders and ex-offenders by way of shared outcomes with CCGs and local authorities.

Academic(s): Responsible for clinical and basic research efforts to advance the management, treatment and elimination of hepatitis C.

**Specific title may vary*

To keep appraised

Integrated Care System lead (ICS): ICSs bring together a wide range of local health providers and users, the voluntary sector and elected representatives to coordinate and agree system-wide priorities, and to plan collectively how to improve residents' health.[14]

Primary Care Networks: PCNs are groups of GP practices working closely together with other local organisations, such as community, mental health, social care, pharmacy, hospital and voluntary services. They will provide integrated services, support the needs of the local population that has grown, is living longer, and may need to access local health services more often. PCNs typically cover populations of between 30,000 to 50,000 (with some flexibility).[15]

Some initial questions to consider when forming your steering group include:

- How many CCGs, hospitals, and GP practices are there in my region?
- Which ODN(s) are in the region?
- How many prisons are in the region?
- Who are the local providers of drug and alcohol services and sexual health services?
- Do all local GP practices, drug and alcohol services and sexual health services routinely offer hepatitis C testing?
- Are there other service providers who offer testing and / or treatment in my region that should be considered for inclusion in the steering group?

The core steering group for our region includes:

Core principles

To help you build a hepatitis C elimination strategy for your local area, a set of core principles are suggested. These principles will ensure that steering group members are aligned on ways of working, goals and are aware of the timelines involved in building an effective local hepatitis C elimination strategy.

Managing your local steering group

To help lead steering group meetings and ensure progression against agreed objectives, a Chair and/or secretariat could be established if not already done so. A Chair could help to facilitate steering group meetings and a secretariat could take meeting minutes and keep track of assigned actions so that the development of the strategy stays on track. Local agreement will be needed as to who an appropriate Chair would be, however consideration may want to be given to their role and hepatitis C expertise within your area.

Terms of reference

To bring structure to your steering group and ensure collective buy-in on common goals, it may be useful to develop a terms of reference document that is presented to all individuals interested in joining the steering group and building the hepatitis C elimination strategy.

This document could be developed for informational purposes but could also act as a more formal agreement between individuals to solidify interest in working together on the strategy. You may therefore wish to ask steering group members to sign the reference document as a means of codifying their commitment and understanding.

Terms of reference documents come in all shapes and sizes, however an outline of the various points that could be included in the document can be found below:

- Activity background
- Aims and objectives
- Governance structure
- Membership / collaboration
- Meeting format
- Strategy development
- Communications
- Confidentiality

Timeline and milestones

Ahead of the first steering group meeting, it is advisable to develop a draft timeline for creation of a local strategy which contains key milestones that the group can work towards and be held accountable against to ensure progress is being made. The timeline and milestones can then be discussed and ratified by the steering group.

A number of considerations to feed into the development of this timeline can be found below:

- Dates for regular steering group meetings
- Completion of draft local strategy
- Review and approval of draft local strategy by steering group members
- Finalisation of local strategy
- Launch for local strategy
- Implementation of engagement plan around local strategy to ensure political support (if needed)

Frequency of steering group meetings

Depending on the availability of your steering group members and your anticipated timeline, you may wish to hold frequent meetings during the strategy development stage. Regular touch points will encourage members to progress activity. There may be less of a need to meet regularly during the local strategy review and approval stages due to the nature of activity at this stage.

If meeting on a face-to-face basis is challenging, you could consider setting up virtual meetings through a relevant teleconference platform.

Measuring success

Before commencing activity, the steering group may wish to determine specific and measurable performance targets (also known as key performance indicators or metrics) related to the development and impact of the local Framework, so that activity and progress can be appropriately benchmarked, and achievements tracked.

A popular way to develop performance targets is to ensure they are specific, measurable, attainable, relevant and time-bound (SMART).

Examples of performance targets to consider, include:

- ✓ Produce a viable local hepatitis C Elimination Framework in six months
- ✓ Ensure local Government buy-in to the Framework within one year
- ✓ Increase hepatitis C referral rates from primary care and community settings to secondary care by 40 per cent in two years

You may wish to build these performance targets into the terms of reference document or agree them in your first steering group meeting.

