

# Barriers and facilitators to hepatitis C treatment for people who inject drugs A qualitative study

June 2012



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**THE CENTRE**  
FOR RESEARCH ON DRUGS  
AND HEALTH BEHAVIOUR



**LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE**

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## Abbreviations

The following abbreviations have been used in this report:

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
BBV	Blood-borne virus
CDT	Community drug team
CRDHB	Centre for Research on Drugs and Health Behaviour
D&A	Drug and alcohol
DNA	Did not attend
DSA	Disability Support Allowance
GP	General Practitioner
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
JSA	Job Seekers Allowance
LSHTM	London School of Hygiene and Tropical Medicine
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
OST	Opiate Substitution Therapy
PHHR	Physical Health Harm Reduction
PWID	People who Inject Drugs
SAU	Specialist Addiction Unit
SU	Service user
TB	Tuberculosis
UK	United Kingdom
WHO	World Health Organization

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# 1. Executive summary

## Context and rationale

Hepatitis C virus (HCV) infection is a significant global public health problem. The burden of HCV infection is concentrated among people who inject drugs (PWID), with an estimated five million PWID living with chronic HCV in the European Region. HCV antiviral treatment with peginterferon alfa and ribavirin is the standard care for chronic HCV, with a 50-85% cure rate depending on genotype. Research indicates that PWID are interested in HCV treatment uptake and have rates of viral clearance comparable with other populations. Current injectors are not precluded from HCV treatment access in a number of European countries, yet uptake rates are substandard. This qualitative study aims to assess the barriers and facilitators to HCV treatment access and completion for PWID in drug and alcohol (D&A) settings. We examine the barriers and facilitators to HCV treatment by: describing pathways to hepatitis C treatment, including referral, as well as factors mediating treatment access in the D&A setting. Through qualitative interviews with HCV treatment providers and PWID we explore the experience of HCV treatment access and delivery from patient, provider and 'system' perspectives in order to develop guidance regarding HCV treatment system improvement, including referral and coordination, and the provision of psycho-social interventions targeting patients and providers.

## Methods

In 2011 a qualitative study was undertaken to explore the barriers and facilitators to HCV treatment access for PWID in D&A settings. Two London-based partnerships were selected: site A (an established community-based partnership offering HCV treatment delivery and support for PWID) and site B (a nascent partnership about to pilot a HCV outreach programme). In-depth interviews were conducted with service users (n = 35) and service providers (n = 14) from both sites.

## Key findings

Social structural issues, such as those relating to HCV stigma, unstable housing, social support availability, caring demands, benefit access, gender, culture and criminalization, impacted – to varying degrees - on participants ability and inclination to access and complete HCV treatment. Service providers in the two partnerships worked to mitigate some of these barriers by providing practical supports such as help with accommodation and benefit access, the provision of fridges to the unstably housed, translator services and flexible service provision around the long working hours of immigrant service users.

We found that a primary structural barrier to treatment uptake is the hospital based setting, both for its inconvenience, lengthy waiting times and rigid eligibility criteria, but also due to the stigma and discrimination many participants reported experiencing. The partnerships, by locating treatment access at D&A based settings and attending to the specific requirements of PWID, were able to engage participants in treatment who might not have accessed hospital-based therapy. Successes and innovations of the D&A based services that aided PWID HCV treatment access and uptake included flexible appointment times and eligibility criteria, tailored phlebotomy and continuity of care.

Integrated service provision is vital to quality HCV treatment care for PWID. The service partnerships were accessed by service users who often had complex needs, requiring input from a wide variety of specialist service providers. The use of multidisciplinary teams and/or the co-location of a variety of services aided HCV treatment engagement amongst service users. Timely input regarding an



individual's physical and mental health as well as their social and living arrangements aided effective decision making and the effective monitoring of PWID throughout their treatment journey.

## Recommendations

Our study highlights a number of areas where changes to practice or policy could improve HCV treatment uptake and success rates among PWID. An integrated model of care, incorporating partnerships between hospital-based hepatology services, drug and alcohol services and blood borne virus teams is recommended for the provision of HCV treatment to PWID. Service provider cognisance of and attention to the social structural barriers that many PWID face in accessing and taking up HCV treatment will further aid treatment access. Recommended social support interventions include service provider assistance for PWID to obtain stable housing and access appropriate benefits, as well as the provision of vouchers or subsidised access to transport and home help including respite and child care.

