

# Joining the Dots

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Linking pathways to hepatitis C diagnosis and treatment

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**LONDON JOINT  
WORKING GROUP**

ON SUBSTANCE USE  
+ HEPATITIS C



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# Foreword

Patients, their families, clinicians and addictions workers are all excited about the opportunity we now have to cure people of hepatitis C and eventually to eliminate the disease as a public health threat. However, this will only be possible if the many services and organisations that are engaged with people with hepatitis C, and people who are at risk of contracting hepatitis C, join up their data systems so that people who are diagnosed can progress quickly and easily to treatment and care.

This sounds simple, but the reality is not straightforward. People may be diagnosed with hepatitis C at a drugs service, prison, GP practice, or other outreach service. These organisations will have different IT systems and processes for sharing diagnoses with Public Health England, local treatment providers and the local Operational Delivery Network. Further, interpretations of the new General Data Protection Regulation (GDPR) and associated Data Protection Act 2018 (DPA18) regulations have led to confusion in some organisations about data sharing and consent, even though GDPR and DPA18 do not alter the requirements of the Health and Social Care (Safety and Quality) Act 2015 for health and social care organisations to share data that facilitates patient care.

These issues are technical but they are absolutely vital in making the system work for patients. I am pleased that this report shines a light on some areas of confusion and misunderstanding, and makes recommendations for a more streamlined, coordinated approach to data sharing. Whilst many of the insights and recommendations in the report apply to other areas of healthcare, all of the interviews and discussions that provide the basis of this report were specifically hepatitis C related.

This report will be useful to any organization involved in hepatitis C testing, treatment or care. I hope it will initiate many to review their data sharing processes and protocols to ensure these facilitate easy pathways into treatment and allow for data flows that will benefit every patient.

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# About the London Joint Working Group on Hepatitis C

The London Joint Working Group (LJWG) is a group of clinical, commissioning and patient group experts whose goal is to eliminate hepatitis C in drug users and those engaged in drug treatment services in London. The LJWG works with stakeholders to develop recommendations for improving the rates of hepatitis C testing, diagnosis, and referral as well as access to specialist assessment and treatment for people who use or have used drugs. For more information, please visit [www.ljwg.org.uk](http://www.ljwg.org.uk).

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# Summary

Hepatitis C is a blood borne virus that can cause cirrhosis, liver cancer and death. However, NICE approved treatments can cure the virus in around 95% of patients. The responsibility for testing people at risk of having hepatitis C, and treating people who are infected, lies across different services including GP practices, drugs services, prisons, pharmacies and hospitals.

In order to ensure that people at risk are tested, and that people with hepatitis C can access treatment, effective data sharing pathways must be developed between services. This report explores current barriers and solutions to join the dots and improve data pathways between testing, treatment and care for hepatitis C patients.

We identified two major obstacles to effective data sharing in relation to hepatitis C diagnosis and treatment:

1. Confusion about who data can be shared with and under what circumstances;
2. A lack of computer systems that enable care providers to easily share patient data.

In particular, we found that obtaining written consent from patients was often considered the 'best', if not the only, basis on which data could be shared. This is at odds with the Health and Social Care (Safety and Quality) Act 2015 and General Data Protection Regulation, which create an obligation to share data for patient care and provide a legal basis for doing so that does not require explicit patient consent.

We made three recommendations to address these obstacles:

1. Development of clear guidance and training for care providers, particularly those from community drug and alcohol teams, regarding:
  - when explicit patient consent is, and is not, needed to share data;
  - which data can be shared;
  - who data can be shared with and under what circumstances.
2. Provision of additional support for hepatology outreach, particularly in community drug and alcohol teams, but potentially also in other community contexts such as pharmacies.
3. Development of informatics solutions that help care providers to share data, via joint working of Operational Delivery Networks and commissioners.



# Motivation & Approach

## 3.1 Background

### 3.1.1 The Importance of Data Sharing for Hepatitis C Testing and Treatment

In 2016, the United Kingdom signed up to the World Health Organization Global Health Sector Strategy on Viral Hepatitis, which commits participating countries to eliminate hepatitis C as a major public health threat by 2030 [1]. This commitment included signing up to targets of an 80% reduction in incident (new) chronic hepatitis C (HCV) infections and a 65% reduction in mortality from hepatitis C by 2030.

