

London Joint Working Group on Substance Use and Hepatitis C (LJWG)

Understanding the pathway: barriers to data collection and onward referral to specialist hepatitis C services for PWID in London

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Recommendations

These recommendations reflect those made by the LJWG in its publication Commissioning of hepatitis C (HCV) services in London for People Who Inject Drugs report from 2013ⁱ (1) suggesting that there is still significant action and progress needed to increase access to HCV treatment. Exploration of these themes illustrates that a number of related issues continue to contribute to barriers to the care for people with hepatitis C and how, ultimately, this inhibits access to hepatitis C treatment for many in need.

The review has highlighted there is a need for hepatology and hepatitis C treatment to be more attractive and accessible to the disparate community of those with, or at risk of hepatitis C. It should be noted that although there are evident examples where people are effectively supported along the referral and treatment pathway by expert and committed nursing and non-nursing staff, such models of working were described as variable and largely dependent on these individual commitments to make them work. There were frequent examples of where, when individuals were on leave or had left their post, the relevant pathway halted or even failed suggesting lack of institutional commitment and resource.

It is important to note that in the light of increased demands and significant resource reductions and disinvestment in drug and alcohol treatment, there were growing calls for hepatology services to be 'more responsible' for the HCV treatment pathway and lead in the promotion of DAA based treatment. Although drug and alcohol treatment settings are ideally placed to provide HCV support to those using its services and there are good examples of where this works well – it is argued that hepatology services are best placed to promote the hepatitis C treatment pathway and reduce the inherent complexities that make their navigation a barrier to hepatitis C treatment.

Key recommendations made in this paper are as follows:

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- All boroughs should have a strategy in place to address liver disease, in which HCV should form a significant component
- The HCV treatment pathway and data collection should be facilitated by hepatology services and supported by drug treatment services
- Joint commissioning arrangements should be developed between Clinical Commissioning Groups (CCGs) and Public Health to ensure robust and deliverable pathways are established
- During their development HCV treatment pathways must identify and attend to healthcare system and policy barriers that continue to stigmatise people who inject drugs (PWID) and hinder access to treatment
- All boroughs should have a clearly understood HCV pathway in place, which is regularly monitored against performance
- Where possible, an integrated service of HCV treatment in drug treatment services should be commissioned
- Patient support programmes including peer support, education and awareness raising programmes should be commissioned to encourage uptake of treatment
- Hepatitis C antibody testing should be offered in all drug treatment services and other venues, such as needle and syringe exchange programmes, including their delivery in pharmacies
- GP practices should be commissioned to offer HCV testing to former PWID and those not in contact with drug treatment services
- Health and drug addiction professionals in all boroughs should receive training in HCV
- There should be some standardisation of diagnostic tests and eligibility for HCV treatment in London

Introduction

Background

The London Joint Working Group (LJWG) is a group of clinical, commissioning and patient group experts whose long-term 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.

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Hepatitis C (HCV) is a serious public health concern. In England, more than 160,000 people live with chronic HCV, the majority of whom are from marginalised and under-served groups in society, predominantly people who inject drugs (PWID). Without treatment, many individuals can go on to develop serious HCV related liver disease complications including life threatening end-stage liver disease (ESLD) and hepatocellular carcinoma (HCC).

Increasing the identification of people with the infection so that they can be offered HCV treatment has both individual and wider public health benefits in significantly improving health and well-being of people with HCV, reducing HCV related mortality and ESLD and averting HCV infections/future transmission.

Successful HCV treatment prevents health complications, significantly reduces the number of individuals progressing to serious HCV-related disease and reduces the premature mortality among people with HCV, but uptake has been at less than 3% per year (2).

Established in 2015, Operational Delivery Networks (ODNs) are the new structures through which hepatitis C treatment in England is being delivered. The 22 regional ODNs are the new structures which manage treatment decisions and prescribing, and which have a dispersed treatment model which aims to support partnership working and access for local patients. Importantly, ODNs and community providers are required to navigate a new HCV treatment landscape in which highly effective and sought-after treatments must be equitably allocated across the spectrum of services. NHS England announced its target of treating 10,000 patients across England in 2016/17, , and 12,500 2017/18 through the ODNs. This target has been broken down across the networks, with each ODN being assigned a treatment target or 'run-rate' based on prevalence in their area. ODN's are only able to treat up to and not beyond their 'run –rates'.

Recently published modelling data has confirmed that many more patients in England need to be treated to prevent an epidemic of end stage liver disease, cancer and mortality (3). Patient numbers need to increase almost three-fold by 2018, but the current service infrastructure in London will not support this target. In the UK there is currently insufficient HCV treatment access (estimated at 3% of the infected population each year) either to slow the rise in HCV related ESLD and HCC or reduce HCV prevalence among PWID (4,5). Increasing the number of people treated, with greater access to newer and more effective DAA treatment regimens offers the potential to halve disease burden in 10-20 years depending on how quickly complete treatment coverage can be achieved (4). Recent studies have demonstrated high SVR rates in those with cirrhosis indicating that more rapid burden reductions are possible (6).

London has a consistently moderate to high HCV prevalence among people who inject drugs (PWID). Over a quarter of people with hepatitis C in the UK live in London. There are an estimated 60,000 people living with hepatitis C in the capital and around 40% of them remain undiagnosed (7). Current service provision in London is patchy, disjointed and often unable to support the needs of vulnerable, socially excluded populations such as PWID

In 2014 the LJWG published 'A Consensus for London' report (8). Stakeholders came together and agreed how we were going to increase the numbers of London PWID accessing testing and treatment. Efficacy of the recommendations requires robust data in order to secure action from commissioners and policy makers.

In 2013 the LJWG established a pilot project to assess the impact of its recommendations from the first London Consensus in 2011* (8), but data collection proved challenging. The pilot project identified the need for improved data collection – variations in infrastructure for collecting data and a lack of baseline information resulted in lower levels of statistically relevant data than expected. While there are examples of good practice in London, more needs to be done to standardise care across the capital. Commissioning and provider surveys (1) highlighted a significant variation in practice not only between boroughs, but also between services in the same borough. Only around a third of boroughs have a testing-to-treatment pathway in place. Some drug treatment services in the same borough were unaware of the pathway (1)

Using the knowledge gained from the previous pilot, the Understanding Barriers project was designed to work in depth with the pathways within two local authorities. The aim has been to understand further the barriers to data collection and onward referral to specialist hepatitis C services for PWID. The objectives of the project align with Public Health England's goal of eliminating hepatitis C as a major public health threat by 2030 (9).