The partnerships aided HCV treatment access by making modifications to traditional treatment regimes, such as those operating in many hospital settings. Recommendations arising from the success of these modifications include: flexible appointment times: scheduled with the needs of PWID in mind and/ or provided on a drop-in basis; appointment times made to coincide with other appointments; and the minimization of multiple pre-treatment appointments. It is vital that HCV treatment eligibility criteria reflect NICE recommendations that current illicit drug use alone is not a treatment contra-indication. Decisions about treatment need to be made with the full input of the service user. Successful treatment outcomes are possible for individuals who are unstably housed, have substance use dependencies and multiple co-morbidities, but these decisions need to be made on a case-by-case basis, with inputs around physical and mental health and lifestyle stability made by specialized service providers.

Integrated care networks are key to improving HCV treatment uptake and completion for PWID. PWID often have many complex and competing health and social needs that may take precedence over HCV treatment. Access to HCV testing and treatment at locations where PWID are provided support for acute health care can facilitate uptake. Service providers who are able to provide a broad range of services for PWID, such as acute health care, are particularly well placed to introduce information and access to HCV testing and treatment. An onsite skilled and non-judgemental phlebotomist is necessary for PWID who often have poor venous access. A continuum of care is important and maintaining contact with the same service providers can improve engagement with services. Where services cannot serve all client needs, clear and timely communication between service providers is vital to ensure high quality and appropriate care.

## 2. Introduction

### Background

Hepatitis C virus (HCV) infection is a significant global public health problem. Worldwide 180 million people are estimated to be chronically infected, with nine million of these living in the European Region [1, 2]. Surveillance data on HCV in Europe – especially regarding antiviral treatment uptake and access – is limited [3, 4]. In Western Europe, HCV prevalence estimates range from 0.4% to 3% in the general population [5], with estimates as high as 6% in parts of central and eastern Europe [3]. Global mortality rates attributable to HCV are estimated at 350,000 deaths annually [1, 2], with 86,000 of these in the European Region. Routine national data sources in the United Kingdom show that HCV-related deaths, transplants and hospital admissions are continuing to rise, emphasising the need to increase the number of people accessing HCV antiviral treatment [6].

The hepatitis C virus is transmitted through blood-to-blood contact, that is, receiving contaminated blood transfusions and products, using contaminated syringes and other injecting equipment, such as spoons, filters, drug mix and water, receiving a needle-stick or unsterile tattoo procedure and – at a lesser risk – being born to a HCV-infected mother or using contaminated toothbrushes and razors [7]. Injecting drug use is a major route of transmission with over ten million people who inject drugs (PWID) infected globally [8]. In the European Region, the burden of the disease is concentrated among PWID with HCV prevalence among this population varying from approximately 21% in Finland to over 90% in Estonia [8]. Recent projections suggest sero-prevalence is increasing rapidly among new injectors [9]. Modelling studies illustrate that upscaling HCV treatment access to PWID is an effective preventative measure, reducing the pool of communicable disease in the population [10]. The need to continually target this high-risk group for HCV screening and treatment is clear given that over 90% of new infections each year are reported within this population [6].

HCV antiviral treatment with peginterferon alfa and ribavirin is the standard care for chronic HCV, with a 50-85% cure rate depending on genotype [11]. Treatment duration is from six to 12 months and is considered successful if a sustained virological response (SVR) is obtained six months after treatment cessation [11]. Drug toxicity and treatment duration can, however, pose significant challenges to patients and providers, with 10% to 14% of participants in HCV treatment randomised trials discontinuing therapy because of adverse effects [12]. Common HCV treatment side-effects include anaemia, depression, anxiety, fatigue, flu-like symptoms, nausea, alopecia and insomnia. Cases of psychosis, mania and suicide have also been reported [11, 13]. Despite these barriers, research demonstrates that many PWID are interested in treatment uptake. [14-18]. The British National Institute for Health and Clinical Excellence [19] and EASL clinical practice guidelines [5] do not preclude current injectors or those on OST from treatment access. Yet, in the United Kingdom and throughout Europe, HCV treatment access is suboptimal, especially for PWID [3, 10].

