

# HEPATITIS C COMMISSIONING TOOLKIT

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# The essential role of effective commissioning in eliminating hepatitis C

Hepatitis C is a blood-borne virus (BBV) that primarily affects the liver. It is a major cause of liver cirrhosis and cancer.

Hepatitis C can also have a much broader impact and has been linked to cardiovascular disease, mental health issues, kidney problems, and musculoskeletal pain.

The virus is transmitted through blood-to-blood contact, with the majority of transmissions arising through injecting drug use. Overseas medical care, tattooing and receipt of a blood transfusion in the UK prior to 1991 are also potential transmission routes.<sup>i</sup> In addition to people who inject drugs (PWID) or who have injected drugs in the past, particular risk groups include migrant populations from high prevalence regions (particularly South Asian and Eastern European communities), homeless people, and men who have sex with men.

Around 160,000 people in England are chronically infected with hepatitis C, with 40-50% remaining undiagnosed. People infected with hepatitis C often experience few or no obvious symptoms, and can live with the virus for many years without being diagnosed, increasing the risk of severe liver damage.

Between 2005 and 2014, deaths from hepatitis-C related end-stage liver disease in England more than doubled. For the first time in 2016 as a result of the introduction of revolutionary new treatments there was a notable fall in deaths from hepatitis C related end-stage liver disease and in liver

transplants undertaken, sustained in provisional figures for 2017<sup>ii</sup>. This success should be celebrated, but it is important to note that it reflects results for only those with the most severe liver damage who have already been diagnosed.

Crucially, hepatitis C is preventable, treatable and curable for the vast majority of people. Since 2015, treatments with short durations, limited side-effects and cure rates upwards of 95% have been widely available.

## Supporting NHS England in its commitment to eliminate hepatitis C by 2025

In May 2016, the United Kingdom joined 193 other member states in signing up to the World Health Organization Global Health Sector Strategy (GHSS) on Viral Hepatitis, which commits participating countries to the elimination of hepatitis C as a major public health threat by 2030. This commitment included signing up to targets of an 80% reduction in incident (new) chronic hepatitis C infections and a 65% reduction in mortality from hepatitis C by 2030.

In January 2018, NHS England announced a more ambitious objective of eliminating hepatitis C by 2025 at the latest, aiming to become the first country in the world to do so<sup>iii</sup>. To support the 2025 elimination target, NHS England has entered negotiations with the pharmaceutical industry with the intention of reaching a new funding arrangement for hepatitis C

treatments which would drive increased case-finding, testing and treatment.

Effective commissioning and delivery of hepatitis C services is crucial to achieving this goal. Ambitious strategies to increase awareness and the numbers of people tested, diagnosed and treated must be embedded throughout the healthcare system and community services and commissioned at every level.

With the availability of dry blood spot (DBS) testing and DAA treatments requiring minimal supervision, testing and treatment should increasingly be delivered within the community where they are easily accessible to all. Commissioners have a key role to play in enabling a shift from a hospital-based, specialist approach to a community-based approach, making it easier to find those still undiagnosed.

Implementing a joined-up approach to hepatitis C is consistent with ongoing developments in the health system, with Sustainability and Transformation Partnerships and Accountable Care Systems aiming to provide increased coordination and clarity between different elements of the care and commissioning pathway.

## **Reducing mortality from liver disease**

Effective commissioning of hepatitis C services can contribute to reducing mortality from liver disease and help to meet health outcomes indicators and improvement areas.

### *Framework for commissioning*

- The most recent NHS Outcomes Framework includes 'Under 75 mortality rate from liver disease' as one of its key improvement areas in Domain 1: Preventing People from Dying Prematurely.<sup>iv</sup>

- The Public Health Outcomes Framework includes 'Under 75 mortality rate from liver disease' as an indicator under Domain 4: Healthcare public health and preventing premature mortality.<sup>v</sup>
- The CCG Outcomes Indicator Set 2015/16 also includes 'Under 75 mortality from liver disease' as an improvement area under Domain 1: Preventing people from dying prematurely.<sup>vi</sup>

### *Liver disease*

- Liver disease is one of the five 'big killers' in the UK and is the only one of these where mortality is rising.<sup>vii</sup>
- Liver disease causes 6% of all premature deaths.<sup>viii</sup>
- 90% of people who die from liver disease are under 70 years old and more than 1-in-10 deaths of people in their 40s are from liver disease.<sup>ix</sup>
- Deaths from hepatitis C-related end stage liver disease and hepatocellular carcinoma more than doubled from 2005 to 2014 – the majority occurring in people under the age of 60 – although cases have been falling since 2015, with the arrival of the new hepatitis C treatments.<sup>x</sup>
- This is in contrast to the other major causes of death in this country, which affect fewer people, and at a later age than ever before, whilst liver disease affects growing numbers of increasingly younger people.
- Hepatitis C is one of the most common causes of liver disease. The other

primary causes are alcohol, obesity and hepatitis B.

- As hepatitis C is curable (and as such is deemed the type of liver disease most amenable to intervention) addressing hepatitis C will be crucial in efforts to achieve a reduction in mortality from liver disease.

### Preventing further infections

Prevention is a vital component of an integrated hepatitis C policy. A growing body of evidence suggests that the combination of effective substance use treatments, treatment for hepatitis C and support for safe injecting among drug users can lower the incidence and prevalence of hepatitis C infection.<sup>xi</sup>

### Reducing future costs

Investment in hepatitis C prevention, testing and treatment mitigates a much greater financial burden further down the line. While NHS England Specialised Commissioning has responsibility for hepatitis C treatment costs, the financial burden of care for patients with chronic liver disease falls on Clinical Commissioning Groups (CCGs). With the risk of liver disease increased by the length of time a patient is infected with hepatitis C, there is a clear long-term financial benefit to CCGs of investing in hepatitis C prevention and testing, leading to increased numbers of people getting treated and cured.

- Patients who are treated and cured of the hepatitis C virus are more than four times less likely to be hospitalised, or die for a liver-related reason, than those patients who are not cured.<sup>xii</sup>
- People dying from liver disease often have complex end of life care needs and over 70% die in hospital.<sup>xiii</sup>
- Analysis of English Hospital Episode Statistics by Wilmington Healthcare found that £12,651,198 was spent on liver cancer in 2016/17, with nearly 20% of the costs (£2,319,553) related to current or former hepatitis C patients<sup>xiv</sup>.

### Reducing health inequalities

Reducing health inequalities is an important improvement area for Public Health England. Hepatitis C disproportionately affects disadvantaged, vulnerable and socially excluded people, particularly homeless people, prisoners and injecting drug users.

Research in Scotland has found that over 50% of people with hepatitis C are from the lowest socioeconomic quintile and 75% are from the lowest two quintiles<sup>xv</sup>, while almost half (48%) of people with hepatitis C admitted to hospital in England are from the lowest socioeconomic quintile, with nearly three-quarters from the two most deprived quintiles.<sup>xvi</sup>

Diagnosing and treating people with hepatitis C will help commissioners in public health and the NHS to deliver their high level outcome to reduce health inequalities.

## Information checklist for commissioners

Do you have an understanding of what hepatitis C services you are responsible for commissioning?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 6
Do you have an accurate idea of the 'need' in your area, including the numbers of people with hepatitis C?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 13
Are you aware of all relevant NICE guidance related to hepatitis C, including on prevention, testing and treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 14
Are you aware of good practice examples of effective testing and treatment services and strategies?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 15 and appendices
Do you have an understanding of what services are currently available to people with hepatitis C in your area?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 15
Do you have an understanding of the kind of hepatitis C-related outcomes needed to act as drivers to improve health?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 16
Have you engaged with relevant local health professionals and, in particular, Hepatitis C Operational Delivery Networks?	<input type="checkbox"/> Yes <input type="checkbox"/> No - see page 15
Do the measures that you are currently using to evaluate the effectiveness of hepatitis C-related services require revision?	<input type="checkbox"/> Yes - see page 17 <input type="checkbox"/> No
Do you require additional sources of data?	<input type="checkbox"/> Yes – see page 18 <input type="checkbox"/> No

# Who is responsible for what?

## *Roles and responsibilities*

### **NHS England (NHSE)**

NHSE operates independently as an arms-length body that sets the priorities and direction of the National Health Service (NHS) in England.

Certain health services in England are categorised as 'specialised' services and are commissioned by NHSE. Treatment for hepatitis C falls within this group. This means that NHSE commissions treatment (the drugs themselves) directly and on a national basis for hepatitis C.

### **NHS England Health & Justice**

NHSE Health & Justice is responsible for commissioning healthcare for children, young people and adults across secure and detained settings.

NHSE Health & Justice's responsibilities include the implementation of opt-out testing for blood-borne viruses (BBVs), including hepatitis C, and ensuring access to treatment pathways for those who are diagnosed with hepatitis C.

### **Local authorities (LAs)**

LAs have a ring-fenced public health budget, through which they have responsibility for improving the public health of their local population. This includes the commissioning of drug and alcohol services and sexual health services.

LAs are responsible for commissioning:

- Testing for hepatitis C in drug services
- Needle exchange programmes in pharmacies where harm reduction messages may be given

- Testing for hepatitis C in sexual health clinics
- Local awareness campaigns around hepatitis C.

Local authorities are also responsible for ensuring that contracted service providers are able to evidence strong partnership working with other relevant services, e.g. the local NHS Trust, in order to ensure clear referral pathways.

### **Clinical Commissioning Groups (CCGs)**

CCGs are responsible for planning and commissioning most secondary health care services across local areas of England.