Identification strategy (Part 1)

Aim of this section:
These principles are intended to spark discussion in the development of your own local elimination strategy. Overleaf are questions to help gather initial data and flesh out the key principles unique to your region to inform your identification strategy.

Overview: As many infections are asymptomatic for several years, or may result in non-specific symptoms, people are often unaware of their infection until the symptoms of severe liver damage are experienced. As a result, many individuals with chronic hepatitis C remain undiagnosed. These individuals can present later with complications of HCV-related end-stage liver disease (ESLD) and primary liver cancer, which have poor survival rates.[3]

To eliminate hepatitis C as a public health threat, a concerted approach is needed in diagnosis. This should include broader testing and awareness building among high-risk populations and effectively identifying and engaging with those from more marginalised and underserved communities, such as the homeless and people who inject drug (PWIDs). You could also consider the benefits and challenges of the provision of self-testing for people with hepatitis C.[16]

Interventions to engage, screen and ultimately treat hepatitis C-infected persons in the PWID population is crucial for achieving elimination, with the PWID population the greatest source of new hepatitis C infections[3] and, as such, likely to be the 'highest transmitters'.[17] The aim should be to implement different strategies across healthcare and community settings, including testing approaches targeting groups at higher risk, community-based testing services and dried blood spot testing.[18]

Identification strategy principles

Outlined below are three underlying principles for any hepatitis C identification strategy – be it national, regional or local.

Incentive schemes to encourage testing for all drug users

All people who inject drugs or have ever injected drugs should be screened; examples include reward schemes for people from recognised high-risk groups volunteering to participate in a full screening and treatment journey

Case-finding software and informatics

Use of information and data strategies to target at-risk groups; this can involve communication and pooled resources between primary care, sexual health services, drug services, Accident and Emergency departments and prison to encourage cohesive and streamlined identification of people living with hepatitis C

Confidential testing

The option of confidential testing should be offered utilising clinic numbers for recognition rather than full name and address

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COVID-19 and the normalisation of self-testing pathways

Covid-19 has helped 'normalise' the concept of self-testing, self-sampling and self-referral for testing, and this is an area that is being explored and researched further:

- The Self-Testing for HCV Re-infection in MSM (SELFIE) study is an ongoing (estimated completion date 2023) randomised clinical trial of self-testing in HIV positive men who have sex with men that have been cured of a hepatitis C viral infection but who are at risk for HCV re-infection (5-10% per year).[19]
- The *Dried blood spot self-sampling at home is a feasible technique for hepatitis C RNA detection* study showed that at home sampling is a suitable and feasible technique for diagnosing HCV in at-risk populations but also carries opportunities for diagnosing other blood borne viruses such as HIV-1 infections.[20]

These studies are two examples of ways that self-testing approaches can reach populations at highest risk of infection, and demonstrate the feasibility of more frequent and home-based testing for HCV on the time to diagnosis and treatment of HCV re-infections.[19,20] Lots of work is also underway to develop new kinds of point of care tests (POCT).[21,22]

Hepatitis C testing service:

The Community Pharmacy Hepatitis C Antibody Testing Service was added to the Community Pharmacy Contractual Framework (CPCF) in 2020, commencing on 1st September. The introduction of this new Advanced Service was originally trialled in the 5-year CPCF agreement, but its planned introduction in April 2020 was delayed by five months because of the COVID-19 pandemic.

https://psnc.org.uk/services-commissioning/advanced-services/hep-c

Reaching homeless communities

New approaches combining peer outreach with point of care testing and treatment are proving an effective means of reaching homeless communities by targeting community based temporary residential settings, helping overcome barriers to treatment.[23,24] This approach has been rolled out on a wider scale throughout the COVID-19 pandemic which has provided opportunities to reach more homeless people being sheltered in temporary residential community settings.

Identification strategy (Part 2)

This page contains a checklist of questions on identification for you to consider as a group. While certain questions will refer to data held by an individual person or organisation, such as the local authority's public health team or the ODN, this section provides a space to codify where key data is held – and by whom. It will be organised to inform your identification strategy. There is also working space for you to indicate principles that may be specific to your local region.