#### ***HCV treatment in the European Region***

Estimates of coverage of HCV treatment relative to treatment need or demand among PWID are largely absent in the European Region. Peginterferon launch and sales data for 21 countries in the WHO European Region show that the number of people ever treated ranged from 16% of prevalent cases in France to less than 1% of cases in Romania, Poland, Greece and Russian Federation, suggesting unequal access to optimised therapy [20]. Data from the new EU Member States and neighbouring countries is scarce, but indications are that the number of people enrolled in HCV treatment over the three years from 2004 to 2006 was as low as 150–300 in Bulgaria and Slovakia,

approximately 500 in the Czech Republic and Latvia, with upper estimates at 1300 in Hungary and 4000 in Romania. However, in most of these countries PWID, including those receiving opiate substitution therapy (OST), do not receive HCV treatment [21].

Engagement with drug treatment, and especially OST, is known to enhance HCV treatment access, uptake and adherence among PWID [22], as it does with HIV treatment [23-25]. It is estimated that in 2010 670,000 people in the European Region were receiving OST [26], however access to OST is limited in many countries, especially in the east of Europe where there can be a greater policy emphasis upon criminalization [27]. In Russian Federation, where there is a large HCV treatment need among PWID [8, 28], OST remains legally prohibited. In the United Kingdom the majority of opiate dependent PWID in contact with drug and alcohol services in the United Kingdom receive OST. Clinical research has shown that people on OST should not be excluded from HCV treatment as their rates of compliance and sustained virological response do not differ from that of non-drug users [29, 30]. Yet in the United Kingdom only around 3% of all diagnosed patients are receiving HCV treatment each year, with this number considerably lower among PWID, including those receiving OST.

### ***European policy environment***

In a recent analysis, data from 44 of the 53 countries in the European Region show that 68% of countries report having a designated pathway for hepatitis diagnosis, treatment and care [4]. A number of examples of pathways provided, however, consist solely of a referral to a hospital or specialist [4] and the collected data does not demarcate between HCV and HBV, thus constituting a lost opportunity for a greater understanding of systemic barriers to HCV treatment access. Seventy five % of the 44 countries report some provision for government funding of HCV and/or HBV treatment with only 57% reporting funding for the treatment of both viruses [4]. The cost of HCV treatment in the Region is estimated to range from EUR 2,000 for the least expensive drugs registered in Belarus, to EUR 22,800 in the Czech Republic, with an average cost of EUR 12,600 for a year-long course of treatment [21]. As of 2007, health insurance was required in the majority of central and eastern European countries to help pay for HCV treatment, insurance which is lacking for the majority of PWID. HCV treatment funding eligibility and policy differs widely across the Region. For example, in Latvia partial coverage by the state is available, in Belarus treatment is subsidised only for the first three months and in Ukraine not at all. In Bulgaria, the 2007 HCV treatment policy was to cover costs for 50-60 individuals, although at that time there were an estimated 200,000 people living with HCV in Bulgaria, including 15,000 PWID and approximately 500 on OST [21].

Despite evidence of the efficacy of HCV treatment among current illicit drug users, people on OST and with psychiatric conditions [22, 31-34], extant European HCV treatment guidelines vary regarding their treatment eligibility recommendations, with the majority taking a conservative view. The latest EASL clinical practice guidelines state that “no general recommendation for treatment of active drug users can be made” [5](p.259), instead advising case based multidisciplinary evaluation and careful monitoring for current injectors and people on OST, coupled with abstinence from alcohol consumption. National HCV treatment guidelines in the majority of central and eastern European countries – Belarus, Bulgaria, the Czech Republic, Estonia, Hungary, Lithuania, Romania and Slovakia – consider current drug injecting and often alcohol use as contraindications for treatment, with 6 month abstinence requirements common [21]. Spanish guidelines advise treatment postponement and detoxification for people dependant on alcohol or illicit drugs [35], while United Kingdom NICE guidelines recommend treatment for all HCV patients, including current injectors, except where contraindicated [19].