Whilst drugs for hepatitis C are paid for nationally by NHS England (as a specialised service), other parts of hepatitis C treatment and care are either commissioned by CCGs or are the responsibility of CCGs. These include:

- Testing for hepatitis C by GPs and in hospitals
- Referral on (by a GP or consultant) to a Hepato-pancreato-biliary (HPB) hospital service
- Monitoring of treatment if overseen in a hospital (including tests and outpatient appointments).
- Treatment costs for some associated health complications arising from hepatitis C infection (others fall under NHS England Specialised Commissioning)
- Ensuring appropriate levels of hepatitis C knowledge among relevant staff, e.g. GPs.

Public Health England (PHE)

PHE has the responsibility of working with other key organisations across the health system, both national and local to protect and improve the population's public health and to reduce health inequalities.

As an infectious, blood-borne virus and one that predominantly affects disadvantaged people, hepatitis C is a public health issue that very much falls under the remit of PHE.

PHE produces annual reports on hepatitis C in England and hepatitis C in the UK, collecting and bringing together national level data on hepatitis C – from infection, awareness and prevalence through to treatment and care<sup>xvii</sup>. As of 2016, this report is framed in terms of progress towards the elimination of hepatitis C. Local PHE teams provide advice to local authorities.

### **Department of Health (DH)**

Each year the DH presents a mandate to NHS England (NHSE), setting out its budget and the Government's objectives and requirements for NHSE.<sup>xviii</sup> The DH also sets out the outcomes and corresponding indicators that are used to hold NHSE to account for improvements in health. These are laid out in the 'NHS Outcomes Framework'.

The most recent NHS Outcomes Framework 2016/17 includes 'Under 75 mortality rate from liver disease' as Improvement area 1.3 in Domain 1: Preventing People from Dying Prematurely.

### **Operational Delivery Networks (ODNs)**

Since August 2015, Operational Delivery Networks (ODNs) have been set up in 22 areas across England, to oversee delivery of the new treatments for hepatitis C.

Each ODN area has a 'clinical lead' and operates through a 'hub and spoke' model,

with the hub being the leading hospital for each area with specialist expertise.

In each ODN 'hub' a multi-disciplinary team (MDT) makes prescribing decisions on which patients in their area should receive treatment, in accordance with NHS England policy and NICE technology appraisals. The MDTs are made up of a range of different experts and specialists (including at least two clinicians experienced in managing hepatitis C and a Hepatologist).

Patients in each ODN area are referred to the MDT for review by local services that have been in charge of their care up to that point, including primary and secondary care services and prisons.

There is a service specification that has been developed for the ODNs, providing a framework within which they must operate, including the overarching principle that access to care, and supervision of treatment, must be tailored as far as possible to the needs of the patients. It also specifies that "*all eligible patients will have access to care and treatment services irrespective of their sexual orientation, gender, race, disability, psycho-social circumstances or geographical location.*" It also states that "*an important feature of all services is that appropriate pathways are developed for socially disadvantaged patients who are often difficult to engage.*"

Other ODN requirements include:

- A plan to "*optimise working with patients, such as a patient forum or other modes to increase patient involvement in the design and functioning of the network.*"
- Delivery of outcome data by service providers on "*patient experience of outpatient services,*

*through a patient questionnaire developed and validated with appropriate patient representative groups.”*

(elbasvir/grazoprevir), Harvoni (ledipasvir/sofosbuvir), Eplcusa (sofosbuvir/velpatasvir) and Vosevi (sofosbuvir/velpatasvir/voxilaprevir).

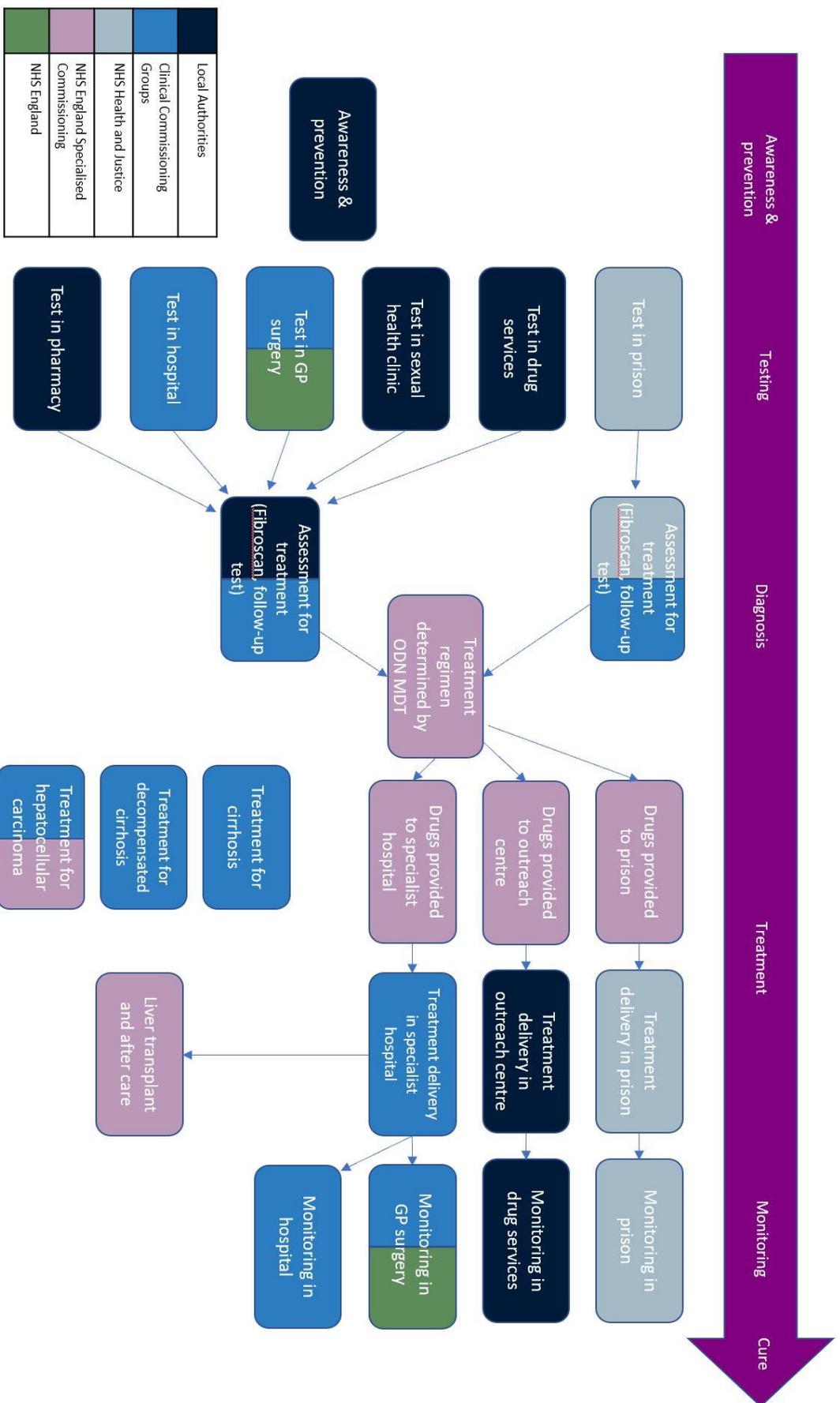
National Institute for Health and Care Excellence (NICE)

NICE undertakes technology appraisals that may lead to recommendations on the use of specific new and existing drugs or treatments within the NHS.

NICE regularly produces technology appraisals of the clinical and cost effectiveness of treatments for hepatitis C. Five NICE-approved regimens are currently used by clinicians – Mavyret (glecaprevir/pibrentasvir), Zepatier

The handbook to the NHS Constitution states that ‘when a NICE technology appraisal or highly specialised technology assessment results in a recommendation for the use of a drug or treatment, the relevant health body must fund that drug or treatment for patients when it is clinically needed’.<sup>xix</sup> In the case of these new hepatitis C treatments, the relevant health body is NHS England, as national commissioner for specialised services

Figure 1: Commissioning pathway map



# How the toolkit works

## Commissioning for the Outcomes Framework

The aim of this toolkit is to support commissioners of hepatitis C services to commission for the high-level outcomes set out in the NHS, CCG and Public Health Outcomes Frameworks.

### The ABC Model

The ABC Commissioning for Outcomes model focuses on developing outcomes that are based on need, evidence, quality and knowledge. It reflects the commissioning cycle and provides the commissioner with a foundation to develop outcomes within a competency framework.

Sections A, B and C focus on deciding on the outcomes for a particular area through assessing need, identifying best practice and relevant evidence, and reviewing current practice to identify gaps.