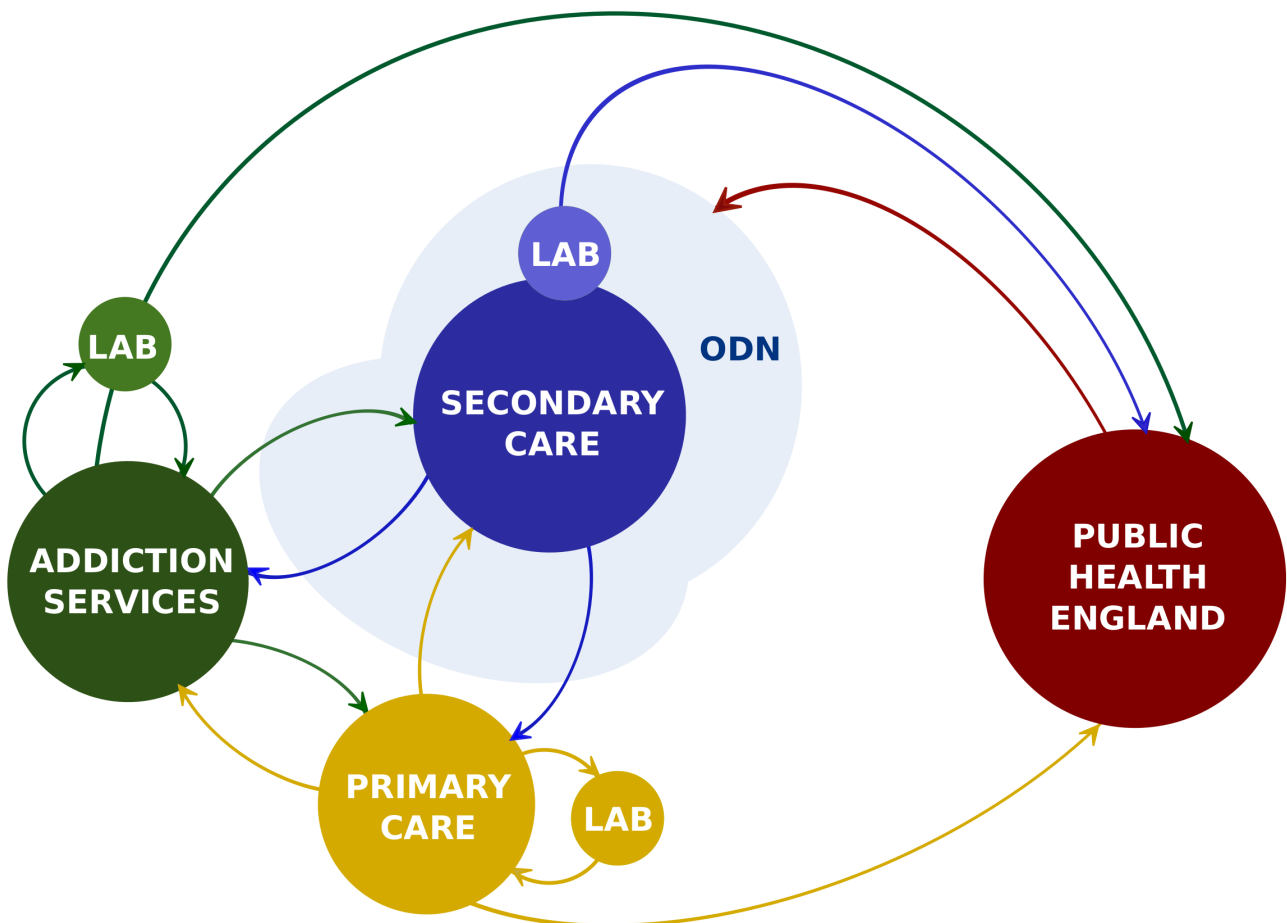
In 2018, NHS England took this commitment further by announcing their own target of eliminating hepatitis C by 2025 at the latest, aiming to become the first country in the world to do so [2].