Marginalised communities

Those with highest risk of HCV infection are those with current or past experience of injecting drug use, and black and minority ethnic populations who have close links to countries with a high prevalence of HCV infection. Therefore it is important to consider the settings whereby these groups may be reached. For example, HCV affects a larger proportion of people in prison and other detention centres, than the wider population, principally as a result of the relatively higher levels of injecting drug use that are observed among this population.[25]

1. What support could be put in place locally to introduce comprehensive healthcare assessments, including hepatitis C testing, to homeless people entering a hostel or hostel bed space? What is the feasibility of testing kits being given to outreach teams supporting people sleeping rough in your area?
2. What encouragement could be given to implement innovative screening using platforms where healthcare professionals have regular interaction with the PWID population, such as the dispensing of opioid substitution treatment (e.g. methadone)? To what extent do such services already exist locally?
3. What are the opportunities to increase provision of knowledge and information about hep C in marginalised communities and in particular injecting drug users. Lack of information contributes to delays in seeking testing and to poor experiences of diagnosis.
4. Is there an opportunity to encourage testing in alternative healthcare settings such as dressing and ulcer clinics? Are there opportunities for piloting testing in community pharmacies, as these are often a portal for the wider healthcare system?
5. Are there opportunities to utilise or implement local self-testing / self-sampling pathways?
6. How many drug and alcohol service users are screened already? How many additional service users could be screened with universal uptake in the context of existing services? How many extra cases would be identified?
7. What sexual health services are available in your community?
8. How many prisoners are screened already? How many more prisoners could be screened with universal uptake? How many extra cases could be identified?
9. Have links been established between probation services? Are they currently engaged in testing? Are they linked-in to the testing and screening pathways in prisons?
10. Are there Hepatitis C Trust Peers active in your area? What are they doing to drive improvements in the testing and identification of people living with hepatitis C? Are there opportunities to foster closer collaboration?

Primary care screening / case-finding

1. How many people living with hepatitis C in at-risk groups are screened already? How many additional people with hepatitis C in at-risk groups could be screened with universal uptake? How many extra cases could be identified?
2. What is the opportunity for and feasibility of linking-up NHS IT services so that if someone is tested once, the other services they interact with are informed in your area?
3. What is the total number of people in your catchment area that have been diagnosed with hepatitis C? Have there been any prevalence studies (or equivalent) to suggest the total number is different?
4. Do any local GP practices utilise primary care databases? If so, what are the outcomes? Is there the opportunity to scale-up existing practices?
5. Can hepatitis C awareness campaigns be piloted in local GP practices to put a spotlight on testing, diagnosis and care?

Consider the following individuals as co-opted representatives for the development of the identification sub-strategy:

- GPs
- Community pharmacist
- Homelessness services
- Mental health services
- Patient organisation
- Academic(s)
- Drug Action Teams (DATs)
- Prisons
- Sexual health centres