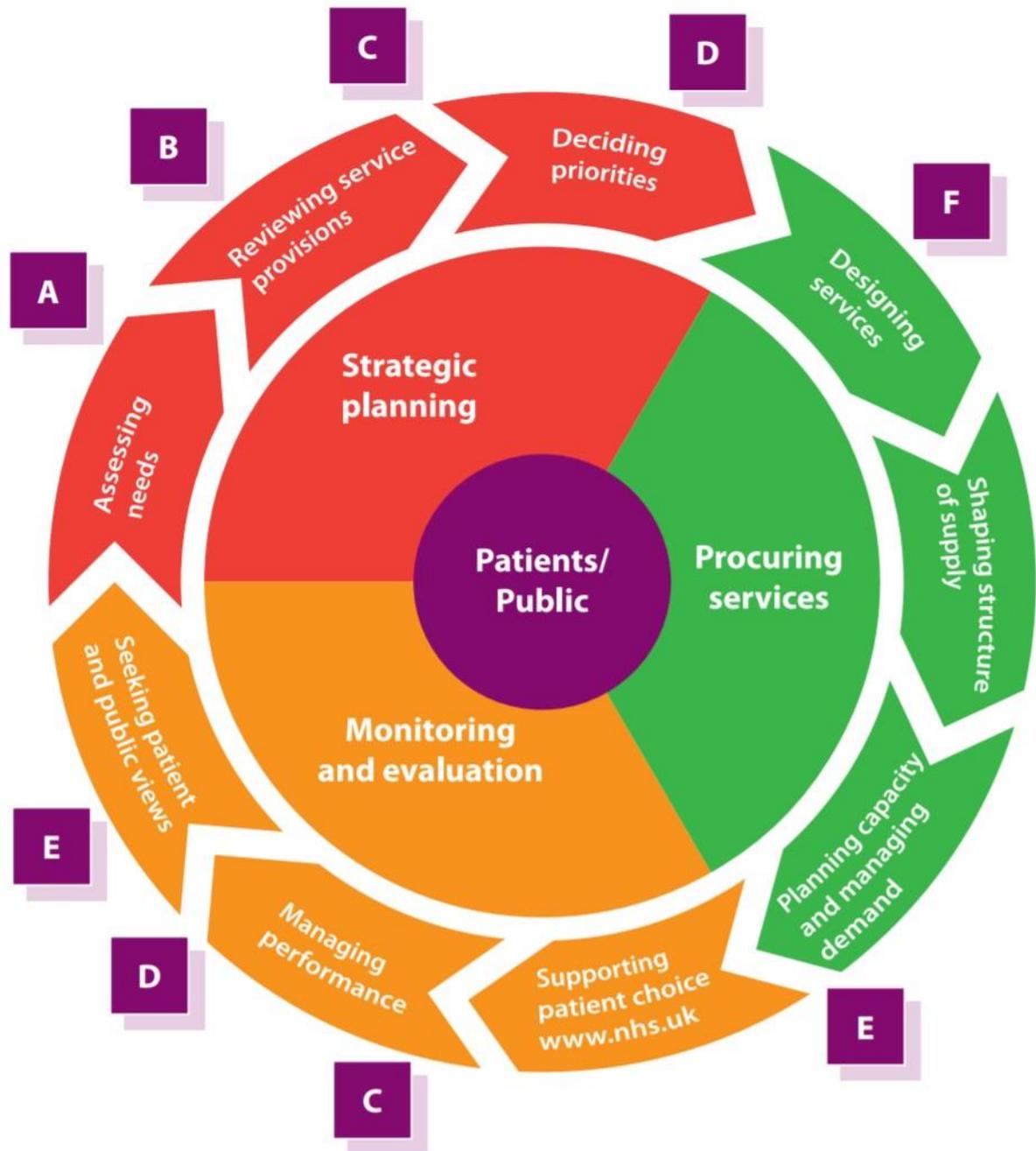
Section D helps the commissioner to develop high-level outcomes to act as a driver to improve health.

Section E asks commissioners to think about evaluating the quality, efficiency and effectiveness of the proposed services before they are actually commissioned rather than after in order to identify the right information that will be needed in a formal evaluation.

Section F asks for an appropriate dataset to be formulated in order to collect the right information on both patients and services.

The Outcomes Strategic Map gives an overview of the services involved in achieving these desired high-level outcomes.

Figure 2: The commissioning cycle



# The ABC Model

## A

### Assessing the need: what is required to support people with hepatitis C and develop hepatitis C services in your area of commissioning responsibility?

Questions to consider:

Has the 'need' been clearly identified? Has hepatitis C been included or addressed, for example, through the JSNA process, and do you understand the needs of people infected and affected by hepatitis C?

Do you understand the geographical patterns of hepatitis C or the needs of certain groups or communities with hepatitis C e.g. South Asian community or current and former drug users?

Do you have data on the prevalence and incidence of the disease, the numbers of people with a positive test for hepatitis C against the numbers treated?

- Refer to Public Health England's [Hepatitis C Commissioning Template for Estimating Disease Prevalence](#), which shows prevalence estimates for each ODN area
- Refer to data from your local drug treatment centre
- Refer to the [2<sup>nd</sup> Atlas of Variation for Liver Disease in England](#)

Has there been any disease burden modelling done in your area (e.g. an understanding of local figures for consultations, planned and unplanned admissions, cost of care and cost of treatment etc.)? Also is there an

understanding of the implications of not treating people?

Have the 'costs of care' been estimated for individuals embarking on and receiving the full course of treatment based on NICE recommended therapy and NICE price estimates?

What will make the biggest contribution to achieving the strategic aims of your organisation in treating and managing hepatitis C (e.g. reducing potential life years lost)?

What impact will developing hepatitis C services have on reducing health inequalities?

How do the hepatitis C services you are developing contribute to the achievement of targets of agreed importance (i.e. reduction in mortality rate in under 75 years of age for people with liver disease)?

Have you consulted with experts - for example, Public Health England regional leads or the clinical lead for your Operational Delivery Network - to understand the local landscape and challenges to tackling hepatitis C?

## B

### Best evidence for the prevention, testing, treatment and management of people with hepatitis C

Consider the best available evidence, for example:

- Prevention:
  - [NICE public health guidance 52. Needle and syringe programmes](#)
  
- Testing:
  - [NICE public health guidance 43. Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection](#)
  - [NICE medtech innovation briefing on the OraQuick HCV point-of-care test for rapid detection of hepatitis C virus antibodies](#)
  
- Treatment and management:
  - [NICE technology appraisal guidance 507 Sofosbuvir–velpatasvir–voxilaprevir for treating chronic hepatitis C](#)
  - [NICE technology appraisal guidance 499 Glecaprevir–pibrentasvir for treating chronic hepatitis C](#)
  - [NICE technology appraisal guidance 430 Sofosbuvir–velpatasvir for treating chronic hepatitis C](#)

## C

### Review current practice

Consider the following questions and actions when reviewing services:

Do you know where the provision of care is and where the gaps are? E.g. how many prisons provide hepatitis C care in the area?

Review the take-up of services and what steps can be taken to increase it. E.g. if geographical barriers are resulting in high 'Did Not Attend' (DNA) rates, this could be ameliorated by delivering outreach treatment locally, or incorporating some support worker/volunteer support in the treatment pathway.

Review service capacity and identify areas where additional resource might be needed. E.g. Are there enough nurses, clinic rooms, and prison staff to facilitate testing? Can anything be done to fill these gaps?

Do you know what works well (locally and from the evidence)? E.g. are there local examples of good practice, and have you reviewed HCV Action's online good practice case studies?

How effective are the clinical networks for hepatitis C? E.g. can patients be directly referred from substance misuse services?

How streamlined are care pathways, and how well are smaller or more remote services connected to a wider regional strategy?

How informative is your original dataset? What other information could help you? E.g. commissioners of substance misuse services should ask if testing data reflects the number of individuals who received a hepatitis C test, rather than just the number of individuals offered a test.

Has the provider achieved the desired inputs, outputs and outcomes outlined in service specifications?

Do you fully understand the costs attributed to each service?

What can you learn from the stakeholders/users of the services? E.g. have service users been asked for feedback?

Can you identify risks and reflect on learning from positive feedback and complaints?

What are the perspectives from the health professionals working with people with hepatitis C?

How does current practice compare with the best evidence and recognised pathways of care?

Has your organisation carried out any internal or external audits?

## D

### Develop outcomes to act as a driver to improve health

Examples of outcomes are:

- Increase in public awareness of hepatitis C
- Increase in awareness of hepatitis C among service workers
- Decline in numbers of new hepatitis C infections
- Sufficient provision of injecting equipment and opioid substitution therapy
- Increase in screening and testing of hepatitis C to improve early diagnosis
- Reduction in waiting time between diagnosis and initiation of treatment
- Reduction in mortality rate under 75 years of age for people with hepatitis C
- Reduction in health inequalities
- Increase in the numbers of patients receiving treatment for hepatitis C
- Increase in the percentage of patients achieving SVR
- Reduction in liver cancer and transplantation
- Reduction in decompensated cirrhosis

- Reduction in unplanned hospital admissions
- Reduction in DNA rates

*N.B. Each service will likely have additional process and outcome measures that are not indicated here*

## E

### Evaluate

To evaluate the service, consider the collection of data in the following format:

1. Pre-implementation (ensure you have the right data set agreed before starting)
2. Implementation (ensure that data set is being collected, reported and reviewed continuously)
3. Post-implementation (identify an appropriate time to evaluate the service/programme)

Minimum areas for evaluation should be:

- Effectiveness (the outcomes)
- Efficiency (productivity – numbers of patients/clients seen including drop-out rates etc.)
- Quality (patient safety, patient experience and satisfaction, effectiveness [linked to the outcome domains])

Effectiveness / outcomes – see section D

Efficiency – examples below

- Number of people diagnosed (at all sites excluding prison)
- Number of people tested (at all sites excluding prison)
- Number of people tested in prison
- Number of people diagnosed in prison
- Number of people treated in prison
- Number of people referred to treatment service
- Numbers of patients seen in treatment service
- Number of people commencing treatment

- Number of people completing treatment
- Percentage of people achieving SVR
- Number of emergency admissions of people with hepatitis C with complications
- Number of emergency readmissions of people with hepatitis C with complications
- Full implementation of dry blood spot (DBS) testing
- Proportion of blood samples reflex tested for hepatitis C

Quality – examples below

- Patient satisfaction questionnaire
- Is the service following [NICE testing guidelines](#)?
- Is the service fulfilling NHS England's [service specifications](#) for ODNs?
- Are staff up to date with hepatitis C guidelines and competencies?
- Is testing performed in an approved laboratory?
- Is accurate data being collected to ensure appropriate follow-up and eliminate unnecessary re-testing?