The boroughs were selected because they both were enthusiastic about tackling HCV, but had different models. One is the largest HCV treatment provider in London and operates an HCV treatment outreach project at drug and alcohol services. It has a specialist nurse role in the drug service. The other borough has a drug treatment provider with multiple staff testing and then referring those who are positive into HCV treatment via their GP.

** The London Consensus was first published in 2011 and updated in 2014*

When the pilot commenced in April 2015 the environment was different to that at the time of writing this report during the last quarter of 2016. The interviews indicate a changing landscape, even between people working in the same services. People in different roles were interviewed at different times in the interview timescale of April 2015 to June 2016. In the same time period changes in national policy, local guidelines and partnerships as well as comprehensive changes to existing management structures have taken place.

Aims and objectives

The primary focus of the project is to work with drug treatment and specialist hepatitis treatment service providers, users and commissioners at two sites in London, and building on the findings of the LJWG 2013 pilot project, to identify the barriers to comprehensive data collection and the barriers to onward referral along the pathway into specialist care.

Key questions

The key questions which were addressed in this service review were:

1. What are the barriers to (i) comprehensive data collection, and (ii) onward referral along the pathway into specialist HCV treatment?
2. Having identified the barriers to data collection and onward referral, what pathway interventions can be recommended to address these?

Method and design

This project used a combination of methods of inquiry, specifically: documentary analysis, non-participant observation, key informant depth interviews, and focus groups. The project looked at two sites comprising service configurations located in two different London boroughs.

Project sites

The two boroughs which participated are referred to as Borough A and Borough B to maintain confidentiality for all interviewees.

Selecting participants: number and characteristics

The data collection methods used for this project were as follows:

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1. **Documentary analysis** was performed at each of the two sites. Available documentation, relevant to testing service users for HCV and referring them on to specialist HCV services where appropriate was collected and analysed. These documents included but were not limited to practice guidance, policy statements, and data collection instruments (paper and electronic templates).
2. **Non-participant observation** was conducted in an HCV treatment clinic session, at one site. With the permission of the staff and service users in the session, observations were made of the activities and events that took place in the reception / waiting area and consulting room/s.
3. **In- depth interviews** were undertaken with 18 key informant service providers and stakeholders across both sites. Interviews were conducted with key informants including Addiction Psychiatrists, Hepatologists, Gastroenterologists, Nurses, Specialist Nurse Managers, Outreach Nurses, Directorate Management in a 3rd Sector organisation, Mental Health Trusts, Borough Leads, Service User Organisations, Drug Service, Managers, Drug Service Team Leaders, Joint Commissioning Managers, Public Health Managers, GPs including some with a specialist interest in people who use drugs (PWID), and an administrator in a general practice. Emphasis was placed on interviewing key informants with the greatest knowledge of current data collection limitations and pathway constraints.
4. **Focus groups.** Two groups, one at each site, were conducted, one with 6 participants and the other with 12, including those with recent experience and those with established experience of HCV treatment. Attempts were made to interview both men and women and service users of different ethnicities, of different ages, and living in different circumstances (notably, in their own home vs. those who are homeless). The rationale underpinning this is that characteristics such as gender, age, ethnicity, and living situation might be expected to impact on service users' engagement with and experience of HCV treatment.

Researchers

One researcher has a background managing drug and alcohol services in the London area, has worked as a policy lead in London in the drug, alcohol and hepatitis C sector and is in recovery from addiction. The second researcher is a qualitative consultant and collected data for 'Barriers and facilitators to Hepatitis C treatment for People who inject drugs A qualitative study' WHO Regional Office for Europe. June 2012.

The service evaluation did not need to acquire a Research Ethics Committee (REC) review. Borough A Mental Health Trust required that the evaluation have Clinical Governance approval and Borough B received approval from the R&D Director and Research Department. Participants were not required to sign consent forms before taking part in the project. At the same time, however participants' contribution should remain anonymous as the interviewers agreed that personal identity would be confidential. It should not be possible to identify participants from the resulting report.

Data Collection

Data collection was done through a process of recording and transcribing one to one interviews and note taking. Focus groups were recorded and transcribed, clinic observation was done via taking notes during an afternoon of an open drug clinic where hepatitis C tests were offered. The interviewees were all told that the interviews would be confidential and the permissions were taken via recording rather than signed confidentiality agreements as this is a service review.

Data Analysis

The analysis was done by transferring information from recordings made of each interview and focus group. A thematic analysis of the group and individual interviews was conducted from written transcripts from those recordings.

Findings

An analysis of interview based data, collected across two London boroughs, generated the following interlinked themes around accessing hep C treatment : Health care system and service user barriers along the hepatitis C treatment pathway including pathways to HCV care, lack of confidence in referral pathways, system and policy barriers, stigma, diversity and multiple needs, phlebotomy, lack of peer support, treatment experience, worker competency, confidence and information giving; and barriers to data collection, including data limitations, data responsibility and evolving Operational Delivery Networks (ODNs) requirements and IT systems incompatibility.

Exploration of these themes illustrates that a number of related issues continue to contribute to barriers to care for people with hepatitis C and how, ultimately, this inhibits access to hepatitis C treatment for many in need.

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- Overall it was apparent that there is a lack of certainty around responsibility for the Hepatitis C pathways; who tests, who and how to refer to treatment and who monitors treatment adherence. Although most participants were able to describe HCV treatment and referral pathways, there was little confidence in them and uncertainty in how they worked in practice. Repeatedly, when describing pathways, participants made recommendations to the interviewers to approach others across the drug treatment, hepatology and commissioning systems, to clarify arrangements, or specifically, how pathways operated in practice rather than in theory.
- There was general agreement that drug and alcohol treatment services are best placed to recruit and retain service users, and that the outreach model (HCV testing and treatment support services in drug and alcohol services) is the best one. Further, although the outreach HCV model to drug and alcohol treatment has been shown to work well in supporting people who use drugs into and through HCV treatment, it is argued that this level of support might be increasingly unnecessary as interferon-free based treatment is made more available.
- There are growing calls, for hepatology services to be 'more responsible' for the HCV treatment pathway. This included promotion of newer treatments amongst a community of people whose current perceptions of the service are negative and typically based on direct or indirect experiences of interferon based treatment. Although more difficult to evidence or 'prove,' many participants highlight how most people who inject drugs commonly experience significant stigma when using health services as a result of their 'lifestyles' and that this may continue as a significant barrier to their accessing HCV treatment and care.
- The report found that there are evident examples where people are effectively supported along the referral and treatment pathway by expert and committed nursing and non-nursing staff, such models of working are fragile and largely dependent on these individual commitments to make them work. There were frequent examples of where, when individuals were on leave or had left their post, the relevant pathway halted or even failed suggesting lack of institutional commitment and resource.
- There is the suggestion from several participants – both implicit and explicit – that there is need to look beyond outreach screening by hepatology nurses in drug and alcohol services and consider, among other options, outreach in GP services for shared care service users but also for those people affected by hepatitis C who maybe unaware of their status and who wouldn't identify as a current drug user. Certainly, there is a need

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'normalise' hepatitis C treatment and consider how this may be made more attractive to both those engaged with drug and alcohol treatment but also to the significant populations of those who aren't engaged. It is uncertain how large this population might be although recent data from PHE states that around 60% of all opioid users in England – the majority of whom inject – are in drug treatment suggesting a significantly sized community with no evident access to HCV testing, treatment or care.