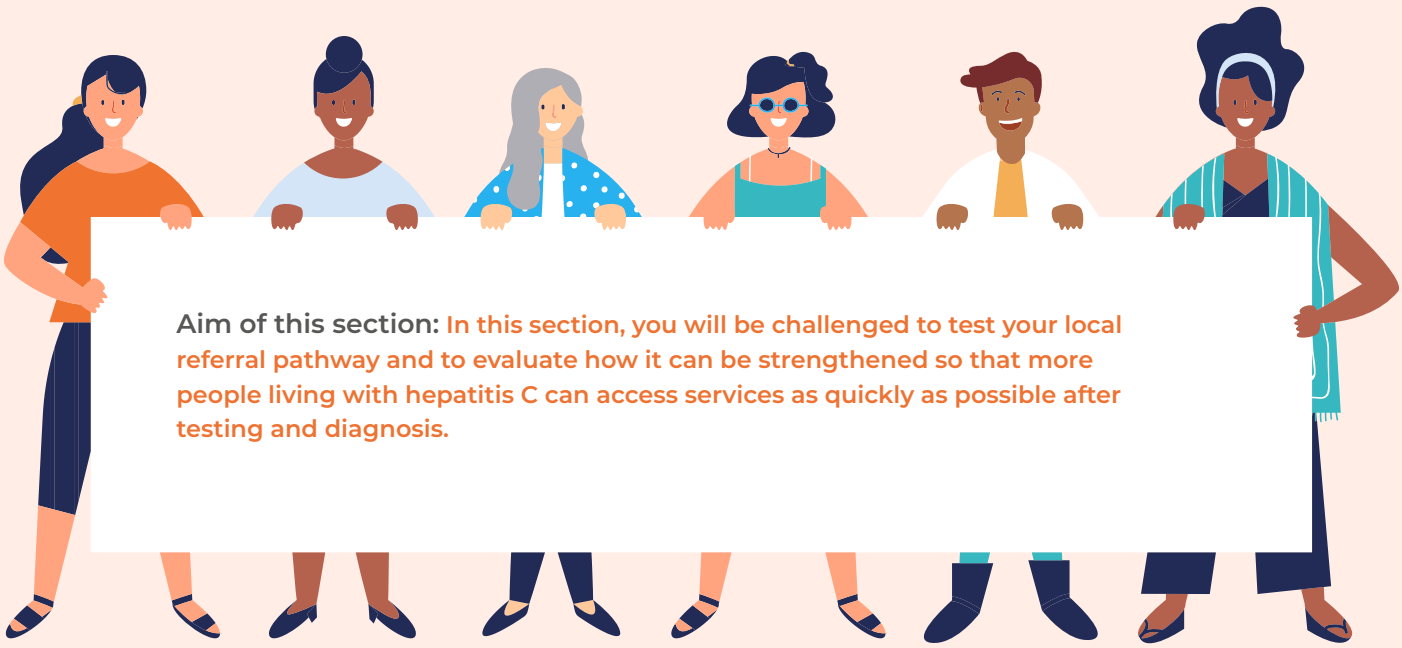
The key principles for our identification strategy include:

Referral strategy (Part 1)

Overview: Once a person has been identified to be living with hepatitis C, it is critical that they are quickly referred to specialists who can provide the appropriate treatment, care and support, so that each individual has the best chance of becoming and staying hepatitis C-free.

Referral pathways across England often differ according to the provision of services available locally. In some regions, the CCG or Trusts working in tandem with local stakeholders such as hepatologists, will publish guidance on the optimal hepatitis C pathway.

Considering the current treatment paradigm, local pathways should aim to connect people who have been diagnosed with hepatitis C with secondary care for treatment as quickly as possible to avoid long-term hepatitis C-related health complications such as liver cirrhosis and to mitigate against the high-patient drop-out rate which occurs at this stage.[26] By doing this, more people are likely to be cured and onward transmission of hepatitis C prevented.[27]



Aim of this section: **In this section, you will be challenged to test your local referral pathway and to evaluate how it can be strengthened so that more people living with hepatitis C can access services as quickly as possible after testing and diagnosis.**

Referral strategy principles

Outlined below are three underlying principles which have been identified as key to any hepatitis C referral strategy – be it national, regional or local.

Key principles:

Simplify pathways
To ensure that people diagnosed with hepatitis C in different settings (including in prisons) move quickly through the care system, services should be designed as simply as possible or should even be provided in the same setting if feasible[27]

Ensure the pathway is patient-centric
Consider the whole patient journey when evaluating the effectiveness of the referral pathway so that services and appointments can be easily accessed and patients wider health needs are catered for

Distinguish routes of referral
There should be clear guidelines locally regarding not only how GPs or nurses in primary care settings refer people living with hepatitis C on to secondary care, but also on how those working in community services and prisons can do the same

Integrated care models in Lewisham and Tower Hamlets

Models of integrated care have been developed in some London boroughs, including Lewisham and Tower Hamlets, which provide evidence that bringing specialist hepatitis C services to where the people living with hepatitis C are (in this case - drug treatment services or GP shared care) results in increased use. The programme started with analysis and observation of care between two boroughs to identify unmet needs in care.

Drug treatment services were utilised as one way to increase linkage to care. This model allows people who are not ready to initiate treatment to have their condition monitored on an ongoing basis rather than fall out of the system, with the view to being treated further down the line instead.[28] It also enables better follow-up and engagement on people's wider health needs.

At the time of publication information about the funding for this service was not available.