### ***HCV treatment in drug and alcohol settings***

The hospital-based setting is one evidenced barrier to HCV treatment uptake among PWID [21, 36, 37]. In order to counter this barrier, HCV treatment is being increasingly located at sites such as drug

and alcohol (D&A) services which may be more amenable to and convenient for PWID. Regular medical and pharmacy contact has been posited by agencies such as the UK Health Protection Agency (HPA) as offering a ready-made platform for enhancing PWID compliance with the demanding HCV antiviral therapy [6]. Initiatives to enhance treatment uptake among PWID by introducing HCV treatment and management into D&A settings, have been taken up by countries such as Australia and Canada and are at a nascent stage in the United Kingdom [38]. These initiatives are not uncontroversial, with concerns raised regarding the discriminatory attitude of some drug treatment staff to people with HCV [39], and other problematic organizational and structural factors which might influence the delivery and effectiveness of HCV treatment in pharmacotherapy clinics [40]. Evidence points towards the enhanced impact of harm reduction services when they work in combination, including the beneficial relationship between access to drug treatment and social support and adherence to HCV treatment [38].

## Rationale for current study

The Health Protection Agency Centre for Infections (2009) recommended that all primary care organizations in England and Wales should ensure that integrated pathways of care available for patients with HCV. Britain's National Institute for Health and Clinical Excellence (NICE) has also recommended that HCV treatment should be cost-effective and should be given to *all* patients, including patients undergoing OST and those who are currently injecting. Yet multiple barriers to access, uptake and completion of HCV treatment remain for PWID. A key focus of this qualitative study is to better understand the accessibility, quality, barriers and facilitators of HCV treatment services for PWID. There is limited evidence on the factors influencing the accessibility and quality of service delivery for PWID in relation to the embryonic and variable scale-up of HCV treatment in drug and alcohol settings. If universal access targets are to be achieved at the European Regional level, there is a need to understand better the social and structural factors which shape accessibility and quality.

## Aim and objectives

This qualitative study aimed to explore the barriers and facilitators to hepatitis C treatment for PWID in two London drug and alcohol settings by:

- describing pathways to hepatitis C treatment, including referral, as well as factors mediating treatment access;
- exploring the experience of hepatitis C treatment access and delivery from patient, provider and 'system' perspectives; and
- developing guidance regarding hepatitis C treatment system improvement, including referral and coordination, and the provision of psycho-social interventions targeting patients and providers.

Accordingly, the primary research question addressed by the study was *'What are the individual, social and structural factors shaping the accessibility and quality of HCV service delivery to PWID?'*. Multiple secondary research questions were also explored:

- What are the barriers and facilitators to treatment access adherence and completion for PWID?
- What access to information and support do PWID have, including those who are contemplating, undergoing and recovering from treatment?
- What measures (such as increased provider education, individual, social and structural supports) are required to facilitate treatment referral, access, adherence and completion for PWID?
- What are the barriers and facilitators experienced by providers in relation to treating and supporting PWID who are contemplating or undergoing HCV treatment?

- What are the needs and attitudes of providers in regard to HCV treatment for PWID, and what measures are required in order to improve the experience and/or motivation of providers in relation to treating and supporting PWID?

The intended outcome of our analyses of the factors shaping the accessibility and quality of hepatitis C treatment service delivery is to (a) inform local community advocacy and policy guidance and (b) produce recommendations on indicators of quality and delivering quality services in relation to HCV treatment.

## **How this report is structured**

This study draws upon the experiences of service users and providers in two health partnerships in London. Given the complexity of the two London partnerships selected for analysis, a description of these is first provided (Chapter 2). Chapter 3 then describes the methods used to collect and analyse data for this qualitative study. We provide a brief description of the service users and service providers (Chapter 4), and then present the main findings. The findings section is divided into three sections focussing on social-structural context, system context and service integration (Chapters 5 – 7). The first of these findings sections overviews social structural factors, such as housing, stigma and social support, which were found to impact on participants' capacity and inclination to commence and complete HCV treatment. The following section focuses more specifically on the meso environment of the hospital and of the drug and alcohol settings in which HCV treatment is delivered, and explores how treatment access for PWID is differently configured within these environments. We focus primarily on core concerns relating to appointments and eligibility. The final section focuses on the way in which HCV treatment access, uptake and completion can be facilitated by practices of integrated care, with examples used from the two study sites. We end with a summary of findings and recommendations based on the research.

### 3. The community-based HCV service partnerships

Given the complexity of the two partnerships analysed in this qualitative study, it is necessary to first provide a description of each study site before explaining the methods used to collect and analyse the data.