## F

### Formulate an appropriate data set

Data is key to driving improvements in care. It is essential that there is an appropriate data collection system built into the commissioning and procurement of services. To prevent duplication of data consider the following questions:

What providers are involved in providing the different sets of data?

What levers do you have to negotiate the information flow (e.g. will this be in a service specification or contract)?

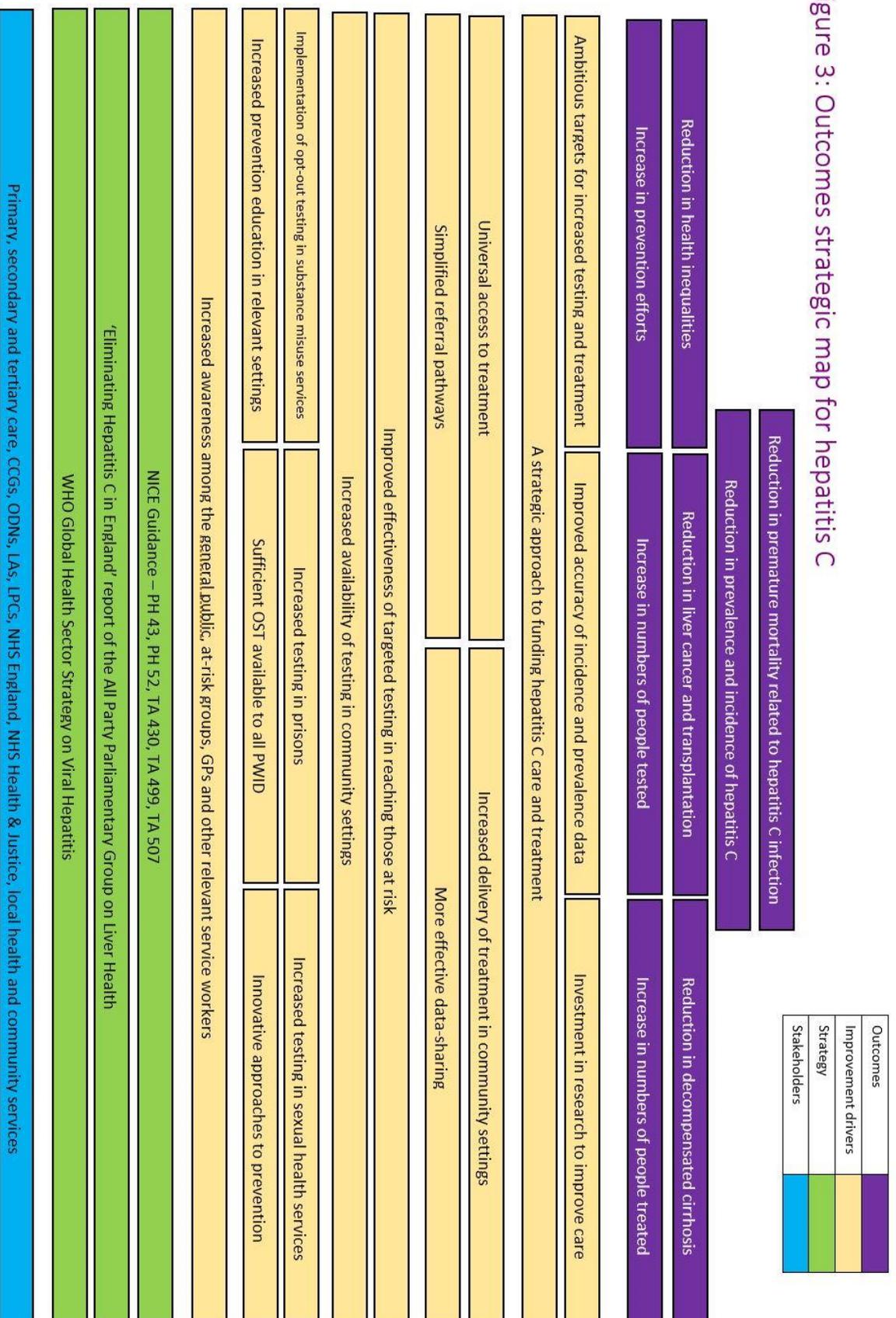
What data recording tools do the provider or providers already have?

What data is provided to the commissioning organisation already? ODNs, for example, are required to provide a range of outcome data which could be helpful, including on:

- The proportion of the population who are estimated to be infected.
- The number of patients who initiate treatment with NICE-approved therapies.
- The number of patients who achieve an SVR.<sup>xx</sup>

The outcomes highlighted in section 'D' and in section 'E' are essential to collect and databases should be set-up to collect these outcomes as well as the process and outcome measures identified for each service.

Figure 3: Outcomes strategic map for hepatitis C



## Appendix 1

# Template service specification for substance misuse services

### Aims and objectives

The aim of the service, in relation to hepatitis C, is to deliver interventions that specifically aim to prevent, test and diagnose hepatitis C, as well as to link in with local treatment providers in order to ensure a clear referral pathway.

The objectives of the service are to:

- Contribute towards a reduction in the number of new infections.
- Raise awareness and knowledge levels of hepatitis C among service users and staff
- Provide hepatitis C testing and ensure all positive diagnoses are referred on to treatment services.
- Support service users into and through hepatitis C treatment.

### Partnership working

In order to provide these services, the provider shall work with all relevant local partners, which may include but are not limited to:

- The local Hepatitis C Operational Delivery Network
- GP surgeries and other primary care services
- Public Health England
- Local prisons
- Mental health services
- Homelessness services

The provider should agree Memorandums of Understanding with secondary care services to coordinate the collection of testing data and treatment outcomes. Where possible, these should include agreements for delivery of treatment within the services.

### Provider responsibilities

Text in purple indicates HCV Action's recommended assessment criteria to be used by commissioners during the commissioning process.

The provider shall:

- Provide pre- and post-hepatitis C test advice, information and counselling to service users.
  - *Services will evidence that staff are trained to deliver advice, information and counselling.*
- Support the delivery of the relevant local authority-led hepatitis C/BBV strategy.
  - *Services will evidence awareness of and participation in all relevant local strategies.*
- Screen service users for hepatitis C and other BBVs.

- *Services will provide information on proposed 'opt-out' testing procedures, proposed testing pathway, and evidence that sufficient numbers of staff are trained to deliver dried blood spot testing.*
- *Services should ideally provide evidence of previous successful testing and diagnosis procedures.*
- Provide referrals for service users to access treatment for hepatitis C.
  - *Services will evidence familiarity with the referral pathway and awareness of the local ODN structure.*
- Provide a 'one stop shop' for service users in partnership with the preferred hepatology department on initiating treatment for hepatitis C.
  - *Services will evidence awareness of the local ODN structure and experience of working in partnership with secondary care services, as well as information on how it will work alongside the ODN to deliver treatment in a community setting.*
  - *Services will provide evidence of previous Memorandums of Understanding with secondary care services.*
  - *Services will be able to demonstrate adequate clinical space to host outreach treatment clinics.*
- Ensure all staff have the knowledge and skills needed to engage with service users regarding hepatitis C.
  - *Services will provide evidence that all relevant staff have undertaken, or there are plans for them to undertake, appropriate BBV training (N.B. this should not be solely online training).*
  - *Services will have a BBV lead appointed within the service to oversee workforce development.*
- Support, train and liaise with community pharmacies providing needle and syringe exchange.
  - *Services will provide evidence of previous engagement with community pharmacies, and experience of delivering training.*
  - *Services will provide evidence of engagement with community pharmacies to increase access to hepatitis C testing for needle and syringe programme clients.*
- Provide advice and information on injecting risks and behaviours.
  - *Services will provide evidence of staff knowledge levels and previous experience of providing harm reduction advice and information, particularly in relation to hepatitis C. Services should also detail plans to deliver peer education sessions.*
- Support service user involvement in the design and delivery of key interventions
  - *Services will provide evidence of peer support programmes or plans for such programmes, as well as the incorporation of service user feedback into the design / re-design of services.*

*Support service users to engage with treatment and track outcomes*

- *Services will provide evidence of procedures supporting clients to engage with treatment following referral.*
- *Services will monitor, be able to report on, and evidence staff awareness of the treatment outcomes of clients.*

## Performance outcomes

The percentage of service users currently injecting or receiving opioid substitution therapy who have been offered a hepatitis C test:

- To be 100%

The percentage of service users currently injecting or receiving opioid substitution therapy who have accepted the offer of a hepatitis C test:

- To be a minimum of 75%

The percentage of service users currently injecting or at continued risk of infection who are offered a re-test every six months:

- To be a minimum of 80%

The percentage of eligible service users testing positive for hepatitis C who are referred on for treatment:

- To be 100%

The percentage of service users referred into treatment for hepatitis C with known and recorded treatment outcomes:

- To be a minimum of 70%

## Appendix 2

# ITTREAT (Integrated community-based Test – stage – TREAT): A business case template for developing an integrated hepatitis C community service for people who inject drugs

### Business Case Template

#### Hepatitis C Test & Treat Nurse-Led Community Based Service

[Name of relevant clinician/manager]

Version [n.n]

dd mm yyyy

#### 1. Template Summary and Guidance

*The purpose of this business case template is for use in local health systems, in order to establish an integrated community based nurse-led hepatitis C virus (HCV) service to engage people who inject drugs (PWID) through the funding of a specialist hepatitis nurse. The template should be locally amended to include local data and to fulfil local service requirements.*

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The epidemiology and demography of hepatitis C virus (HCV) infection varies significantly in different parts of the country, and it is unlikely that a single model of service delivery will be optimal in all locations, i.e. there will not be a “one size fits all”. Networks with a geographically small but densely populated catchment area may be able to deliver the majority of their care centrally, while those with large areas to cover will need to establish multiple outreach services and would be expected to enrol multiple local providers as part of a network.<sup>1</sup> Specific local models are likely to be needed to provide a service to prisons and other secure environments. Whilst this business case template is based on a community hepatitis nurse, it may be that other individuals would be delivering the community service e.g. an addiction nurse specialist or a pharmacist. Additionally, the location of the community service could vary for e.g. substance misuse service primary care, pharmacy, and homeless hostels. Finally, while this business case is focused on PWID, it could also be adapted for other vulnerable adults to include the homeless and the immigrant populations. In some places greater use of technology may allow some ‘virtual’ management of patients.