Referral strategy (Part 2)

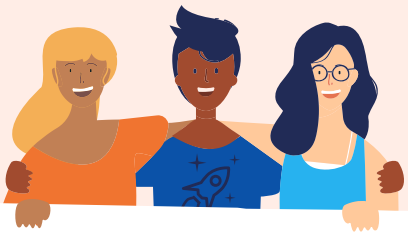
This page contains questions on the referral pathway for you to consider as a group. While certain questions will refer to data held by an individual person or organisation, such as the local authority's public health team or the ODN, this section provides a space to codify where key data is held, by whom, and how it will be organised going forward to inform your referral strategy. There is also working space for you to indicate principles that may be specific to your local region.

1. Which local body or organisation has led on the development of the hepatitis C referral pathway in the past?
2. Has the ODN fed into or led the design of the hepatitis C referral pathway?
3. When was the hepatitis C referral pathway last updated?
4. Do you consider that the current referral pathway is fit for purpose? To this point, what has been successful or challenging locally?
5. Are there any steps in the pathway that could be removed or simplified to help streamline processes?
6. Are traditional primary care services such as GP surgeries and sexual health clinics clear on their role in referring hepatitis C patients and associated guidelines, or do they need additional training on referring people living with hepatitis C?
7. Are there any peer-to-peer networks or support programmes available in the local area? What is the referral rate for primary to secondary care services?
8. Are broader community services (drug and alcohol services, pharmacies, homeless shelters) currently included in the referral pathway? Could these be better utilised to support hepatitis C referral?
9. Are prisons currently included in the referral pathway or is there local guidance that ensures prisoners can access care and treatment quickly if diagnosed with hepatitis C?
10. Is data-sharing between services being optimised so that people diagnosed with hepatitis C can be appropriately managed and cared for?

Consider the following individuals as co-opted representatives for the development of the referral sub-strategy:

- Local GP
- Drug and alcohol services lead
- Prison Clinical Lead
- Sexual health services

The key principles for our referral strategy include:



Treatment strategy (Part 1)

Aim of this section:
These principles are intended to spark discussion in the development of your own local elimination strategy. Overleaf are questions to help gather initial data and expand the key principles unique to your region to inform your treatment strategy.

Overview: Effective treatments for hepatitis C are available on the NHS and these can now cure over 95 per cent of people living with hepatitis C.[29]

Once diagnosed, it is important to get a prompt referral to a specialist who can provide treatment (usually a hepatologist, clinical nurse specialist, gastroenterologist or infectious disease specialist) who will assess the virus, genotype and current liver health (if possible following effective treatment). This will then help establish whether treatment should be started and what treatment course would be best for the individual.[30]

Treatment and care for hepatitis C is delivered through 22 ODNs.[3] However, the COVID-19 pandemic has had a major impact on the way that drug and alcohol services are treating patients. Some are not running face to face clinics, and in some cases, they may not go back to that system. As the response to COVID-19 settles, there is a need to ensure that any long term changes to standard delivery models are properly evaluated for impact on clinical and public health outcomes and inequalities.[3]

Treatment strategy principles

Outlined below are three underlying principles which have been identified as key to any hepatitis C treatment strategy – be it national, regional or local.

Streamlining of treatment services
Streamline treatment services to ensure lifestyle changes and regular blood tests (as best practice but not as a necessity) to optimise treatment pathways

Full access to NICE-recommended treatments in prison
Full access to NICE-recommended treatment programmes for all hepatitis C positive individuals within the prison system

Different treatment for different kinds of the virus
Treatment selection tailored to the individual patient, their infection and general health and other medicines

Edinburgh Access Practice (EAP) outreach service

EAP provides healthcare for homeless people, who are disproportionately likely to be affected by hepatitis C. The service is run by a GP, a liver specialist and a clinical support worker running one session a week at EAPs clinic. Patients referred to the service as flexible especially because the medication could be picked up at the same time as other prescriptions.[31]

52 people living with hepatitis C received treatment at EAP between January 2017 and June 2018. Early indications demonstrate good adherence and response rates. Interviews with people living with hepatitis C revealed positive responses to engagement with the clinic, with ongoing relationships with staff members cited as a significant factor.[31]

At the time of publication information about the funding for this service was not available

Treatment strategy (Part 2)