#### Study site A

The HCV treatment services for PWID at site A is an established partnership between three independent services: a hospital-based hepatology service, a specialist drug and alcohol (D&A) service and a blood borne virus (BBV) service. Operating since 2005, this service provides a low threshold community-based HCV treatment programme to PWID with complex addiction problems and multiple co-morbidities. It is a highly regarded service with a good track record of successful HCV treatment care and delivery for PWID [41]. The hospital hepatology service engages with an integrated pathway of HCV treatment delivery and care based at the specialist D&A service. The HCV outreach service is delivered by a senior hepatology consultant alongside the BBV team who is represented by one highly skilled and experienced nurse-practitioner who is based at the site full-time. D&A key workers refer clients to the BBV nurse who provides HCV testing and care as part of a broad package of interventions. The BBV nurse-practitioner provides HCV testing and advice to clients and offers eligible clients appointments at a monthly HCV clinic for a chance to discuss treatment options. At the monthly clinics the hepatology consultant and the BBV nurse discuss treatment options with the clients and make joint decisions about client suitability for treatment, taking in to account information from the D&A team about psychiatric suitability. The BBV nurse-practitioner provides the day-to-day treatment, support and monitoring of the clients.

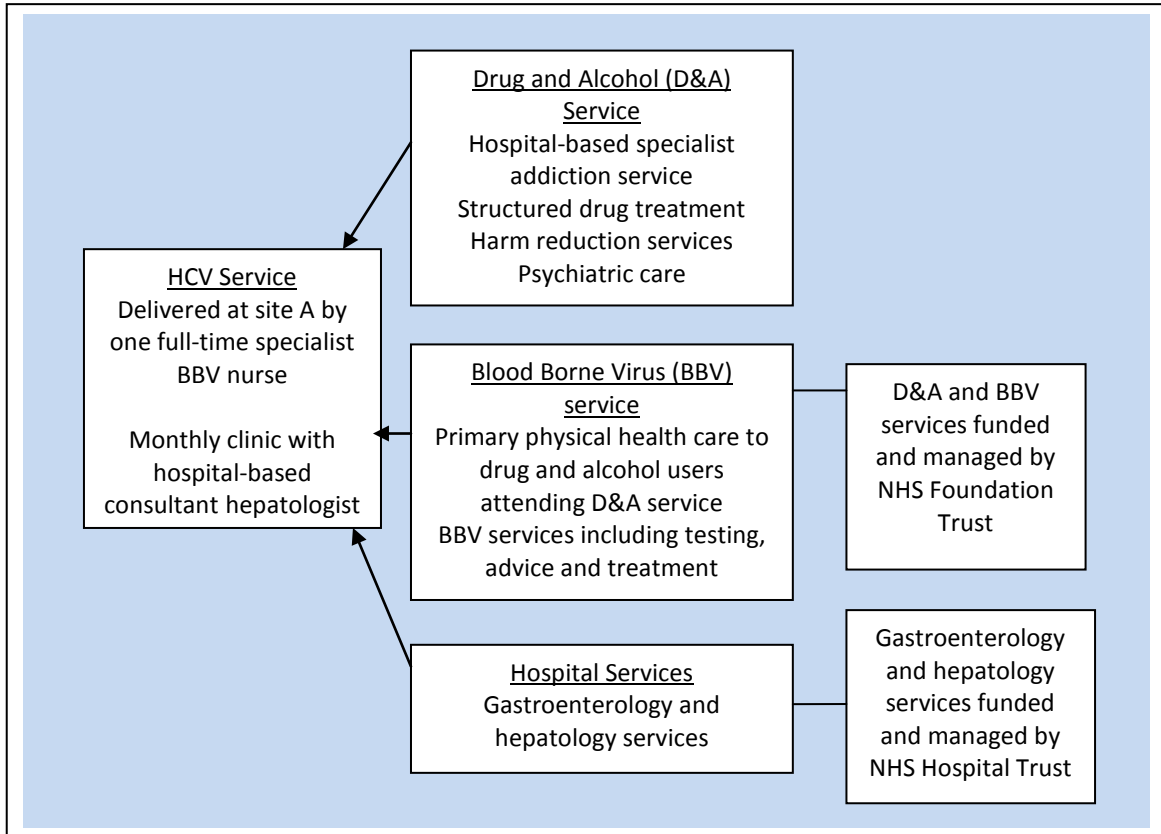
#### ***The Blood Borne Virus service***

The BBV service provides primary health care to drug and alcohol users across the NHS Foundation Trust. The services provided by the BBV team include virology and TB screening, vaccination, tissue viability, sexual health and pregnancy tests, parasitic infections, HIV treatment and monitoring, liver disease assessment and safer injecting advice and information.