- Many participants highlight the change in the population of substance users, such that opiate users and injectors are becoming older. Services identified a rise in injecting among steroid users and also Chemsex (sexual activity engaged in while under the influence of stimulant drugs such as methamphetamine or mephedrone, typically involving several participants) among men who have sex with men (MSM). They point out that the latter two populations are unlikely to access traditional drug and alcohol services. Thus, there is a need to explore effective ways of working with them i.e. MSM pathways being through sexual health services
- Data collection and matching was a key barrier. When asked about data collection across the pathways, many participants - from both drug and HCV treatment services - described this process as 'getting in the way' of hepatitis treatment. There was no agreement between the two groups of specialists (addiction and hepatology) regarding who should be collecting HCV-and-substance use-relevant data from substance users and people with HCV.

1. Healthcare system and service user barriers along the hepatitis C pathway

a) Pathway to specialist HCV care

Although participants were broadly able to describe pathways into hepatitis treatment, there was expressed lack of confidence in the pathways working effectively. There was considerable concern that referrals to specialist hepatitis treatment were inconsistent and typically dependant on individual staff, usually blood borne virus (BBV) nurses, facilitating the patient journey and maintaining pathway quality. When key staff were on leave, the pathway and effective communication needed to facilitate the pathway, on behalf of patients, effectively stopped.

Yes, you could say because normally I'm on people's case. I sent everybody a text reminder before I went on holiday "Don't forget you've got your ultrasound scan this date, this time, telephone," but I was away for three weeks so actually I think there was definitely a breakdown there (Site A, interview 11, Lead Nurse)

There was a strong and consistent claim from participants that new pathways needed to be established and that these should be the responsibility of hepatology – it was stated that hepatology wasn't doing enough to facilitate pathways, evidenced by the fact that only 10% of people tested positive for hep C receive treatment.

I wonder whether hepatology services should be doing the full end-to-end pathway. They should take the testing all the way through to treatment and take full personal responsibility for these clients' treatment and stop expecting drug workers - loads of whom are fantastic people in recovery but have no medical training whatsoever - to do their job for them.

That needs to be understood by the acute sector. They need to understand why they are not engaging enough people in treatment and why their services are not attractive to clients (Site A, interview 10, Consultant)

One of the two goals of our service evaluation and our interviews with key informants was to identify specific barriers to HCV treatment. This goal assumes necessarily that there are definite points at which pathways into treatment fail and so failures that may be addressed and corrected.

However, one participant expressed a different view but one that again indicates that the pathways to HCV treatment are unstable and largely worker dependant:

Pathways – people use the word, the term pathways endlessly but it's never entirely clear quite what they mean by pathways? ... And as we've discussed today, I think a lot of what actually happens depends on the personal relationships and they are very fragile; so [Viral Hepatitis CNS] leaves, [another Viral Hepatitis CNS] is redeployed to do something different and the whole thing fragments. I've had no say in that. I can have no say in it. I can't change it.

You know, [Viral Hepatitis CNS] doing outreach work in the community changes because three nurses leave and we are waiting to replace three other nurses; so you know, I can't control that, I can't influence it; so pathways are pretty fragile. They exist in people's – a lot of them exist in people's drawers – on sheets of paper in somebody's drawer or on their computer but they don't actually happen. [Yeah] So, no, the concept of pathways is difficult. I don't think there's a clear answer as to what works and what doesn't and I think it comes down to talking and meeting people. (Site B, interview 13, Consultant Hepatologist)

One of the participants challenged the view that pathways are a relatively stable phenomenon that can be manipulated for the good of the service user and argues it is

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impossible to identify specific pathway components that can be improved or replaced (“with what works”); instead said “it comes down to talking to and meeting people.

Here are some examples of where the interviewees identified barriers to people accessing treatment.

Yeah. When we were at (named drug and alcohol service) that wasn't the issue. The issue that we had was trying to get appointments for hepatology. We had a designated person whereas now we have our lead nurse, but she's a nurse prescriber, so it's part of her role. But then it also falls on managers around managing through supervision.

... I don't know what that would look like in reality in terms of lead nurses job, because there was always a lot of chasing as far as I remember with hepatology (Site B, interview 3, Manager)

Well the feedback that we were having from the hepatology is that they get a lot of DNAs: they had a fair number of referrals but not much uptake for appointments. That's another interesting point because I think after we do a signpost to GPs requesting for a referral I'm not sure that we do much more – we've got other things to do – and we make an assumption (Site B, interview 4, Consultant)

One of the services participants reported that they had no idea what happened to people who were referred to a GP after they had been tested in the drug service. They said that there was currently no system in place to track whether the person went to the GP, were referred through the ‘choose and book’ system to specialist care, or if they had any follow up assessment or treatment. Another commented that some people do not have a GP and cannot be referred because of this, yet another suggested the overall problem was that there is no one body overseeing the whole pathway so that onward referral gaps and any breakdown in communication can be identified.

Our part of it is to test. If the person is positive we make a referral to the GP and then it's the GP's responsibility to make the referral to hepatology. That's all I can say about that really... we would just inform the GP and they would make the referral to hepatology. In the past when we used to make the referrals to hepatology there might have been more questions about ensuring that we go to the GP to inform them. (Site B, interview 3, Manager)

Clients need to have a GP, but we've got clients who live in the borough who don't have a GP. Every service is different. We give them a certain window of time to register and then they don't always do it. So, a lot of the guys who I've tested who have come back positive and they haven't got a GP, it's like, “Well you're going to have to get one. You're really just going to have to do it now. (Site A, interview 11, Nurse Lead)

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I guess one of the big gaps, actually probably the biggest gap in this pathway is that no one has, no single organisation or person has oversight or responsibility for the pathway. I think that's the biggest issue. (Site B, interview 5, Public Health)

A number of participants reflected that increased demands and reduced income across drug and alcohol treatment increasingly meant that workers were less likely to prioritise hepatitis C. There were calls for new models for working where drug treatment services promoted and encouraged testing but where hepatology services, supported by an NHS England tariff that required treating people in drug services, had responsibility for engaging people into treatment and delivering the end to end treatment and care pathway.