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<sup>1</sup> NHS England. HCV Networks <https://www.england.nhs.uk/commissioning/wp-content/.../hep-c-networks-spec.pdf>

Therefore this template needs to be adapted according to local needs. Each section will need adjustments based on local differences in epidemiology and where a different community-based setting is proposed. This business case includes:

1. This template summary.
2. Background - This section references the Brighton-based service which is used as the basis for evidence for the community model of HCV testing and treatment. It also summarises the national and international context of HCV.
3. Aim and Objectives - This provides a clear aim and objectives that will apply in most settings.
4. Policy and Evidence - This section details the International and National Policy including targets. The section also includes the data from Brighton that shows how effective the service has been and details the Public Health Outcomes relating to hepatitis C. *This section also includes a table for addition of local data - HCV testing and treatment and Public Health Outcomes data.*
5. Planned Service Delivery - This provides details of the service provided in Brighton.
6. Service Benefits
7. Resource requirements - This section reflects the national resourcing
8. Conclusion
9. Acknowledgements
10. Appendices

## 2. Background

This business case supports the development of an integrated community based nurse-led HCV test, stage & treat service for vulnerable adults who inject drugs. This would be based in the local community service that would best suit the epidemiology of the local population.

The business case is modelled on a recently mainstreamed service developed in Brighton & Hove. The information and data used to support this business case is taken from scientific conference publications and personal communications with the Academic Hepatology lead at the Brighton & Hove service. The acute hospital trust, Brighton & Sussex University Hospital, employed a specialist nurse who worked full time in the community based SMS. For the purposes of this document, the term 'the Brighton Service' will be used.

The importance of the Brighton Service is the delivery of a fully operational integrated nurse-led HCV specialist service in a non-acute, community setting. In England, the majority of HCV treatment specialist clinics are delivered in an acute hospital setting, which had previously been the case in Brighton. The difficulty this presents is that 90% of individuals with HCV in England are people who inject drugs (PWID)<sup>2</sup>, a highly vulnerable and disenfranchised cohort with poor engagement with health services. In 2011, with the help of research funding, Brighton appointed a hepatitis nurse to work at the Substance Misuse Service to perform blood borne virus (BBV) screening with onward

referral to the hospital. Only 5% of those referred actually attended their hospital appointment with none being eventually treated.<sup>2</sup>

The WHO Global Health Sector Strategy on Viral Hepatitis aims for elimination of viral hepatitis as a major health burden by 2030.<sup>3</sup> This WHO target is unlikely to be achieved without directly engaging PWID; only by reducing seroprevalence in this cohort will HCV elimination be a realistic goal. In England, the HCV services are now delivered within the framework of HCV Operational Delivery Networks (ODNs).<sup>4</sup> A national CQUIN (Commissioning for Quality and Innovation framework for payments) is used to support delivery of HCV services through stewardship and measures the effectiveness and cost of treatment of patients within a nationally agreed run rate per network. There is also a governance payment for each network which is expected to be used for network development and is awarded retrospectively on the submission of quarterly evidence. The Brighton specialist nurse post positively contributes to the CQUIN achievement and is a model the network is intending to roll out in East and West Sussex. Brighton is the hub for the Sussex ODN where there is a weekly multi-disciplinary team (MDT) to discuss potential HCV treatment patients.

### 3. Aims & Objectives

#### Aim

- To reduce the morbidity and mortality from HCV-related liver disease and as a consequence of treatment, reduce onwards viral transmission; in order to achieve national and WHO targets for elimination of viral hepatitis as a major health burden by 2030

#### Objectives

- To provide a nurse-led community-based test-stage-treat service for those at risk of HCV infection with Hepatologist and multidisciplinary team support
- To access 'hard to reach' PWID at high risk of HCV infection in a local Substance Misuse Service and ensure continuity of care
- To provide HCV testing with dried blood spot testing and pre- and post-test discussion.
- Utilising transient elastography (mobile Fibroscan) to provide onsite non-invasive staging of liver scarring (fibrosis)
- To work up patients for referral for MDT assessment
- To provide onsite treatment following MDT assessment (with the supervision of the Consultant Hepatologist)
- To provide multidisciplinary support to the specialist hepatitis nurse
- To work with managers and commissioners to ensure high quality and effective service delivery including achieving local and national HCV targets

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<sup>2</sup> Marufu M, Williams H, Hill SL, Tibble J, Verma S. Gender Differences In Hepatitis C Seroprevalence And Suboptimal Vaccination and Hepatology Services uptake Amongst Substance Misusers. *Journal of Medical Virology*, 2012 Nov; 84:1737-43

<sup>3</sup> WHO target

<sup>4</sup> NHS England. Improving HCV Treatment Pathways through ODNs. 2016

#### 4. Policy & Evidence:

##### Policy Guidance<sup>5</sup>

- Viral hepatitis is the leading cause of death globally (1.46 million deaths in 2013), compared to HIV (1.3 million), TB (1.2 million) and malaria (0.5 million). In 2016, WHO developed a strategy to tackle hepatitis with targets for viral hepatitis control:
  - Ensure that 30% of people infected with HCV are aware of their status in 2020 and 90% in 2030
  - Reduce HCV-related mortality by 10% in 2020 and by 65% in 2030
  - Reduce new HCV cases by 30% in 2020 and 90% in 2030.<sup>6</sup>
  - In the UK, mortality has remained stable year on year with a reduction of 8% in 2015, probably related to greater access to new direct acting antiviral (DAA) drugs.<sup>7,8,9</sup>
- According to UK surveys, only half of PWID were aware of their HCV status.<sup>9</sup> Public Health England shares the WHO vision to halt transmission and ensure all those infected are offered safe and affordable care and treatment.<sup>5</sup> UK data supports progress towards the WHO targets for 2020<sup>5</sup>, but more work is needed to meet the 2030 targets.
- NHS England has produced a service specification for Operational Delivery Networks to provide specialist oversight of hepatitis C treatment including the five domains of the NHS Outcomes Framework (preventing people from dying; enhancing the quality of life; helping people to recover; ensuring a positive experience; and treating and caring in a safe environment). NHS England provides funding to improve HCV Treatment Pathways through Operational Delivery Networks. These payments are made directly to each NHS trusts where they are part of an ODN.<sup>9</sup> A national CQUIN is used to support delivery of HCV services through stewardship and measures the effectiveness and cost of treatment of patients within a nationally agreed run rate per network. The governance payment for network development, is awarded retrospectively on the submission of quarterly evidence.

##### Activity

The Brighton Pilot was a 4-year Integrated Test-stage and TREAT (ITTREAT) community HCV project (December 2013-2017) Ethical approval was obtained (REC ref 13/EM/0275). Research funding ran out in Dec 2017, but a subsequent successful business case was presented to the Brighton and Sussex University Hospital NHS Trust. This has ensured permanency of the community nurse and will allow this service to run for the foreseeable future.

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<sup>5</sup> PHE. Hepatitis C in the UK. 2017 Report.

<sup>6</sup> WHO reference

<sup>7</sup> NHS England. Clinical Commissioning Policy Statement: Treatment of chronic Hepatitis C in patients with cirrhosis. 2015 NHS England B07/P/a. Available from: <https://www.england.nhs.uk/commissioning/wpcontent/uploads/sites/12/2015/06/hepc-cirrhosis-policy-statmnt-0615.pdf>.

<sup>8</sup> NHS England. Interim Clinical Commissioning Policy Statement: Sofosbuvir + Daclatasvir/Ledipasvir +/-Ribivirin for defined patients with Hepatitis C. April 2014. NHS England A02/PS/b. Available from: <https://www.england.nhs.uk/wp-content/uploads/2014/04/sofosbuvir-pol-stat.pdf>

<sup>9</sup> NHS England. Improving HCV Treatment Pathways through ODNs. 2016

Project ITTREAT is based at a local substance misuse service (SMS) and has recruited 550 individuals to date of whom 250 (45%) are HCV PCR positive. Despite a mean age of only 40 years, 43% of individuals who underwent community fibroscan had clinically significant liver scarring (fibrosis). Approximately 179 (72%) individuals have been suitable for HCV treatment, of which 116 have commenced/completed treatment in the community with treatment outcomes comparable to secondary care (SVR12 rates of ~90%). In 2016/17, 34 patients were treated as part of the service; this is 15% of the total treated in all Sussex. At time of publication, 32 had been treated in the 2017/18 year, which is 17% of the treatment run rate year to date.<sup>10</sup> Appendix A details the most recent presentation for this work (presented at the British Viral Hepatitis Group (BVHG) and British Association for Study of Liver (BASL) Best Practice for ODN Stakeholders meeting Jan 2018).<sup>11</sup> Additional qualitative, health economic and patient reported outcomes are also being collected and will be analysed at a later date.