Current strategies have resulted in increased access to treatment, but as Public Health England have noted [1]:

“Our ability to sustain the current increase in numbers accessing treatment will ultimately be limited by our capacity to find and treat those who remain undiagnosed, and to help those who are diagnosed but untreated to engage with local services; only then will we be able to build on the current fall in avoidable HCV-related deaths.

— Public Health England [1]

Ensuring that people with HCV are identified via testing, and then able to access treatment requires the involvement of multiple care providers and commissioners. Testing for HCV is primarily conducted by Community Drug and Alcohol Teams (CDATs) as this service user population has the highest prevalence of hepatitis C [3,4], but testing is also conducted by General Practitioners (GPs). Testing is also conducted in prisons, and has commenced in some community pharmacies, but this is outside the remit of the current report.



**Figure 3.1** Information sharing pathways between care providers involved in hepatitis C testing and treatment. The arrows indicate the flow of information to and from the different care providers that is needed to ensure successful testing and completion of treatment.

Local authorities are responsible for commissioning HCV testing in drug services, but the responsibility for testing in GP services lies with Clinical Commissioning Groups. Additionally, testing for HCV by CDATs and GPs is usually outsourced to either hospital or commercial laboratories, although some providers are moving toward point of care testing using capillary RNA tests and oral swab testing for antibodies.

Although testing is generally undertaken by CDATs and GPs, the responsibility for delivery of HCV treatment lies with secondary care providers and the Operational Delivery Networks (ODNs). However, NHS England is responsible for commissioning the drugs used to treat HCV on a national basis.

As shown in Figure 3.1, this network of care providers and commissioners creates a situation in which all the data needed to provide HCV treatment does not reside with a single data controller. Consequently, effective data-sharing strategies are essential in order to provide service users with an efficient and easily navigable pathway from diagnosis to successful completion of treatment.

## 3.1.2 Data and Data Sharing

Collecting data on patients' health and sharing that data between care providers is at the core of optimal patient care. However, the concept of 'data', and thus 'data sharing', is interpreted in a variety of ways by people and organisations involved in the delivery of health and social care.

This ambiguity, and the resulting anxiety about what sharing is or is not permissible, means that patient information is often not shared, even when this would be in the best interests of the patients [5]. This confusion has been further exacerbated by the introduction of the GDPR. In this report we consider three 'levels' of data and associated data sharing:

**Aggregated** These data consist of anonymised information from many individuals grouped together, providing a large-scale perspective, such as looking at trends in HCV testing rates over time. These data are only valuable as a whole – there is no intention or need to examine information from specific individuals. Identifying information, such as an NHS number, may be needed to link data from different sources (e.g. treatment and mortality data) but once this is completed, any identifying information is removed from the data set. This type of information may be used in health care planning and policy, but it has no impact on individual treatment.

**Individual** These data consist of large amounts of information about a specific individual, such as their entire GP medical record, and may contain information about many aspects of an individual's health care (e.g. vaccination records, prescriptions, test results). It is the data that is used for making decisions about an individual's healthcare, and therefore identifying information such as NHS number, name, and date of birth need to be retained in order for it to be used effectively.

**Item** This is a specific piece of information about a specific individual, such as the result from a single HCV test. As with individual data, identifying information needs to be retained in order for it be used in providing individual care, although it may also be shared as part of aggregated data collection (e.g. reporting of HCV testing to PHE). The important aspect of 'item' data is that its scope is very clearly defined. Giving someone access to this piece of information does not necessarily mean that they have access to an individual's entire medical record.

These different types of data are not necessarily subject to the same regulations regarding consent and data sharing. What is and is not permitted under current regulations depends on the type of data collected, what is it being used for, and who is using it.

### 3.1.3 Regulation of Data Sharing

Regulations regarding data sharing were originally set out in the Health and Social Care (Safety and Quality) Act 2015, which implemented recommendations from the Caldicott Review [5]. This specifies that health and adult social care organisations have a legal obligation to share information with each other about patients under their care in order to provide the best care possible [6].

Attention became more focused on data sharing in 2018 with the implementation of the European Union General Data Protection Regulation (GDPR) and the associated Data Protection Act 2018 (DPA18). The DPA18 is designed to provide continuity when the UK leaves the European Union, but also provides additional provisions not covered by GDPR and therefore both need to be reviewed in relation to data sharing [7].