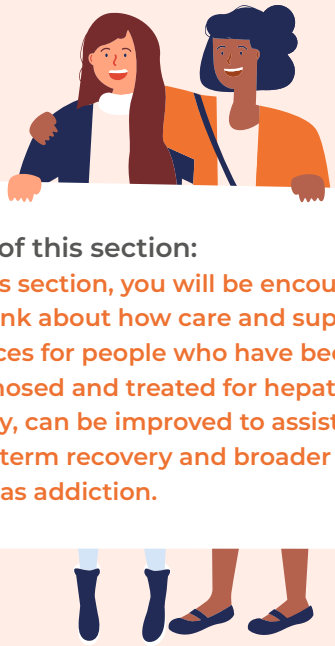
This page contains a checklist of questions on treatment for you to consider as a group. While certain questions will refer to data held by an individual person or organisation, such as the local authority's public health team or the ODN, this section provides a space to codify where key data is held, by whom, and how it will be organised to inform your treatment strategy. There is also working space for you to indicate principles that may be specific to your local region.

1. Are any treatment services situated in drug treatment or primary care services?
2. Do clinics run at convenient times? And are appointments easy to book and clearly communicated, with reminders provided by phone, text or email?
3. Do patient education leaflets about hepatitis C and its treatment exist, and are they provided in relevant languages to engage the local community?
4. Do pre-treatment discussions 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?[32]
5. Do pre-treatment discussions planning a suitable start date take into account any family, social, housing or employment issues?
6. Are appointments for antiviral therapy coordinated with Opioid Substitution Therapy (OST) appointments, and phone, email or text reminder messages used?
7. Are there any peer-to-peer networks or support programmes available in the local area?
8. Do people living with HCV have a regular review during treatment, to have side-effects monitored, and have the opportunity to discuss any problems?
9. What efforts have been made to ensure that prisoners can continue their treatment uninterrupted, and that provision is made for continuity of care on release or transfer to another prison?
10. Do treatment administration strategies need to be flexible to account for the fact that some people living with hepatitis C do not have the capacity to effectively store medication?

Consider the following individuals as co-opted representatives for the development of the treatment sub-strategy:

1. Consultant hepatologist
2. Liver and ID specialist
3. Hepatitis nurse specialist
4. Prison clinical lead
5. ODN lead

The key principles for our treatment strategy include:



Continuing care strategy (Part 1)

Aim of this section:
In this section, you will be encouraged to think about how care and support services for people who have been diagnosed and treated for hepatitis C locally, can be improved to assist with long-term recovery and broader issues such as addiction.

Overview: Being diagnosed with hepatitis C can be a difficult experience for many individuals[33] – they therefore need tailored support at each stage of their care journey, including during and after treatment. For example, individuals may benefit from accessing wider support services such as counselling and rehabilitation. These services may be provided by local health bodies but may also be delivered by patient group organisations operating in your local region such as The Hepatitis C Trust, Liver4Life and We Are With You (formerly known as Addaction).

Continuing care principles

Outlined below are three underlying principles which have been identified as key to any continuing care strategy – be it national, regional or local.

Key principles:

Integrate health and community services

Ensure that individuals who have, are going through, or who have finished treatment are aware and directed to appropriate services that they may benefit from such as addiction support or mental health services, to assist their long-term recovery

Educate those working in community settings

Prioritise upskilling workers who are likely to encounter people who have been diagnosed or treated with hepatitis C so that they are better equipped to assist them

Monitor broader progress for people living with hepatitis C post treatment

Ensure that a robust system is in place which collects information on the number of people treated as well as reinfection rates and broader health interventions recommended – to help shape the future of local hepatitis C services and the pathway

Weston-super-Mare: Community based treatment and continuing care

A treatment clinic is held on a fortnightly basis at the We Are With You (formerly known as Addaction) service in Weston-super-Mare. People are supported through treatment and uptake of treatment after testing is higher than before. Care during and after treatment is offered because the service is already in operation to support addiction and alcohol issues alongside hepatitis C testing and treatment. Providing treatment at an existing support centre encourages people living with hepatitis C to be able to easily access a community, mental health services and encouragement toward a drug free life.[34]

Funding for this approach was made available by the Local Authority directly after representation was made by a number of groups (including local GPs; patient groups and drugs services such as We Are With You (formerly known as Addaction) and Broadway Lodge) that the needs of people in the town were not currently being met.