We need to get providers of hepatology interventions who actually want to work in the new world of healthcare rather than the old world where people are very much stopping people coming on to their big acute hospitals. This is the future of healthcare for hard-to-reach groups, getting out to where they are. We need an NHS England tariff that responds to that and we need providers, including senior hepatologists, who are willing to run regular clinics in these service centres - come out to where the patients are, because they're not going to come to you, certainly not the ones who are acutely unwell. (Site A, interview 10, Consultant)

b) Healthcare system and policy barriers

A number of responses suggested that a significant proportion of people using drug and alcohol treatment services who would benefit from hepatitis C treatment were being excluded from hepatitis treatment or having treatment deferred. This was commonly because of concerns around 'lifestyle' factors such as alcohol use and here drug and alcohol saw a role in supporting service users in managing their use.

It's slightly different, so the referral form now says 40 units of alcohol or less a week. A lot of our clients are drinking more than that but I would still refer them into the service because trying to get them to engage. I've had some clients who were drinking way above and then they've reduced their level of alcohol right down, which is absolutely fantastic (Site A, interview 11, Nurse)

Hepatitis services were considered inflexible in accommodating the needs of service users who were still using street drugs or using alcohol heavily, this was variable with some centres less willing to do so than others.

Let me say even their criteria was more relaxed than (hospital named) What I'm saying is that there will be people that will fit in with that criteria and would be treated here, but if they'd gone to (hospital named) they wouldn't have got treated (Site A, interview 16, Manager)

There were consistent comments around service users' perceived lack of motivation and reticence to engage with specialist treatment, compounded by unsettled lifestyles and how rigid application of policy typically resulted in discharge.

I presume that people can't get up in the morning. I don't know. I don't know what the chaotic lifestyle is like, I've got absolutely no experience... But morning appointments, very rigid appointments, you get one chance to attend and if you don't attend as a new patient, that's it, you're discharged. (Site A, interview 18, Nurse Lead)

Drug and alcohol treatment has evolved to support service users who may be marginalised and participants described the need for flexible working to accommodate individuals and support them along the hepatitis pathway. Various participants discussed that drug and alcohol services were sensitive to drug user circumstances and commented on how HCV treatment services needed to better respond to the needs of people who use drugs and facilitate increased access to HCV treatment.

I think just, you know, because our clients are – maybe their lifestyle at the time it can be very difficult for people to commit to appointments. At the beginning – so you know it could be that people find it hard – so here we are very, you know, if people do miss an appointment we can be quite flexible. We can be quite understanding of that, especially when people are at the beginning of their treatment.

But, honestly, I think acute hospitals being able to try and speak to drug users would be pretty helpful. Most of the transmission of hep C now, in this country, is between IV drug users. (Site A, interview 16, Manager)

There are some service users who, I think with the best will the world, are probably not ready. But that's a bit of a threshold issue. And the more we can make treatments tailored to relatively active drug users, that will come... the number of people will come down. I think people are very afraid of it. (Site A, interview 12, Consultant)

c) Stigma, diversity and multiple needs

Negative experiences of hospital based treatments were reported by most participants of the service user focus group. Users often experienced stigma and discriminatory practice that contributed obstacles and barriers to treatment.

There's a lot of deep feelings really, even like if you go to a hospital just for something normal and they say have you got an issue with hospitals and everything so if you say drugs

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or whatever their attitude completely changes towards you and it's like you're the scum of the earth (Site A, focus group, service user participant)

I think (a) because what they would hear from other people is how unpleasant the treatment was, (b) they weren't treated with an awful lot of respect, and (c) they were inevitably told you're drinking or you're using too much drugs, come back in six months' time, which was seen as a complete rejection. (Site A, interview 16, Manager)

Additionally, fears of disclosure (of being diagnosed with hepatitis or just being tested) was an expressed concern.

But are you picking up the fact that there are people who are purposely not testing themselves for various reasons as well? Such as, I don't know, some people are worried it'll come up, affect their work or insurance, life insurance and things like that. (Site B, focus group, service user participant)

Many people across drug using communities and in contact with drug treatment services were highlighted as being homeless and having multiple needs, often compounded by limited access to a GP or with no recourse to state benefits. These factors were seen as key obstacles for people who otherwise might be suitable for hepatitis C treatment and care.

The problem is they're so chaotic a lot of these people. They're living in garages or living in cemeteries. They're not interested in treatment anyway. Do you see what I mean? They're so chaotic, they'll drop in, they'll drop out. (Site B, interview 1, Nurse)

I'd say the changing thing about that part of the population is that they can often have a whole lot of other problems, homelessness, no benefits, no employment, drug use on top of that, high alcohol use sometimes, as well. And, obviously, if people are squatting or living in unstable accommodation, or street homeless, you don't know where they're going to be from one week to the next. Certain parts of the population in X bring challenges, particularly now we've got so much homelessness, we've got people with no benefits, there are times when it feels like people, they're up against so much (Site B, interview 2, Team Leader)

I can't give you percentages, but definitely this is a very diverse area so it's got a high percentage of BME clients. I saw something the other day. I think 70% of clients are BME. Don't quote me on that actually. We're seeing now a lot more transient people perhaps EU nationals, people who are homeless, who are Eastern Europeans. We're seeing more of that particular client group coming through the door, and perhaps homeless, transient, very difficult to engage. They drop out of treatment very quickly. But it's a much more transient population. (Site B, interview 3, Manager)

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I think if you can't speak English and you've got hep C I think you're probably just side lined, maybe not intentionally but you're out of the loop, definitely out of the loop (Site A, focus group, service user participant)

d) Phlebotomy

The first step in the pathway to HCV treatment is always identification of the HCV status of the service user (SU). At the time of the study Dried Blood Spot Testing (DBST) wasn't available within drug treatment service in site A and phlebotomy was used to diagnose hepatitis C. The need to have blood taken for diagnosis was reported to act as a barrier by some service users.

I think it's a real put off for people to even get that first step on the ladder to say I want to be tested because of the difficulties for some people in having bloods taken. So for me that's a real barrier, in a sense it's the first barrier on the ladder... (Site A, focus group, service user participant)

Predictably, phlebotomy remained a barrier beyond diagnosis and into treatment itself and stated as a key issue for focus group participants as reflected here:

Last week I had to have some bloods taken and obviously, the tests for hep C were done at the time and I think like something that really bothers me and it's been bothering me for quite a while now is the difficulty I have every time I go in to have bloods taken... (Site A, focus group, service user participant)

The main issue for me is they can't get enough blood out of me. You get that bad vibe because you go in and it's hard for them to get you so you have to declare straightaway so they can tell, they look at you and there's not a vein in sight, that you're a user. (Site B, focus group, service user participant)

Phlebotomy and the need for venepuncture for initial screening of hepatitis C status was highlighted by most professional participants as an evident barrier in site A (where at the time of the study, dried blood spot testing (DBS) wasn't available).