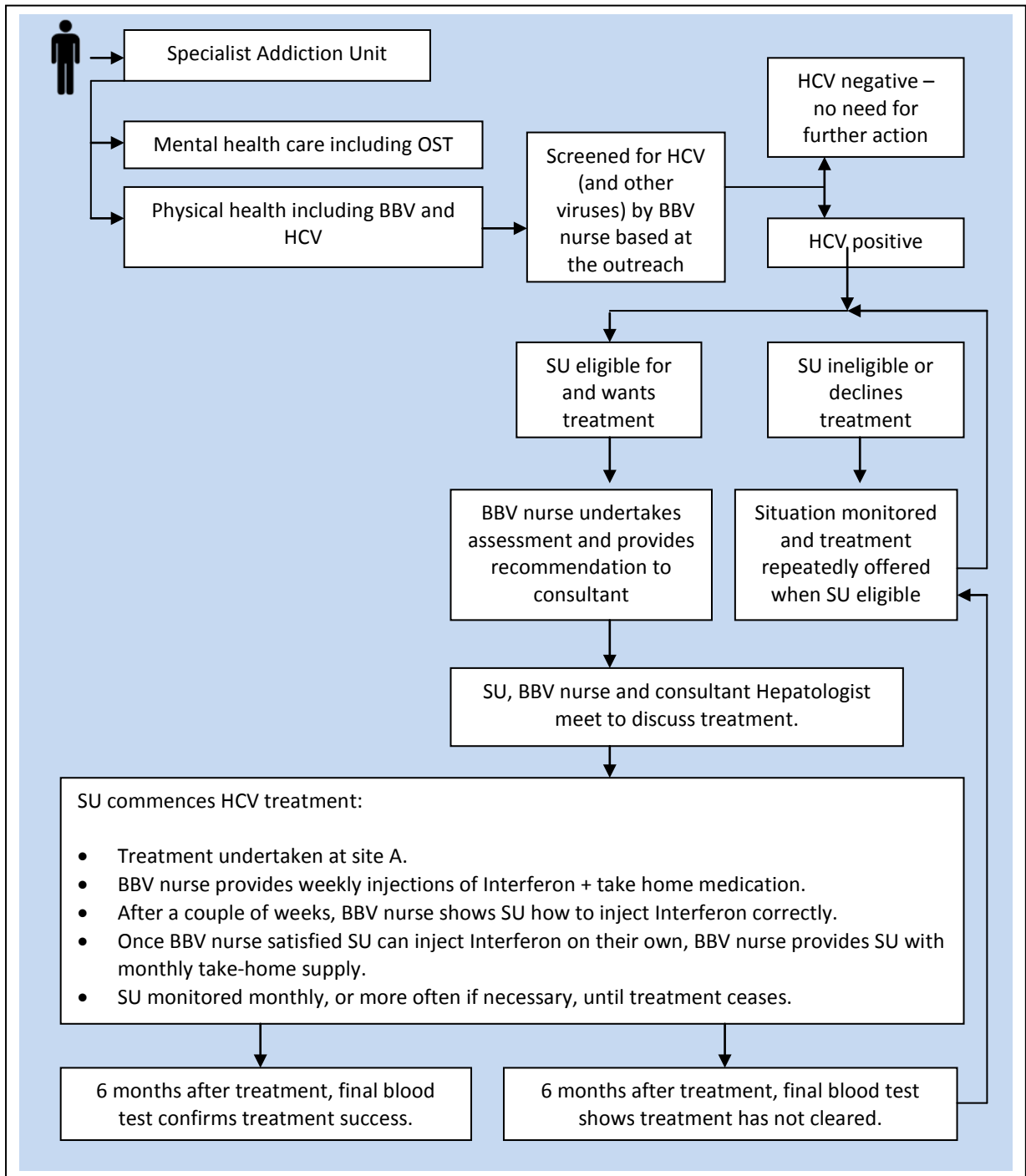
#### ***The specialist drug and alcohol service***

The specialist D&A service receives referrals from GPs and community D&A services of clients with complex addiction problems and multiple co-morbidities. The service is headed by a senior psychiatrist who is supported by two other doctors and a team of mental health nurses who along with one of the doctors, are key workers. The service provides assessment, care and treatment to patients whose D&A related needs require specialist interventions from a multi-disciplinary team. The specialist addiction service have expertise in stabilising, promoting D&A recovery and facilitating wider social inclusion for service users. The service is known for treating the most marginalized of substance users, many of whom have multiple mental and/or physical health co-morbidities. Many are homeless or live in unstable accommodation. As an integral part of the local D&A treatment system, the service also mainstreams users into other treatment agencies and primary care.