Continuing care strategy (Part 2)

This page contains questions on the topic of continuing care for you to consider as a group. While certain questions will refer to data held by an individual person or organisation, such as the local authority's public health team or the ODN, this section provides a space to codify where key data is held, by whom, and how it will be henceforth organised to inform your continuing care strategy. There is also working space for you to indicate principles that may be specific to your local region.

1. What broader community services such as mental health services are currently integrated into the care pathway?
2. To what extent are peer-to-peer patient organisations engaged to provide additional support?
3. Is any collaborative work being undertaken between housing associations and local healthcare bodies to ensure that people living with hepatitis C who are currently without permanent residence and are going through treatment or who have finished treatment, are housed adequately?
4. Are there any peer-to-peer networks or support programmes available in the local area?
5. Are there any broader services that prisoners can be offered to ensure long-term recovery?
6. What current community services or patient organisation programmes have worked well locally? Can these be replicated, enhanced or made more widely available for people going through hepatitis C treatment?

Consider the following individuals as co-opted representatives for the development of the continuing care sub-strategy:

1. Local patient group representative
2. Drug and alcohol services representative
3. Community mental health lead

The key principles for our continuing care strategy include:

Measuring impact and evaluation strategy (Part 1)

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

In 2017 a National Hepatitis C patient registry was established – making it possible to record and monitor treatment uptake, outcomes and increased diagnosis rates in real time.[3]

National reports, like the annual *Hepatitis C in England* report[3] – led by Public Health England – are important tools for reporting progress against the Global Health Sector Strategy (GHSS) targets to eliminate hepatitis C.

Aim of this section:
These principles are intended to spark discussion in the development of your own local elimination strategy. Overleaf are questions to help gather initial data and flesh out the key principles unique to your region to inform your evaluation strategy.

Every regional elimination strategy should include an impact and evaluation framework that describes how the implementation and effectiveness of the programme will be measured and assessed.

Measuring impact and evaluation strategy principles

Outlined below are three underlying principles which have been identified as key to any hepatitis C evaluation strategy – be it national, regional or local.

Set numerical goals
Distinguish numerical goals for testing and successful treatments in a year

Check progress
Check progress against outlined goals per annum, particularly focusing on: numbers tested, testers trained, community-based sites set up

Undertake a qualitative study
Undertake a qualitative study with testing centres and care providers to understand success 1 / 2 / 3 / 4 / 5 years after implementation

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co-EC study – Melbourne, Australia

The co-EC study, which is based across six clinics in Melbourne Australia, aims to test, treat and cure gay and bisexual men who are infected with both hepatitis C and HIV, and measure the impact on hepatitis C infection and re-infection by integrating a hepatitis C/HIV surveillance system and database to deliver and monitor the impact of the program at the local level.[35]

This is done by a scale up treatment programme within hospital settings beginning with an open label, non-randomised clinical trial of hepatitis C treatment for people with HIV coinfection.

Funding for this study was made available by Bristol-Myers Squibb.

Measuring impact and evaluation strategy (Part 2)

This page contains questions on how to measure impact and evaluation for you to consider as a group. While certain questions will refer to data held by an individual person or organisation, such as the local authority's public health team or the ODN, this section provides a space to codify where key data is held, by whom, and how it should be organised to develop your evaluation strategy. There is also working space for you to indicate principles that may be specific to your local region.

1. Out of the following data points, how many of the following are being collected and by whom?

   - Tests offered
   - Tests performed
   - Positive results
   - People living with hepatitis C referred to specialist care
   - People living with hepatitis C offered treatment
   - People living with hepatitis C starting treatment
   - People living with hepatitis C completing treatment
   - The reasons patients decline testing or treatment
   - People living with hepatitis C experience measures
   - Genotypes and sub-types
   - Numbers of people living with hepatitis C attending specialist clinics after being referred
   - The reasons people living with hepatitis C discontinue treatment

2. If any of the above data points are not being collected, could they be and by whom?

Consider the following individuals as co-opted representatives for the development of the monitoring and evaluation sub-strategy:

1. Researcher within the Immunisation, Hepatitis & Blood Safety Department at the Communicable Infectious Disease Surveillance Centre, Public Health England
2. NHS England Regional Programme of Care Manager (Blood and Infection)
3. Patient group representative
4. Chair, Health Scrutiny Committee
5. Prison clinical lead
6. Academic

The key principles for our evaluation strategy include:

Index repository

MSD cannot be held responsible for information held within third-party websites

What is hepatitis C?