Table 1 shows local, regional and national Public Health England data for Hepatitis C (Public Health Outcomes Framework - Public Health Profiles)<sup>12</sup>:

- Detection rate of confirmed cases of Hepatitis C per 100,000 is higher in Brighton
- Percentage of PWID in Substance Misuse Services, who have an HCV test (2014/15), was 92.6% in Brighton and Hove, which is higher than both the regional and national percentage.
- Hospital admission rates for Hepatitis C related End Stage Liver Disease (ESLD)/Hepatocellular carcinoma (HCC)
- In Brighton and Hove since 2001 until 2011, under 75 mortality rates for HCV related ESLD and HCC has been 29.7/100,000 (2001-2003 rolling average), considerably higher than the national rate (0.72/100,000). In 2013-2015 this has reduced to 1.4/100,000, which is approaching the national average. This suggests a correlation both with the advent of new direct acting antivirals (DAA) and the local ITTREAT project

Table 1: Local Data

*Use this table to add you own local and regional data.*

Public Health Outcomes Framework	Time period	Local (B&H)	Regional (South East)	National (England)
Hepatitis C detection rate/ 100,000	2016	58.4	N/A	19.7
% PWID in Substance Misuse Service with HCV test	2014/15	92.6%	85.4%	81.5%
Hospital admission rate for hepatitis C related end stage liver	2012/13-2014/15	4.8	1.9	2.4

<sup>10</sup> Hashim A, O’Sullivan M, Williams H, Verma S. Developing a Community HCV Service: Project ITTREAT (Integrated Community based Test - stage - TREAT) Service for People who Inject Drugs. Primary Health Care Research and Development. 2017 (Dec 4<sup>th</sup>)

<sup>11</sup> O’Sullivan M, Jones AM, Williams H, Verma S. Project ITTREAT (Integrated Community Based Test-stage-TREAT): HCV Service for People who Inject Drugs (PWID). Presented at the BVHG/BASL Best Practice for Operator Delivery Network stakeholders meeting, Manchester, 11–12<sup>th</sup> January 2018.

<sup>12</sup> PHE. Public Health Outcomes Framework. [www.fingertips.phe.org.uk](http://www.fingertips.phe.org.uk)

disease/hepatocellular carcinoma				
Under 75 mortality rate from HCV related ESLD and HCC	2014-16	1.12	0.58	0.67

## 5. Planned Service Delivery

The purpose of this business case is to establish an integrated community based nurse-led HCV service through the funding of a specialist hepatitis nurse.

This Nurse led service provides:

- An autonomous community specialist nurse led service for people with viral hepatitis undergoing treatment, within an integrated team structure of doctors, nurses, Psychiatrists, drug and alcohol workers, peer mentors, social workers, Pharmacist and Pathway Administrator.
- Community nurse-led assessments for patients with viral hepatitis
- Clinical assessment of new and follow up patients who attend the community hepatitis clinics, including performing fibroscans.
- Treatment Initiation, monitoring and adjustment as necessary, in conjunction with and under supervision of a Hepatologist
- A plan of care for all patients in accordance with agreed protocols and clear patients records
- Blood sampling from patients, adhering to the venepuncture in Adults Policy
- Patient follow up in the community as appropriate (including home visits and phone consultations)
- Ensure all relevant information/literature is made available enabling patients to make informed choices regarding treatment
- Expert nursing advice and support to patients, their significant others and healthcare professionals following diagnosis and throughout treatment as part of the MDT
- Continuity of evidence-based nursing care, assessing health, health related and nursing needs of patients and their significant others
- Effective care as part of the MDT, including: managing a patient caseload of patients on antiviral therapy; monitoring of viral hepatitis patients who have not responded to treatment, are not suitable for treatment and those who have declined treatment; ordering diagnostic tests as per agreed protocols and pathways; making and receiving referrals relating to antiviral therapy issues; monitoring and interpreting blood results; home visits if clinically indicated; regular education of drug and alcohol workers, psychiatrists, peer mentors, social workers and General practitioners including training in BBV testing
- Performing HCC and variceal surveillance in those with HCV related cirrhosis according to guidelines and in conjunction with specialist MDT
- Develop, implement and evaluate integrated care pathways and systems of documentation in collaboration with the MDT.

- Service user involvement in providing feedback of their experience of the current service and suggestions for improvements
- Cross cover for hospital based hepatitis clinics
- Establish and co-ordinate patient support forums/groups

## 6. Service Benefits

This service will ensure a targeted approach to PWID through a multidisciplinary one-stop service. The Brighton data indicates the value of providing a community-based HCV service for delivery in SMS settings. Such a strategy represents patient centred care with the potential to: provide opportunities for earlier intervention, improve diagnosis rates; improve linkage to care rates, and improve treatment outcomes aligned to national commissioning guidance. This innovative pathway will also contribute to reduction in HCV related morbidity and mortality, onwards viral transmission, and health inequalities.

The local Brighton data corroborate this: The unlinked Anonymous Monitoring Survey of People who inject Drugs (Brighton Summary 2005-15) show that compared to 2013, in 2015 two years after project ITTREAT commenced, HCV seroprevalence amongst PWID reduced from 70% to 50%. In addition the local Public Health Outcomes Framework shows improvements in local indicators (Table 1).

Project ITTREAT has provided a service model for replication across the country, and has been presented at:

- Public Health England/ HCV Action meeting Brighton (Nov 2015)
- European Liver meeting (EASL), Apr 2015 and American Liver meeting (AASLD), Boston Nov 2016
- BVHG meeting, London, Mar 2017 (obtained highest feedback score 4.86/5)
- Regional British Society of Gastroenterology Meeting (BSG), London, Feb 2015 (Best Poster) and Mar 2017
- Hepatology Matters Meeting, Birmingham, June 2017
- International Symposium on Hepatitis C in Substance Users, New Jersey, Sept 2017
- American Liver Meeting (AASLD), Washington, Oct 2017
- BVHG/BASL Best Practice for ODN stakeholders meeting, Manchester, Jan 2018

## 7. Resource requirements:

NHS England provides funding to improve Hepatitis C Treatment Pathways through Operational Delivery Networks. These payments are in two elements:

1. Governance and Partnership Working;
2. Stewardship and NICE guidance compliance

These payments are made directly to each NHS trusts where they are part of an Operational Delivery Networks (ODNs).<sup>13</sup> A national CQUIN is used to support delivery of HCV services through stewardship and measures the effectiveness and cost of treatment of patients within a nationally agreed run rate per network. The governance payment for each network, which is expected to be used for network development, is awarded retrospectively on the submission of quarterly evidence. BSUH and the Sussex network met all the criteria in 2016/17 and are expecting to do the same in 2017/18. The CQUIN is of 3 years and 2017/18 is Year 2.

The cost of a Band 7 specialist hepatitis nurse is £31,696-£41,787. The post generates income through the CQUIN and tariff once the service is up and running.

The service secured funding for a portable fibroscan at a cost ranging from 30-50K. However the fibroscan is not essential as other non-invasive markers such a blood tests can be used (APRI, FIB-4 test). Nonetheless the Brighton team has found the fibroscan to be a strong facilitator for engagement.

The Brighton service has kindly agreed to share their own data (see Appendix B).

## 8. Conclusion

This service has demonstrated a clinically effective model for delivering accessible community based test and treat HCV services:

- Access the vulnerable client group
- Deliver on WHO and PHE targets
- Deliver NHSE run rates and CQUINs
- Generate income for the service once established

This service is an innovative and ground-breaking service that is expected to be replicated nationally as part of HCV CQUIN developments. The post holder has been largely responsible for the success of this project. This is due to her expertise in both addiction medicine and viral hepatitis, her passion to engage with vulnerable adults to provide holistic care and her ability to work with drug and alcohol workers, peer mentors, social workers and psychiatrists in a multidisciplinary manner.

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<sup>13</sup> NHS England. Improving HCV Treatment Pathways through ODNs. 2016

## 9. Acknowledgements

This business case template is based on data from a pilot study undertaken in Brighton. Therefore acknowledgements to Dr Sumita Verma, Reader in Medicine Brighton and Sussex Medical School and Hon Consultant Hepatology, Brighton and Sussex University Hospital, Specialist Hepatitis Nurse Margaret O'Sullivan, Brighton and Sussex University Hospital and to all other staff at Brighton services (acute trust, substance misuse & public health) who have supported this important HCV development. Thank you to Alison McKinlay, Service Manager Brighton and Sussex University Hospital, for sharing the BSUH business case and local financial data. The template has been funded and commissioned by Gilead Sciences Ltd. Gilead had no editorial control over the document.

### Appendix A - Brighton Service data

Table 2 describes the additional clinic activity in Brighton and associated costs:

Table 2 Additional activity

	Units	£
New clinic activity	428	34,240
New Telephone clinic activity	450	10,350
Total	878	44,590

The weekly schedule for this post is shown in Table 3. The post offers daily face-to-face clinical time, telephone clinics and domiciliary visits. Due to the nature of delivering this direct clinical activity with the group of patients identified above, clinic times are used flexibly with undertaking other work such as clinical administration (e.g. reviewing results, clinic letters), engaging with patients and support workers via regular networking, teaching and training.