So, some of our clients, you know, can – so their vein, their access can be quite poor; it can be quite hard to get bloods because of their iv drug use, they may not have used iv for years but it can be quite anxiety provoking for people. You know maybe they've had experience with somebody who has tried to take their blood, you know a few times and oh God, it's very uncomfortable, you have to go quite deep; that can stop people. (Site A, interview, 17 Team Leader)

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In contrast, across Site B progress had been made to roll out DBS for screening of hepatitis C with participants citing significant advantages to traditional phlebotomy.

We only do dry blood spot tests. We have no one here who takes bloods anymore. All our key workers have responsibility for dry blood spot testing. It's the key worker's responsibility for the dry blood spot testing, or the duty worker will offer it at the triage stage.

From a client's perspective it's a lot easier, because there's another thing about getting blood. How many times has the client coming through and: I've got no blood. There have been times depending on who our nurse was over the years that somebody would have to be sent wherever to have bloods taken. So there are advantages in that sense. I think it's far less intrusive for our client. (Site B, interview 3, Manager)

e) Social barriers: (absence of) peer support

Another barrier reported by service user participants was technically the absence of something typically seen as a facilitator, namely the provision of information from a peer who had been through treatment themselves. Crucially, peer support of this kind was described as an adjunct to rather than a substitute for the professionalism of a HCV nurse.

I think it adds value if you have somebody that's kind of done the same thing before that you're about to do and are coming from the same place. So obviously [HCV outreach nurse] probably hasn't I guess been through treatment for hepatitis C herself, but she has the expertise to be able to talk somebody through that and go through that but I think the added value of having somebody that has been through treatment just to kind of walk alongside the person that's about to go through the treatment has some value (Site A, focus group, service user participant)

According to this service user, personal experience engenders an ability to communicate differently to hepatitis C specialists.

The absence of peer support was seen as a barrier during, as well as prior, to the onset of treatment with lack of support being cited as a reason why some failed to complete hepatitis C treatment. There is the suggestion that the reassurance and guidance provided by a peer who had themselves been through HCV treatment may carry more credibility than that of "somebody with technical expertise". The role of family members or partners was also highlighted as being critical.

I think a common experience between people going through the same sort of thing, you know, things that are going to come with it like fear, disillusionment, disheartenment and wanting to give up, things like that, that you've got a chance anyway of dealing with some of

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those issues with somebody who's already been through the treatment, definitely, which is something that somebody with technical expertise may be able to reassure you, they may be able to give you some guidance, but not in the same way as somebody who's actually experienced the treatment. (Site A, focus group, service user participant)

No, I think a lot of people probably failed completing their treatment because of it. I completed mine, but I'd have my partner kicking my arse all the way to the hospital to make sure I did it. If I wouldn't have had that support I'd have woken up one day and thought, 'there's no way I'm going to the hospital'. (Site B, focus group, service user participant)

The lack of peer and social support was identified by drug treatment staff as a concern and a contribution to barriers to hepatitis C treatment for many service users; in particular, those who might be homeless or have literacy issues. Delivering peer support was seen to have multiple benefits.

So, some of our clients can be quite socially isolated, they are trying to break away from the drug using community so they will then – so they can meet a new crowd of people. The services users can facilitate and assist them getting to places, setting up things for them – so similar – so less of the clinical stuff – or none of the clinical stuff. I've known peer support go to the cinema with them, yeah, so just to do nice stuff. Go to the gym, assist them with filling out forms and stuff that they are really struggling to do – yeah, so to sort of introduce them to like book clubs and things like that. And it's also good for the peer support to build their skills in working with people for their future development also. So, it's kind of a mutual aid type thing almost with sort of like helping each other, which is really good. (Site A, interview 17, Team Leader).

Here's a nice typical example, so I envisaged that the GP was right and was doing a referral, a letter would be sent from hepatology to the patient but the patient can't read English, can't read, doesn't look at their mail, is homeless, is itinerant. And so, these are the sort of problems that our service users have. We tend not to write to them so much, they don't look at letters; letters coming in brown envelopes are not opened (Site B, interview, Consultant)

And to get really vulnerable people either to a GP or to appointments you need peer navigators. That's the same for anything to do with health and homeless and drug users. It's not about hepatitis C; it's about any form of primary care or secondary care. It's not specific. But I think there is an additional barrier in that no one bothers because why get them to treatment if there is no treatment for hepatitis C available. (Site B, interview, Commissioner)

So now this GP extra leg has been put in, almost, it's like it wasn't there, needs to be, straight from service straight to the hospital. I believe there was some breakdown of communication at that point, but this was added in by the public health department in that has to go through GPs. Have you had any feedback from clients, at all, former services users, about

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whether or not, when they're given a diagnosis, so you've got a great system working where people are offered testing, they're getting tested, so there must be diagnosis coming through, how are they negotiating that process of having to go to a GP on their own volition, without support, if you know what I mean? How do they manage that? (Site B, interview 2, Team Leader)

f) Treatment experience

The experience of interferon based hepatitis treatment was cited by participants of the service user focus group as one of the main barriers to treatment. Although successful interferon based treatment was identified, the predominant theme was that people on interferon based treatments, even when support was available often struggled with side effects causing them to drop out of treatment and this informed the understanding of most people eligible for hepatitis treatment.

The side effects are horrendous. It's like the same feeling you get, similar to the feeling that you get when you're withdrawing from heroin but it goes on for like six months. You know, it's not over in ten days, it just goes on and on and on and on and on. And it's kind of like you have one injection a week, you have the injection and you don't feel bad, you don't feel hardly anything, but within 48 hours, like 24 to 48 hours you start to feel sick and then you get really sick and then your blood pressure drops and then you can't move and then you have trouble with mobility and you have trouble eating and if you're on your own you're stuffed. And then you're just getting like yourself back together and it's time for your next injection and that goes on for six months basically. (Site A, focus group, service user participant)

Yeah, I do hear a lot of conversations with clients and they say, "I'm not going to have that injection, I've heard horror stories." Everyone knows someone who the hair's fallen out and they've become very very unwell, and obviously, some people do have terrible side-effects and some people do have hardly anything (Site A, interview 11, Lead Nurse)

Yeah, you've got to have chronic cirrhosis before they put you on the new treatment. There's no interferon involved; if there's interferon it was the worst drug I've ever taken all my life, for 12 months it just made me a different person. (Site B, focus group, service user participant)

About interferon: they told me lots of the implications of it and the severity of it. But no amount of talking can prepare you for it (Site B, focus group, service user participant)

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One participant noted that once interferon free treatment became available, and that service users became aware of the potential for an all oral treatment with few side effects, that the uptake for treatment would increase and that DNA would reduce.