The GDPR and DPA18 set out a range of scenarios for the sharing and processing of patient data, not all of which require explicit patient consent. Under the common law duty of confidentiality, there are two types of consent:

**Explicit** This may also be known as express consent, and it is obtained when a patient actively agrees to use and/or disclosure of information, either verbally or in writing.

**Implicit** This is obtained in circumstances in which it would be reasonable to infer patient agreement with use of the information, although a patient has not been directly asked to provide consent.

Explicit consent may be required to use patient data for research purposes but is not necessarily required for the use and processing of data for direct care processes. While consent processes and maintaining patient confidentiality are related, the requirements are not identical, and the absence of explicit consent does not automatically mean that data sharing violates patient confidentiality. The Information Governance Alliance explicitly states [7]:

*“Consent is one way to comply with the GDPR, but it is not the only way, and in many health and social care contexts obtaining GDPR-compliant consent (which is stricter than that required for confidentiality) may not be possible...Organisations should consider the other conditions available before choosing to rely on consent.*

— Information Governance Alliance [7]

Relying on consent as the legal basis for processing data has practical implications that need to be considered when deciding whether this is the most appropriate route for an organisation. Most importantly, the consent obtained must be compliant with GDPR standards, even if obtained historically. There must also be a clear mechanism in place for individuals to withdraw their consent. The consequence of this is that if an individual withdraws their consent, this removes the legal basis for processing personal data about them [7].

Thus, the focus should not be on consent as the sole legal basis for sharing and processing patient data. GDPR does not alter the requirements defined by the Health and Social Care (Safety and Quality) Act 2015 which place an obligation on health and adult social care organisations to share data that facilitates patient care. Fulfilling this obligation does not necessarily require explicit patient consent.

All publicly funded health and social care organisations are permitted to process patient data in the delivery of care, and for administrative purposes, under Article 6 and Article 9 of the GDPR [7]. This can be done on the basis of implied consent for direct care, and

also for administrative purposes where it is a reasonable expectation and/or the patient has been informed. This does not preclude discussions about data sharing with patients, and providers should give patients the opportunity to raise any concerns about this.

From a regulatory perspective, there are no theoretical obstacles to data sharing between publicly funded health and social care organisations; where data sharing specifically relates to patient care (e.g. sharing of HCV test results or HCV treatment status) there is in fact an obligation to do this. This definition may appear to preclude sharing of medical information with non-NHS organisations, but this is not necessarily the case. Medical data can be shared with non-NHS organisations provided that NHS governance requirements are met, data sharing agreements are in place, and there is a clear specification of who will have access to which data and for what purpose.



### Duty to Share

Data sharing without explicit patient consent is permissible under GDPR where sharing is for optimal patient care as this is a public task and it is potentially problematic for other care providers not to have this information. There is essentially a "duty to share" where this is for patient care and when it could be reasonably expected by patients as part of that care.

This definition may appear to preclude sharing of medical information with non-NHS organisations, but this is not necessarily the case. Medical data can be shared with non-NHS organisations provided that NHS governance requirements are met, data sharing agreements are in place, and there is a clear specification of who will have access to which data and for what purpose.

## 3.2 Aims and Objectives

Despite the theoretical lack of obstacles, there may be many practical obstacles to efficient sharing of data relating to HCV diagnosis and treatment due to the multitude of providers involved in delivering care.

In light of this, the aim of this report was to investigate barriers and facilitators to data sharing between care providers, and how this may impact upon case-finding and completion of treatment for HCV. Specifically, we investigated:

- Data sharing gaps in testing and onward referral for treatment;
- Data sharing between care providers during treatment.

## 3.3 Data Collection

Data were collected during 2018 via note taking during individual or group interviews undertaken in person or over the telephone depending on interviewee preference. The interviewees were all told that the interviews would be confidential and participant contributions would remain anonymous. To avoid identifying participants in the resulting report, no names of individuals or institutions are used and no direct quotes are used. Consent was implied by agreeing to proceed with the interview, and participants were informed that they could refuse to answer any questions or terminate the interview at any time. Interviews were conducted by interviewers who had no relationship with interviewees, minimising the potential for any perceived pressure to participate. Individuals were invited to participate based on their knowledge and/or experience of different aspects of HCV case-finding, diagnosis, and treatment.