- NHS overview of hepatitis C: https://www.nhs.uk/conditions/hepatitis-c/
- American Liver Foundation information video: https://www.youtube.com/watch?v=a8sgubOKVKU
- Outline by British Liver Trust: https://www.britishlivertrust.org.uk/liver-information/liver-conditions/hepatitis-c/
- Symptom outline by Hep C Trust: http://www.hepctrust.org.uk/information/symptoms-hepatitis-c
- Hepatitis Trust 2018 update: http://www.hepctrust.org.uk/blog/jan-2018/nhs-england-publishes-update-hepatitis-c-treatment-programme
- CDC General information: https://www.cdc.gov/hepatitis/hepatitis C/PDFs/HepCGeneralFactSheet.pdf

Background to elimination

- Liver Health APPG: http://www.appghep.org.uk/download/reports/Eliminating%20Hep%20C%20APPG.pdf
- WHO's strategy on hepatitis C elimination: http://www.who.int/hepatitis/strategy2016-2021/Draft_global_health_sector_strategy_viral_hepatitis_13nov.pdf?ua=1
- Reward systems to encourage people to get screened: https://www.wdp.org.uk/Handlers/Download.ashx?IDMF=58a624ea-79b5-4afb-88cc-ad755f406381
- Hepatitis C Action 2017 Report: http://www.hcvaction.org.uk/sites/default/files/resources/Hepatitis%20C%20in%20the%20Uk%20report%202017.pdf
- Financial case for action on liver disease: http://www.hcvaction.org.uk/sites/default/files/resources/financialcaseforactiononliverdiseasepaper.pdf
- Cambridge, Good Practice Roadshow: http://www.hcvaction.org.uk/sites/default/files/resources/Cambridge%20Roadshow%20Summary%20Report.pdf
- European Policy Guidelines for Elimination of hepatitis C: http://www.hcvbrusselssummit.eu/images/documents/reports/hepatitis C-Elimination-PolicyGuidelines.pdf
- Hepatitis C: The beginning of the end—key elements for successful European and national strategies to eliminate hepatitis C in Europe: http://www.hcvbrusselssummit.eu/images/documents/reports/The_beginning_of_the_end-key_elements.pdf
- Hepatitis C Trust Leave no one behind: A manifesto for hepatitis C elimination: http://www.hepctrust.org.uk/blog/nov-2019/leave-no-one-behind-manifesto-hepatitis-c-elimination

Screening

- SN Joshi: Hepatitis C Screening: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4295744/
- E Gupta et al: Hepatitis C virus: Screening, diagnosis, and interpretation of laboratory assays: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3943138/
- Rational for screening: https://www.uptodate.com/contents/screening-for-chronic-hepatitis-c-virus-infection

Identification

- Needle and Syringe programmes: https://publichealthmatters.blog.gov.uk/2016/10/12/eliminating-hepatitis-c-as-a-major-public-health-threat-needs-a-two-pronged-attack/
- Combination intervention programmes: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3722076/

Diagnosis

- Hepatitis screening and testing https://www.hepatitisc.uw.edu/go/screening-diagnosis/diagnostic-testing/core-concept/all
- BMJ Best Practice: https://bestpractice.bmj.com/topics/en-gb/128
- NICE quality standard on liver disease: http://www.hcvaction.org.uk/sites/default/files/resources/Liver%20disease%20-%20Quality%20Standard.pdf

Treatment

- NICE pathways, information: https://pathways.nice.org.uk/pathways/liver-conditions/hepatitis.pdf
- NHS treatment outline: https://www.nhs.uk/conditions/hepatitis-c/treatment/
- Hepatitis C factsheet: https://www.who.int/news-room/fact-sheets/detail/hepatitis-c

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