Oh yes, I mean it's going to make a staggering difference, yes, as the word filters out that the treatment is much, much easier and has fewer side-effects and is much more successful. You know, we are beginning to see people coming to clinic who have disengaged with the service for years and they are coming back because they've heard that the new treatments are available and they work.

All I can say is of the people who have been diagnosed and have engaged in the past, more of them are coming back and engaging again and I think probably – I don't – I think our do not attend rate, our DNA rate, is lower now than it used to be (Site B, Interview 13, Consultant Hepatologist, ODN)

g) Worker competency, confidence and information giving

Training workers to be able to use dried blood spot testing was seen as a significant opportunity advance to increasing capacity and opportunity for hepatitis testing in drug treatment settings. However, there were examples of worker resistance to screening, suggesting a perceived conflict of interests regarding their roles, or insufficient training and a lack of confidence around hepatitis C and information giving – seen as a prerequisite to testing.

The other bit of that of course is that some key workers may feel quite resistant to doing something like a dry blood spot testing. I've never had to do it personally but I think, oh, I don't know. A bit squeamish. I would do it because it would be part of my training. I wonder for some key workers; does it feel like that? That could be a barrier. I think it's confidence rather than resistance (Site B, interview 3, Manager)

Some interviewees described workers having resistance to testing and an ideological dislike of handling blood or needles; some people didn't like the idea of active screening as part of their core role, often they had a counselling background for example and they thought it would be disruptive to the relationship that they're trying to build up with their client. Some staff who do not want to screen for HCV are excellent in other aspects of their core role and managers are unwilling to discipline them for not being willing to test. Some staff asked to screen for HCV are being paid substantially less than nurses and are not trained to a standard to authoritatively discuss HCV with service users.

Managing the change can be really difficult because on the one hand we would like those who have dug their heels in and don't want to screen to start screening, but these might be workers who are excellent in every other parameter of their work so we wouldn't necessarily

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be right to treat it as a critical performance issue: you wouldn't want to sack somebody because they're not doing dry blood spot testing, or would you?

The converted are converted, we don't have to spend time on them; the entrenched were entrenched, we don't have to spend time on them, nothing is going to change their mind. But the core group, the middle group, the third I think there's a real opportunity, so we get them to start doing DBS and then suddenly you've got two-thirds doing it, the minority then feel they should follow suit and then the cultural shift will occur. (Site B, interview 4, Consultant)

In the new teams that were doing the voluntary sector, of course most people aren't nurses. And there is quite a substantial training need to make sure that drug workers from a variety of backgrounds are able to authoritatively and helpfully talk to clients about Hepatitis C. Clients won't have tests unless they are... unless the staff talking to them about it are very well trained. And that is actually... that is quite a big issue. So, when you've got voluntary sector staff paid half as much as the nurses (Site A, interview 12, Consultant)

So, we tried to work through those nurses rather than against them, saying, 'It won't just be one nurse; all the nurses can do dried blood spot testing'. And the idea was then we would say, 'By the way all the workers can actually'. So, that's the way we did it. It took a very long time. There was a lot of resistance, there was a lot of sabotage in different ways; but we eventually got all the nurses doing dried blood spot testing, and then we rolled it out to all the workers doing dried blood spot testing. (Site B, interview 8, Commissioner)

The lack of information about hepatitis C was a common theme among service user focus groups. When information was available it was valued by staff and service users although the delivery of information was inconsistent. Several responses suggested that many workers don't have the confidence or knowledge to extensively inform service users around hepatitis C.

If you've got hepatitis C you've got to go and get your own information... I was just going to say the only time I found out about the new treatment originally was on Facebook. Some drug companies or something, but anyway it had come from an American source. And since the only other time was through the booklets that I just found here recently. (LJWG LSHTM Hep C Info and Hep C Care booklets) And in answer to your question I thought they were really well and plainly written, and it's the most information I've actually ever had about hep C altogether, both from the little blue one and the other two. So, yeah, they were literally the most information I've ever had, the most clearest and what seemed to be the most up to date. (Site B, focus group, service user participant)

I know a few people who've got it mixed up when they've gone for the first test and they've thought they've got hep C and they've gone for a second time and been told they're clear. Obviously, they're happy but they're shocked. It must be horrible. So, obviously, someone

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didn't explain something properly there, did they? Because it is a little bit of a while, isn't it, between your first test and when you get your second one. And if that's not explained properly to you it's a little bit nasty to leave someone thinking they've got something like hep C when they haven't, for the sake of spending two or three minutes giving them a little bit more information. That's horrendous. (Site B, focus group, service user participant)

I've never really been given information (about genotypes). The most information I've had has been reading them recently in the booklets. (LJWG LSHTM Hep C Info and Hep C Care booklets). (Site B, focus group, service user participant)

Just better information. When you go for your first blood tests that's when you should be sat down and given all your information. Like we said, some people haven't even got hep C are walking out of that office thinking they have. If the information is that crap then something definitely needs to be done there. (Site B, focus group, service user participant)

And it's not just about the test, it's about information, because we can be very focussed on the testing and miss... when we talk about barriers, we talk about tests, but it's a bigger thing than just having a test. It's about what the outcome is, does the client understand, what are their feelings about this? (Site B, interview 2, Team Leader)

I guess there's probably always work that we need to be doing about breaking down the myths. I don't probably spend enough time speaking to services, not about hepatitis C - I haven't a conversation for a long time - but I remember when I used to work directly with clients and more directly. Clients still believe that you need to have a biopsy. There are myths still about what treatment is and what that looks like. We do train the team here, but you've got to remember, if you're a key worker these days you have a lot of information to retain. (Site B, interview 3, Manager)

I think you have to be a complete hepatitis C nerd actually to understand and make judgements about what to do. (Site B, interview 8, Commissioner)

And there is information a bit through the drug services and that. But what concerns me is people who aren't attached to the drug services and have hep C, because there's nothing really there in the GPs' offices and everything ever. And I've felt like I know more about hep C than my GP. (Site B, focus group, service user participant)

2. Barriers to data collection

Several themes pertaining to data collection were identified: Data requirements and limitations; data responsibility; ODN data volume; IT systems and compatibility. Additionally, there was a suggestion that hepatitis C treatment data should reflect treatment pathways, belonging to hepatology rather than drug treatment services.

a) Data requirements and limitations

Public Health England (PHE) has responsibility for monitoring the performance of the drug treatment system in England against local and national targets. To this end various performance management reports and statistical releases are produced using data collected through the National Drug Treatment Monitoring System (NDTMS) which collects, collates and analyses information from the drug treatment sector. NDTMS limitations were seen as a barrier to data collection within drug treatment services.