# 4

## Data Sharing in Practice

### 4.1 Sharing with Other Care Providers

Efficient data sharing is important at all stages of HCV testing and treatment, particularly because of the risk of treatment disengagement in this population. If referral and initiation of treatment are not accomplished quickly, the opportunity for treating service users may be lost.

But even after treatment commences, data sharing is important as CDAT and GP care providers can help to monitor treatment progress, assist with meeting treatment requirements, and help to minimise risk of re-infection after successful completion.

Currently, the strategies used for testing, referral, and treatment for HCV are tailored to local services. While this has many advantages, the unintended consequence is substantial variation in how information is shared between care providers and how HCV treatment is managed.

We identified two major obstacles to data sharing in HCV treatment: the legal basis on which data are (or are not) shared, and the system(s) used to share information between care providers.



## Basis for Sharing Data

Although the Caldicott Guardians and Information Governance specialists we interviewed had a clear understanding of the basis on which data could be shared for different purposes, and when explicit consent was and was not required, this understanding has not penetrated all levels of clinical practice.

Amongst those in clinical practice there was confusion about when, and with whom, individual patient records or specific items of information about a patient could be shared.

Confusion over what is permissible without consent, or with only implied consent, has resulted in variation between organisations in how the guidance on information sharing is interpreted.


This has created a focus on obtaining explicit consent for data sharing as this is the only scenario that has consensus across care providers. For example, one third sector organisation has implemented a model in which explicit consent is sought from all service users for processing data and sharing this information with other care organisations such as ODNs.

While taking the explicit consent approach circumvents potential disagreements over data sharing, provided the data are being shared as part of clinical care or in administrative work that supports patient care, this is not necessary under GDPR. Even when an organisation is third sector, rather than part of the NHS, provided that organisation has the same standard of information governance and a data sharing agreement in place, sharing data with NHS organisations is possible.

The experts we interviewed underlined the importance of considering models other than explicit consent, particularly in situations that would result in care providers seeking explicit consent for something that needs to be done as part of clinical practice regardless.

Routinely invoking explicit consent, even when not required, can create the perception that data can only be shared on this basis.

Consequently, rather than making data sharing easier, explicit consent may create barriers if people believe that all the requirements for consent under GDPR need to be met before even a single item of patient data can be shared.



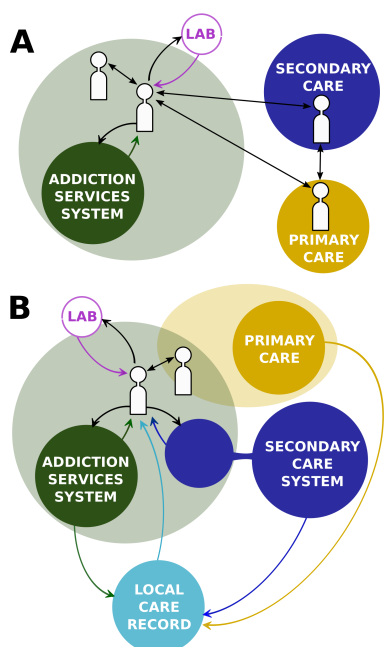
*Routinely invoking explicit consent, even when not required, can create the perception that data can only be shared on this basis.*

## Methods for Sharing Data

1. An electronic medical record is a computerised version of clinical notes, test results, and other patient information. There are many different types of software that can be used to store this information in a secure, electronic format.

All the care providers we interviewed had their own electronic medical record (EMR)<sup>1</sup> system in place, but the specific system for storing, accessing, and updating these records varies even within sectors.

More specifically, the EMR systems used by CDATs, GPs, and hospitals all differ, and even CDATs working under the same umbrella organisation may not currently use the same EMR system. Data are not usually shared automatically between these systems. For example, information entered into the EMR system in a hepatology department about a service user's test results or treatment generally will not automatically appear in the EMR of their CDAT team.