Table 3 Weekly Schedule

	AM	PM
Monday	TELEPHONE: 20-30mins Non direct clinical activity	14:00-17:00 Clinic (3hrs) Non direct clinical activity
Tuesday	0930-12:30 clinic (3hrs) Non direct clinical activity	13:00-16:00 Drop in Clinic (3hrs) Non direct clinical activity
Wednesday	DOM, Telephone clinic 20-30mins	13:00-17:00 Clinic (4) Non direct clinical activity

Thursday	DOM	13:00-17:00 Clinic (4) Non direct clinical activity
Friday	Telephone clinic 20-30 mins Non direct clinical activity	13:00-15:00 Clinic (2) Non direct clinical activity

Table 4 provides a template for local areas to add their own data.

Table 4 - Financial Information

Income	44,590
Pay	26,500
Non-Pay	
EBITDA	18,090
Depreciation	
Surplus / (Deficit)	18,090
Capital (including irrecoverable VAT)	
Cost Improvements (included above)	
Transitional Costs (included above)	

## Appendix 3

### Good practice case study: Outreach treatment in Newcastle

#### Key points:

- The service is based at Freeman Hospital, Newcastle, with outreach centres in eleven locations across the region.
- Prior to the outreach service, hospital attendance at new hepatitis C patient appointments was less than 50%.
- The service has resulted in attendance rates of 75%, an increase in the numbers of people being treated, and comparable Sustained Virological Response (SVR) rates as hospital-based treatment.

#### Overview

People with hepatitis C often face significant barriers when seeking access to care. Whether because of financial, logistical or psychological reasons, many find it extremely difficult to engage with care that is delivered in a secondary care setting. With some people with hepatitis C leading chaotic lifestyles, and with a sizeable proportion coming from areas of socio-economic deprivation, actually getting to appointments can represent an almost impossible challenge.

It is because of this that outreach services are so important in terms of increasing the numbers of people accessing hepatitis C testing, treatment and care. Such outreach services are available in Newcastle and the surrounding area, where the North East and Cumbria ODN delivers outreach clinics in 11 locations across the region. The clinics have resulted in an increase in attendance rates and in the numbers of people receiving treatment, as well as significant improvements in the patient experience.

#### Why the service was established

Like hospital-based hepatitis C treatment services across the UK, the treatment service based at the Freeman Hospital in Newcastle often suffered from low patient attendance. Whether due to the sometimes chaotic lifestyles of people who were being referred to the service, or because of social or economic barriers, more than half of all people referred for treatment in the area failed to attend their first appointment at the Freeman Hospital.

At the Plummer Court Addiction Centre in Newcastle (which was able to refer patients to the Freeman Hospital), there were at least 55 service users with hepatitis C, yet non-attendance at clinics was almost universal. At the Bridge View drug treatment centre, there were 77 service users with hepatitis C; only nine of whom had been referred and just one treated. At the Blyth Harm Reduction Service, too, those people referred on to secondary care often failed to make their appointment due to the distance that had to be travelled from Blyth to Newcastle.

Very simply, prior to the establishment of the outreach component of the service, the hepatitis C treatment service in the region was not meeting the often complex needs of those people who needed it. By locating the delivery of treatment in a secondary care setting, those who required treatment were faced with multiple barriers in accessing it.

## How the service works

In order to address the barriers that were preventing many people with hepatitis from accessing the care they needed at the Freeman Hospital, outreach services were established which now deliver treatment in 11 different locations across the region – five in prisons, five in drug services/needle exchange clinics, and one in a GP surgery.

These clinics are held every four weeks and are nurse-led. A Consultant clinic is held once every eight weeks at Plummer Court and once every four weeks there are Consultant telemedicine clinics at HMP Northumberland and HMP Durham. The service has a portable fibroscan which is taken to outreach clinics meaning the only time a patient would have to attend the hospital is for radiological imaging; however, this can sometimes be organised in District General Hospitals or satellite clinics closer to patient's homes if required. Patients can also receive additional support at these clinics, such as attending with their case worker, and case workers are happy to support the nurse-led service when necessary. For example, case workers can repeat blood tests where required and perform welfare checks on patients undergoing treatment.

In April 2015, the outreach service was further enhanced through changes made to the treatment service provided to inmates at HMP Northumberland. Whereas previously, prisoners often had to come out of prison in order to attend appointments (something which would lead to many dropping out of the pathway, and which required additional prison resources due to the need to accompany the prisoner etc.), now the pathway has been streamlined to ensure that treatment can be delivered within the prison – significantly reducing the barriers to care that prisoners often faced. The re-development of the pathway has led to a significant increase in the numbers of prisons engaged in the pathway and receiving treatment and an outreach service has also been established at HMP Durham.

As part of the service, a dried blood spot (DBS) testing pilot was also established at the Plummer Court Addiction Service, with a combined hepatitis B, hepatitis C and HIV test offered to 100 service users, with a view to assessing whether or not this increased testing uptake. The results were clear, with nobody refusing a test and with 23% of those who were tested shown to be hepatitis C antibody positive. Only 18% of those tested had previously been offered testing, and 39% of those tested stated that they would not have accepted a venous test – clear proof of the value of DBS testing.

DBS testing is now established as the standard of care across the region, which has helped to increase uptake and access to BBV screening. Prisons within the North East and Cumbria ODN were the first to achieve universal offer of testing for BBVs and have a high level of uptake, with 53% accepting the offer of a test.

The outreach team has grown, with three full-time nurses and a part-time nurse employed in the last two years. The nurse team work to promote and facilitate testing and treatment in a wider range of outreach locations. In addition, two hepatology assistants have also been employed to support patients to engage with treatment, including by contacting those who have been diagnosed but disengaged from care, and coordinate peer-to-peer programmes.

## Outcomes

### *Increased attendance at clinics*

Prior to the establish of the outreach service, attendance at the Freeman Hospital was low; owing to a combination of barriers which prevented people with hepatitis C from being able to access care. Since the outreach service was established, attendance at clinics has risen to approximately 75%; meaning that more people are receiving the kind of monitoring, care and treatment that they require.

### *Good treatment compliance and outcomes*

The outreach service acts as further evidence that people who receive care in an outreach setting can have as good, if not better, treatment outcomes than those who receive care in a hospital setting. Since the establishment of outreach services in Newcastle, treatment outcomes are comparable with hospital-based care and patient satisfaction is continually reported as excellent.

In addition to the above, several patients with cirrhosis have been identified and will now receive the appropriate surveillance, which has the potential to lead to significant cost-savings, given the expense of caring for people with advanced cirrhosis.

A total of 620 patients were treated by the North East and Cumbria ODN in 2017/18, with 94% of patients achieving SVR.

### *Improvement in the patient experience*

Delivering care in an outreach setting is the preference of a great number of patients, and provides for a significantly enhanced patient experience. Individuals who receive treatment in prison, for example, no longer need to leave prison at any stage through the treatment process, and those who are being treated in the community no longer have to travel significant distances in order to access the care that they need.

### *Attainment of ODN aims*

Each ODN across England, according to the service specification through which they were established, are required to tailor services, as far as possible, to meet the needs of patients, and are required to “promote access to treatment services locally through partnership and outreach models.”<sup>xxi</sup>

## Appendix 4

### Good practice case study: Increasing diagnosis & treatment in drug treatment settings

#### Key points:

- As part of the HepCATT project, an evaluation was launched into the effectiveness of a complex intervention in drug treatment centres aimed at increasing the numbers of people who inject drugs (PWID) engaging with hepatitis C care.
- The intervention involved the appointment of a part-time facilitator to co-ordinate local activities aimed at increasing diagnosis and enhancing patient referral.
- The intervention was delivered in three drug treatment centres across England, with data analysed alongside five control sites.
- Rates of PWID referral, attendance, engagement and treatment increased at all intervention sites compared to baseline and to control sites. Across the three sites, the estimated odds of engagement with treatment increased tenfold. By contrast, the odds of engagement on average halved at the control sites.

#### Overview

The challenges of engaging people who inject drugs (PWID) into hepatitis C care and the need to develop interventions which increase the numbers of PWID tested and treated have been widely acknowledged. The HepCATT study aimed to explore the impact of a complex intervention into drug treatment services on increasing overall engagement of PWID with hepatitis C care, as well as the impact on proportion of PWID tested, referred and treated for hepatitis C. Unlike most previous studies investigating potential improvements to hepatitis C care in the PWID population, which were observational and descriptive, the HepCATT study measured the impact of a carefully developed intervention against a control group.

#### How the project worked

A 12-month intervention was delivered in 2015-16 at three drug treatment centres in Lincoln, Liverpool and Walsall. Five sites not chosen as intervention sites acted as controls.

This intervention was centred on the appointment of a facilitator to coordinate a range of activities aimed at increasing diagnosis and enhancing patient referral including establishment of peer support teams, staff and patient educational initiatives, simplification of referral pathways, introduction of dried blood spot testing, and active engagement with clients to increase appointment attendance.

The primary study outcome was engagement with a treatment service, defined as patients having completed 1) all tests necessary for a diagnosis 2) assessment of stage of liver disease and 3) a consultation regarding their treatment options.

Secondary outcomes were the proportion of all PWID who were tested for HCV in that year, the number of HCV-infected individuals who were referred for specialist assessment, and the number who started treatment.

### Outcomes

There was strong evidence for the impact of the intervention, with the estimated odds of engagement increasing tenfold across the three intervention sites. At the intervention sites, the numbers of HCV-positive PWID engaged with treatment increased from 10 (11% of all known HCV-positive PWID), three (2%) and three (10%) in the baseline year to 55 (55%), 68 (29%) and 20 (32%) in the intervention period. By contrast, the odds of engagement on average halved at the control sites.