At the time of the service review there was no requirement to record if people had had a positive antibody or RNA hepatitis C test. The NDTMS data (Dataset M) requirements around hepatitis C were limited to the following fields which are unclear therefore difficult to answer. For example, it is unclear if the 'Hep C intervention status' is about testing and if the 'Hep C tested' is antibody or PCR tested (see Table 1).

Table 1

Hep C intervention status
Offered and accepted
Offered and refused
Not offered
Assessed as not appropriate to offer
Hep C tested
Yes
No
Not asked

After the service evaluation interviews were completed NDTMS data requirements have been revised, (NDTMS Adult drug and alcohol treatment business definitions, Core dataset N, February 2017) requiring more comprehensive hepatitis C related data including recording of test date and hep C antibody and PCR test (Polymerase chain reaction test for chronic infection) status to be recorded within drug treatment services.

There was some evidence that local adaptations to data collection were established to overcome the identified NDTMS Dataset M limitations, that the hepatitis C pathway wasn't replicated on NDTMS and that protocols were established to guide and support workers in recording hepatitis C related activity.

The NDTMS is done but then they'd be open onto the system but then nothing would change on that. So we'd be doing all this great stuff, getting loads of stuff done but then the NDTMS didn't get updated (to reflect this). (Site A, interview 17, Team Leader/Nurse)

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No, so it wasn't capturing it – so now I've got a, so I put a bloods recording and sharing results protocol and part of that – so the person that takes the blood is then responsible for updating the NDTMS when the results come back. So again, so that's working well (Site A, interview 17, Team Leader/Nurse)

In response to a question around recording which service users have been tested for hepatitis C, the same participant suggested that although the collection of local data supported the screening element of the pathway, the information was held internally and not shared with commissioners.

No, no, the commissioners don't see it (locally recorded data), it's just for us (drug treatment service) here to ensure the high standards and the best practice. (Site A, interview 17, Team Leader/Nurse)

Since the service evaluation NDTMS data requirements have been revised (NDTMS Adult drug and alcohol treatment business definitions, Core dataset N, February 2017) requiring more comprehensive hepatitis C related data including recording of test date and hep C antibody and PCR test (Polymerase chain reaction test for chronic infection) status to be recorded within drug treatment services.

NDTMS has updated to add some fields, more fields, for hepatitis C, which is what Public Health England has been doing. So, Public Health England Drug and Alcohol Team were the NTA, now they're the Public Health England Drug and Alcohol Team, then don't have any say over what you do or what you don't do, but they've updated, worked with departments to update NDTMS so that it's got more hepatitis C fields to be able to collect data on what's actually happening. (Site A, interview 15, Senior Manager)

b) Responsibility for data

In addition to concerns that NDTMS couldn't provide the necessary data to inform the hepatitis C pathways, there was a strong claim that data collection should be fundamentally linked to targets around HCV treatment, that the hepatitis C treatment pathway sits within or 'belongs' to hepatology services.

I think there are limits to what you can expect NDTMS to do. Drug treatment is under massive pressure.... this really is a pathway that pretty much belongs outside of drug treatment. It belongs to the acute sector. It belongs to hepatology. (Site A, interview 10, Consultant)

The data needs to be collected at the level of the hepatology services. The important target is the numbers in treatment. You change your tariff. You put a mark in place into hepatology

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services and you create a target for numbers in treatment for hepatitis C - that is how you'd engender change. (Site A, interview 10, Consultant)

There needs to be some estimate of the prevalence of hepatitis C in an area for hepatology, which needs to be matched with the number of people treated. Same way that we have prevalence stats for our area and we're expected to treat a certain amount of heroin users within a certain waiting time. Too much of the discourse is about how you can get addiction services to test more. Well, most people know their status. It's not that. The problem is about access to treatment. The only way you improve access to treatment is getting the people who actually provide the treatment and you hold them to account properly. That's all about data at that end. (Site A, interview 10, Consultant)

It was highlighted that data expectations were unrealistic and that commissioning expectations didn't reflect the increased demand on drug treatment services, or amount of worker input needed to engage and support service users meaningfully around hepatitis C. It was stated that competing demands may be compromising the quality of interventions that allow for hepatitis C activity, and so data recording, to be carried out.

And I was writing the tender, and I just said, "Yeah, we'll collect it". I went to see the head of data, the head of IT here, and said, "How are we going to collect it?" he said, "We're not going to collect it. Don't be silly. Just say we will". And I've no doubt, no doubt, that the new providers will not be able to keep up with it. It was utter nonsense.

But because all of this (recommissioning of services), if you get cheaper and cheaper services with less and less... people have less time to focus...and depending on what the agenda is, and what people are commissioned to do, Hepatitis will, you know, take a key worker an hour, probably, to talk properly to someone about hepatitis. And to get them into treatment is a huge... to help and support them to treatment is a huge key working task. And if you've got a caseload of 90, you're not going to get through it. (Site A, interview 12, Consultant)

c) ODN related data volume

Operational Delivery Networks (ODNs) were initially set up by NHS England to administer the 'Treatment of chronic Hepatitis C in patients with cirrhosis' policy (otherwise referred to as the 'interim policy'). ODNs now oversee all patients going onto treatment in a given region. NHS England (2015) have stated that 'ODNs will provide clinical leadership over a given geography, co-ordinating high-quality patient care through a specialist multidisciplinary team (MDT) and delivering oral therapies in line with this policy in largely outpatient (including outreach) settings'.

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A key responsibility of ODNs is to provide clear monitoring data on ODN operation and outcomes for patients, including the impact of the ODN model for improving access and real-life effectiveness of new treatments. However, at the time of this study, participants identified a lack of clarity and concern around the volume of data requirements.

The ODN data, I think what has been identified, the spreadsheet, it's a big spreadsheet of information that they want, and so I think they have identified that out of all of the ODNs, only eight filled it out fully for this April deadline. And so, the people who are supposed to collect this data are the OD managers, but I think that coming into a new post and being expected to gather a lot of data is probably quite difficult, and so I think what people have done is they've looked at what data is needed and they're working forwards rather than backwards. (Site A, interview 18, Lead Nurse)

So, in accordance with us treating patients, we are being required to collect a minimum – what they call a minimum data set... And it's – and yet it's so much that it's laborious and hugely demotivating for the people who are collecting it. (Site B, interview 13, Consultant Hepatologist, ODN)

The legitimacy of the data being required was also challenged. For this participant, the minimum data set was seen “inadequate” and misconceived. Using the example of ethnicity, he criticises the nature of the categories underpinning the data ODN managers were asked to gather. The implication is that certain questions – including those about ethnicity – are more about bureaucratic expediency than answering ‘serious’ epidemiological questions.