**Figure 4.1** Models of information sharing in Community Drug and Alcohol Teams. In A, data sharing depends on direct contact (written or spoken) with a central staff member. In B the central staff member still aggregates information from multiple providers, but it is obtained via EMR not direct contact.

We found that CDATs and GPs used approaches to overcoming these obstacles that fit into two broad categories: personal contacts and outreach staff (scenarios A and B respectively in Figure 4.1). In situations where data sharing is based on personal contacts, the responsibility of obtaining treatment updates usually falls to the keyworker, nurse, or GP who originally initiated the testing and referral. Both GPs and CDAT staff in this situation are likely to be reliant on receiving written updates from secondary care regarding HCV treatment progress. If feedback is not received, this must then be sought either via written or telephone follow-up. Failing that, providers must rely on reports from service users themselves.

Some CDATs had an outreach nurse from hepatology on-site to deliver both HCV testing and treatment in clinics. Despite the complexities involved in delivering prescribed medicine in this context, there was a general consensus that this was an optimal model for HCV care. However, the use of outreach staff does not necessarily resolve issues relating to data sharing between care providers and can, in fact, exacerbate them. Because the different EMR systems are not compatible, outreach staff must duplicate data across multiple EMR systems to keep all records up-to-date and ensure all relevant patient information is shared across care providers. As well as being time-consuming, this introduces greater potential for inadvertent errors or incomplete data.

In some ODNs, care providers do have access to a shared system that integrates EMR information from primary and secondary care in the local area, which can help facilitate sharing of individual patient data. However, in some areas this system is “read-only” so information from the shared system is not used to automatically update the EMR data held by CDATs, GPs, or secondary care. Additionally, these shared local records are generally only available to NHS providers, and so are not available to non-NHS CDATs.

“The use of outreach staff does not necessarily resolve issues relating to data sharing between care providers and can, in fact, exacerbate them”

## 4.2 Sharing with Patients

Successful HCV treatment starts with sharing information with service users about their HCV infection risk. We found that the approach to offering testing and the types of testing offered varied between care providers. In the majority of CDAT services, HCV testing was offered to all service users, and potentially their partners and family members regardless of whether or not drug injection was disclosed. Other providers only targeted those with known risk factors. While this economical approach is suitable for primary care, where the prevalence of HCV is expected to be low, in CDATs this risks missing HCV cases as service users may be reticent to disclose injecting behaviour.

A key source of variation between care providers was the type of testing offered, which has a substantial impact on the timeframe between initial testing and sharing information with service users regarding their HCV status. Some services use dried blood spots (DBS) for testing and automatically request reflex testing. Others, including primary care, use venous blood samples, often without reflex testing, which may require follow-up blood samples to confirm the results and leads to a delay in sharing final test results with users.

There is a move by some providers to finger-prick testing and use of the Cepheid GeneXpert system, which provides results in hours rather than days. Reducing the timeframe in which service users are given this information is likely to have a substantial positive impact on treatment uptake.

## 4.3 Sharing Nationally

We found that responsibility for sharing data between different organisations, and what can and/or should be shared at a national level has been a source of confusion for many care providers. In particular, sending data to, and receiving data from, Public Health England (PHE) was a key focus.

While the legal responsibility to report HCV test results to PHE was well understood by care providers, there was substantial past and present confusion around whether the responsibility for sharing these data lay with the person requesting the HCV test, or the laboratory conducting the HCV test.

There were multiple calls for better data sharing processes between PHE, ODNs, and care providers. Both care providers and PHE have been working with laboratories to improve or imple-

ment reporting systems and ensure PHE receives all the relevant data. However, ODNs also expressed concern that they were not receiving data on new HCV diagnoses and felt that either reporting pathways for PHE should also be harnessed to provide the same data to ODNs, or PHE should provide these data to ODNs.

There was also a desire for the information PHE holds on individuals who have tested positive but not received treatment to be provided to ODNs for follow-up; this was addressed over the time period this report was conducted and these data are now being fed back to ODNs with initial re-contact being facilitated by GPs [8].

# Conclusions

We found that the two major obstacles to effective data sharing in relation to HCV diagnosis and treatment were: (i) confusion over the legal basis for sharing patient data; (ii) the lack of informatics solutions for sharing data between care providers.