The proportion of PWID tested for hepatitis C across the three sites increased 2.5-fold, whereas there was a small drop in proportion of PWID tested at control sites. The numbers of patients who started treatment at the intervention sites increased from 2, 1 and 0 to 15, 31 and 8, showing a significant increase and difference between the intervention and control sites. There was also a substantial positive effect in the intervention sites on the proportion of HCV-positive PWID appropriately referred for specialist assessment.

There was continued drop-out from care along the pathway. Overall, at the intervention sites, 246 clients were referred for specialist assessment, but only 159 (65%) attended their clinic appointment, and only 54 were treated. However, this is in comparison to only three patients treated in the baseline year preceding the intervention.

The HepCATT study indicates that investing resources into complex interventions aimed at improving hepatitis C care pathways for PWID can result in a substantial improvement in hepatitis C testing, referral and treatment rates.

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## Appendix 5

### Good practice case study: Peer-to-Peer Education in substance misuse services

#### Key points

- **112** peer-led workshops were delivered between Septembers 2015-16.
- **806** service users attended the peer-to-peer workshops, with **84% (n=681)** of attendees taking part in a study to monitor the effectiveness of the intervention.
- **70% (n=477)** of those who completed feedback questionnaires indicated that their **knowledge had increased ‘a lot or ‘massively’**.
- Post-workshop data indicated an increase of **141%** in the numbers of people being tested for HCV.

#### Overview

In 2014, Addaction and The Hepatitis C Trust (HCT) formed a partnership through which the two organisations worked together to support people with a history of injecting drug use into the hepatitis C (HCV) care pathway. The partnership project adopted three key interventions; peer-to-peer education, a buddying scheme, and a workforce development programme. An external evaluation was conducted on all three elements of the project (full report available [here](#)). This case study summarises the findings of the peer-to-peer education intervention.

#### Why the pilot was established

The pilot was predicated upon Addaction and HCT’s shared understanding of four key issues:

- That people who inject drugs are at particularly high risk of HCV infection.
- That people who inject drugs find it difficult to engage in HCV testing and the care pathway.
- That there was a need for accurate and current information to be embedded into the drug using community regarding HCV prevention, testing and access rights to treatment
- That people who inject drugs can be cured of their HCV, for some an important step on their recovery journey.

Additionally HCT have run a peer-to-peer (P2P) education programme since August 2010 with employees providing key messages about hepatitis C prevention, diagnosis, treatment and care to people attending drug services. HCT wanted to explore the possibility of using existing networks of volunteers within substance misuse services in order to expand the delivery of this intervention, in the belief that key messages around awareness, prevention, testing and treatment were best and most effectively delivered by peers.

## How the P2P project worked

Peers were trained to deliver workshops using their own experience of hepatitis C as a platform to deliver core messages about the importance of testing, the urgency of linking with care for liver assessment and the availability of new treatments. The project ran across seven areas and workshops were delivered into drug service day programmes, residential rehabilitation units, hostels and homeless shelters in each area.

Workshops typically lasted for one hour and featured the peers' personal story, a group discussion and a feedback questionnaire followed by a short quiz to test understanding at the end of the session. The peer educators were given clear instructions and guidance as to why and how data needed to be collected.

Follow-up telephone interviews with attendees to test long-term retention of the workshop messages and interviews with the peers themselves were also undertaken to form the qualitative arm of the study.

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*"I was in shared accommodation where there was a lot of drug users and there were a lot of needles around in the environment, so it was very relevant, yeah – I knew about being able to catch things from needles but it helped remind me to be extra careful, and I did talk about it with people there and pass on the information"*

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An innovation that was introduced in the final phase of the project at the request of the peers was the on-site availability of hepatitis C testing immediately following the workshop ('Talk & Test').

Between September 2015 and September 2016, a total of 112 peer education workshops were held, attended by 806 participants. A breakdown of the areas in which the workshops were delivered can be seen in Figure 1.

Area	Workshops Established	Workshops Delivered Sept 15 - 16	Total Attendees	Average per workshop
Bournemouth	04/03/2016	10	56	6
Cornwall	09/08/2014	44	334	8
Devon	22/09/2015	10	64	6
Lincolnshire	25/11/2015	2	21	11
Liverpool	30/10/2015	8	54	7
St Helens	22/10/2015	9	65	7
North Somerset	28/8/2014	29	212	7
Total		112	806	7

Figure 1

*Note – drug treatment services are commissioned across local authority areas some of which are therefore county-wide, whereas others are focused on specific towns and cities. Data relates to the period covered by this evaluation. In some areas, workshops only ran for part of the year.*

## Outcomes

### Target cohort reached

Information regarding participants' injecting drug use and sharing of equipment was requested as part of the questionnaire.

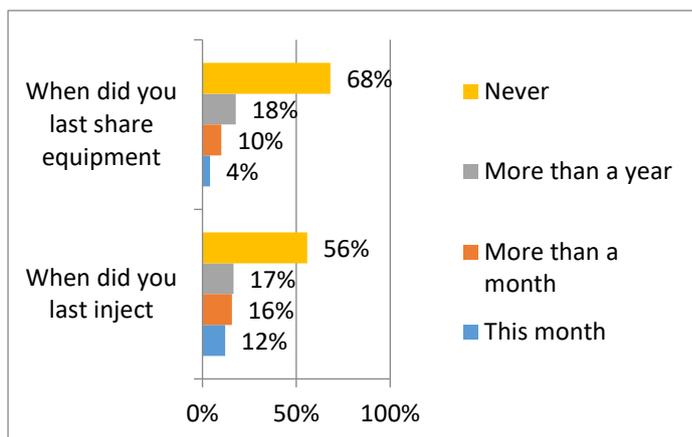


Figure 2

Responses showed that 44% of participants had some form of injecting history (as shown in Figure 2). This indicates that the project reached its intended cohort.

### Improved knowledge and awareness among key at-risk groups

Post-session questionnaires showed that the workshops led to substantially increased levels of knowledge and awareness among participants. Out of the total 806 attendees, 681 completed a five-question quiz to assess their understanding of the key messages. 70% (n=477) of those who completed the questionnaire indicated that their knowledge had increased 'a lot or 'massively' as a result of the workshop, with 89% (n=606) of respondents correctly answering all five questions.

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*"It's definitely changed my behaviour – I do still use drugs but I'd never share a fiver with someone now. It's made me very aware of the possibility of transmission so I am more cautious. I've never shared works [drug injection equipment] but I definitely wouldn't in future because of this"*

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A total of 277 attendees initially consented to be contacted at a later date for further evaluation. As may be anticipated within this client group, 34 individuals (12% of those who initially left contact details, and 4% of all attendees) took part in the follow-up telephone interviews.

Longitudinal analysis, based on these interviews, showed that long-term retention of the information provided in the workshops was excellent, with near-universal recall among those interviewed of the key messages. Additionally, and significantly, a number of those interviewed indicated that they had shared the information with their partners, friends and peers.

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*"I speak about it quite a bit with people I see in the service. I've also seen other service users who've been to the sessions telling others about it outside the main building – it's just quite an interesting topic, it's like one of those subjects at school where you want to come home and go 'Did you know...?'"*

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This indicates that the peer training is successfully embedding accurate information and messages about hepatitis C within the drug using community; messages which are then being repeated organically through the community itself.

### Increased numbers of at-risk service users being tested

Feedback from previous workshops and from peer educators indicated that people may be more willing to be tested if the test was available at the close of the workshop they attended. The pilot responded to this by introducing on-site availability of HCV testing

immediately following a workshop, known as 'Talk and Test'. This innovation was delivered at five of the workshops in Devon.

Overall, there were 27 recorded tests across all the Devon locations in the time preceding the peer sessions and 65 tests in the weeks immediately following delivery of a peer-to-peer education session. This indicates an average increase in testing of 141%, and provides evidence that the sessions play a vital role in ensuring that at-risk individuals realise the importance of getting tested for hepatitis.

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*"I've heard of people who've started using again because they had such a bad time with interferon. But now they've got this new treatment that's very quick and easy. So that stuck in my mind – that it is curable, it's not the end of the world if you do have it. I have to say that made me feel better about the idea of getting tested."*

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HCV test data indicated a particular spike in take-up where testing was available at the end of the workshop (Talk and Test) with a significant proportion of the monthly total (for the month following) having been tested at the end of a session.

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*"I think the session really made me think – it made me a bit more open-minded and willing to learn more about HCV and other things like that – about health risks and what I can do to stop them, it made me think I should care more about my health. I got tested after the session"*

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## Birmingham

The 'Talk and Test' model was then adopted outside of this study in Birmingham through the period April 2016 to October 2016. Overall, 25 workshops were delivered in Birmingham with 195 attendees. 18 of these workshops adopted the 'Talk and Test' model whereby 72 clients received an HCV test within the workshop.

Talk and Test, ensuring that testing was available following sessions, led to significant increases in the numbers of people tested in participating services.

Delivery Date	Number attending session	Test complete on day	
April	8	6	75%
May	18	10	55%
June	21	10	47%
July	18	8	44%
August	28	16	57%
September	25	9	36%
October	26	13	50%
Total	144	72	50%

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*"We were told about where to go for testing, that we can go to our doctor, a clinic at the hospital, or at the R-Hub (Addaction service) where I go; and what the options were for treatment – it's handy to know I can give information to other people if I meet anyone who would benefit from it. I had another test about 6 months ago just for peace of mind. I would definitely advise someone to get checked out every couple of years at least."*

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