[The minimum data set] comprises stuff about demographics and – they are trying to get us to collect stuff on routes of acquisition maybe and various bits and pieces; and my view is that data set is not going to be informative because it's inadequate to answer any research questions that they might be keen to ask. So, if you are really concerned about equity of access and disadvantage then grouping patients into ethnic categories that include Asian and Black, you know, half the world's population is Asian. What the hell is Asian? You know, that's – that's a papering your own backside type question to ask because it's uninformative. Well it requires me to enter data, which is totally meaningless and cannot be used to answer a credible question but allows somebody somewhere to say, “Oh, we asked about ethnicity.” (Site B, interview 13, Consultant Hepatologist)

Further a participant identified how the drug treatment services had evolved their own modified data set that was more suited and applicable to the drug treatment setting although it wasn't established to what extent this informed ODN requirements.

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In terms of data collection and what you can do with it, and so we have a set data set from the Operational Policy, and again, I've revised it heavily, there's lots of stuff that you don't need in there.... "We could use the same spreadsheet but I don't want to put stuff in there that's of no use." And so, we just refined it slightly, and so we kind of do our own thing. The ODN data sets, like I say, it's frustrating because they want a lot of stuff, and we're a really big centre, and so getting that data is difficult. (Site A, interview 18, Lead Nurse)

d) IT systems incompatibility

Another barrier to data collection is the use of data systems that do not 'talk to each other'. Firstly, the system used by the drug treatment services in one of the areas was incompatible to that used by the acute hepatology service. However, sharing relevant client data was to some extent, facilitated by key personnel, for example outreach hepatitis nurses who were able to access and operate across IT systems.

I think their system is completely different from ours. If I'm honest, it's not so much a problem if you've got an Outreach nurse there who has been trained in their system and you can get a laptop with our system on, it's not so much a problem, but I think it could be a problem. (Site A, interview 18, Lead Nurse)

So (Outreach nurses), they use EMIS, which is a system, so what happens to their bloods, because it goes through their system? The blood results get put straight onto EMIS, which we don't have access to.....so then what happens is they get e-mailed to admin on NHS.net, the secure content, yeah, they then – and then one of our admin assistants will put them straight on to Patient Journey. So, they are under assessments, so we've got the full, the actual results but then (Outreach nurses) update the NDTMS – or whoever took those bloods. (Site A, interview 17 Team Leader)

It was highlighted that a local agreement had been established whereby the drug treatment service had access to a hospital (hepatology) records and that the hospital was able to access Patient Journey (the local data collection system) records. However, there were conflicting accounts about how well this agreement was supporting the hepatitis C pathway, in that access to test results was variable.

So, what's happening with Patient Journey at the moment, we can access – so we can access (named hospital A) now, (named hospital A) can now access Patient Journey, so this is the actual hospital; so, there's like a portal – I'm just opening this – so we can, I'm sure it's (named hospital A) as well, I'll double check that – continue, so (named hospital A) – where are we? And the (named hospital B). (Site A, interview 17 Team Leader)

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Because we can access (named hospital A) system now from ours – so instead of turning somebody into a pin cushion, they are like, I only did it recently, we can get those results. (Site A, interview 17 Team Leader)

We haven't got access – we don't have access to EMIS. The only people who have access to EMIS are the GP shared care workers but that's in the surgeries. They wouldn't have access to it here and then once they are in EMIS they only have access to the clients that are registered in those surgeries. (Site A, interview 17 Team Leader)

Summary

HCV data collection is localised and fragile and there is a resistance from organisations to take responsibility for data collection. Local adaptations are often in place which are not necessarily captured in monitoring data or shared with commissioners and there is IT system incompatibility with different services not having access to each other's data. Data collection and pathways are seen by drug services to 'belong to' hepatology, but hepatology is also stretched and disenchanted. Data collection is 'getting in the way' of effective practice.

HCV pathways are also localised and fragile there are ongoing systemic barriers and responsibility resistance. Effective pathways are often reliant on committed and innovative individuals. Services and commissioners interviewed say that there is no centralised pathway responsibility and oversight. Hospitals are seen as inflexible regarding substance use and appointment attendance and there are unhelpful perceptions about referral requirements. Drug treatment services are best to support outreach however this requires dedicated financial support, drug services also reflected staff reluctance to carry out some activities as they did not see it as a part of their role. Limited resources within drug treatment services has led to calls for hepatology to take responsibility for the overseeing of the pathways.

To eliminate HCV as a public health threat by 2030 we need:

- Centralised pathways and data collection
- Adequate resourcing and training is essential for responsibility to be 'owned'
- Commissioning of integrated HCV services in drug treatment services (including peer support)
- All boroughs to have a clearly identified and monitored HCV pathway
- Pathway development to attend to systemic barriers faced by PWID
- Standardisation of diagnostic tests and treatment eligibility requirements
- Upscaling HCV antibody testing in all drug treatment services and needle syringe programmes.

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Dee Cunniffe

Dee Cunniffe jointly set up the LJWG 8 years ago and is the Policy Lead. Dee has worked in the field of substance use over the past 16 years. She has managed a wide range of drug and alcohol treatment services including prescribing services, needle exchanges, DIP programmes, arrest referral services, residential rehabs, day programmes and 'one stop shop' drug services. She was a member of Lambeth Hepatitis C Outreach Team who were early pioneers of outreach for people who use drugs (PWID) from 2009 to 2013. Among her skills and successes is working with organisations at all levels to facilitate effective joint working and collaboration.

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Dr Magdalena Harris is an Associate Professor in the Sociology of Health at the London School of Hygiene & Tropical Medicine. Her expertise lies in qualitative methods and the social sciences of hepatitis C and harm reduction. She is a trustee for the Hepatitis C Trust; associate editor for the International Journal of Drug Policy and Journal of Hepatology, Medicine and Policy; steering committee member for the London Joint Working Group on Hepatitis C and Substance Use and the European Hepatitis C Platform; and board member for the Global Congress for Qualitative Health Research.

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Towards the end of the project and after the interviews in the second quarter of 2016. Borough B is changing the pathway of referral from diagnosis to treatment from GP and then to specialist care to direct referral to the specialist care. This pathway is being put into place post the introduction of the ODN's and through partnership work between commissioners, which has identified that this process may be more effective.

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