Explicit consent is just one mechanism by which care providers are permitted to share data, and it is not always the most appropriate choice. The GDPR has specific allowances for sharing data as part of clinical practice, both in terms of delivering care and administrative work, that do not require explicit consent.

While this is well understood by Caldicott Guardians and Information Governance professionals, these provisions are not clear to all those delivering clinical care. This lack of broader understanding, and differences in interpretation of information sharing guidance between organisations, present important barriers to data sharing and thus to delivery of optimal HCV testing and treatment.

Data sharing for HCV testing and treatment may require additional effort due to the substantial involvement of non-NHS organisations in delivery of care. Data sharing with third sector organisations may be facilitated by NHS Honorary Contracts where individuals require access to specific items of patient information for a defined reason, for example where volunteers are involved in supporting service users through HCV testing and/or treatment. However, where organisations need access to large amounts of data held on individuals, data sharing agreements will still be needed.

Even when the legal basis for data sharing has been agreed between care providers, the absence of informatics solutions that

bridge sectors (e.g. primary and secondary care) presents a major technical barrier. There are lots of local strategies for sharing data, but the majority either: (i) rely on individuals and personal relationships, which presents high risk of failure and/or (ii) require duplication of effort to ensure multiple systems are up-to-date as information is not centralised.

Informatics barriers are not a problem that is specific to the treatment of HCV; this is a problem across the health care system. A large-scale plan for implementing an EMR system that crosses institutional barriers is needed as this is a key rate-limiting step in treatment initiation and successful completion. However, such a system will take substantial time to become available and local solutions will be needed in the interim. There are some examples, such as the Pathway Homeless teams [9], in which systems from one part of the NHS (in this case, the general practice system EMIS), have been used in other parts of the NHS and third sector organisations, but the applicability depends on clinical requirements.

In addition to the two major obstacles to HCV testing and treatment discussed above, the following obstacles and issues came up as themes in our interviews:

**Timeframe to HCV+ result and treatment** Shortening time from testing to result delivery is particularly important for CDAT service users where the window of opportunity for engagement may be short. DBS with reflex testing or Cepheid testing, which have comparatively short turn-around times, may be the best testing options in this context. Even with faster testing, there can be delays of weeks or months before treatment commences; there is broad support for outreach treatment, in addition to testing, in CDATS, GPs, and other contexts such as pharmacies.

**Responsibility for case-finding versus testing** Although ODNs are responsible for case finding, identification of cases for treatment generally occurs in CDATs and GPs. While HCV testing is viewed as important by these care providers, it is not their primary focus. In CDATs this is just one part of clinical responsibilities for services already dealing with substantial financial constraints; child protection and mortality are more immediate risks and thus higher priority. Having outreach hepatology nurses can help substantially with this, and providing this type of support needs to be viewed as a priority. Testing and treating in other community contexts, such as community pharmacies, also needs to be considered. In primary care, there is limited professional training around HCV, so additional education and awareness campaigns may help to support case-finding.

**Reporting requirements** Services need to ensure that either they or the laboratory

share HCV+ test results with the ODNs – there is the potential to harness systems used for PHE reporting to achieve this where they are already in place. There is also potential for PHE to provide this information to ODNs, in line with what is taking place as part of the re-contact exercise.

## 5.1 Recommendations

In light of the findings from this report, we make three recommendations for potential strategies to overcome the obstacles we have identified.

Obstacle	Recommendation
Lack of clarity regarding sharing patient data under GDPR	<p>Clear guidance and training for care providers, particularly CDATs, regarding:</p> <ul style="list-style-type: none"> <li>• when explicit consent is, and is not, necessary for data sharing;</li> <li>• which data can be shared;</li> <li>• who data can be shared with, and under what circumstances.</li> </ul> <p>This could be provided by ODNs and/or PHE.</p>
Lack of informatics to facilitate data sharing	ODNs and commissioners should to work together to find informatics solutions to facilitate data sharing between local care providers, including third sector organisations where relevant.
Lack of resources to support HCV testing and treatment	Additional support for hepatology outreach, particularly in CDATs but potentially also in other contexts such as pharmacies.

# 6

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