**The HCV treatment and service user referral pathway**



**Figure 3.1** Services working together to provide HCV treatment at site A



**Figure 3.2** Site A service user’s HCV referral and treatment pathway



## Study site B

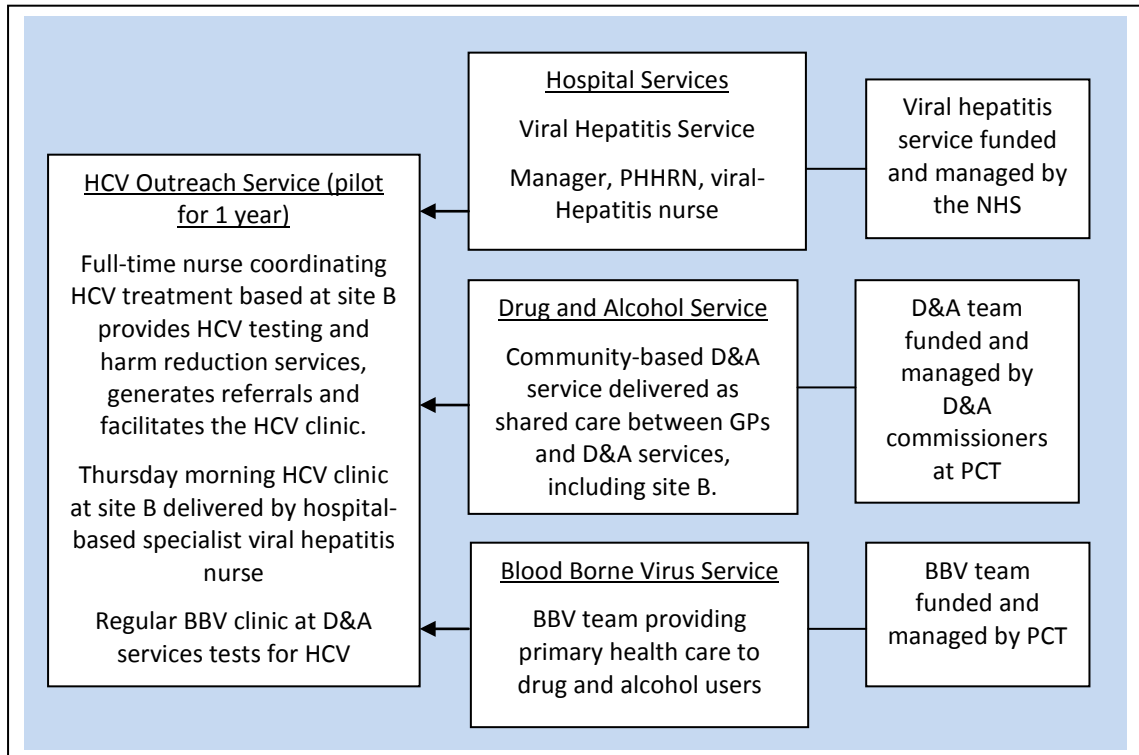
The hepatitis treatment service at site B is a nascent pilot partnership between a hospital viral hepatitis service and a community D&A service. The community-based HCV outreach service at site B has only been operational since mid-2011, around the time we started recruiting and interviewing subjects. One full-time physical harm reduction nurse was employed to coordinate HCV treatment for the duration of the pilot, which was planned to last for one year. This post is a substantial component of the pilot partnership which is funded by a pharmaceutical company. The post is designed to link HCV positive clients at the D&A service with the hospital-based HCV service. Additionally the nurse works with the D&A team to identify and refer clients, provide BBV testing and vaccinations, provide education and harm reduction advice to clients as well as support them with their HCV treatment. The treatment element of the service comprises a weekly half-day HCV outreach clinic located at the D&A service and staffed by a hospital-based viral hepatitis nurse. Service users are able to contact the nurse coordinating HCV treatment by telephone if care is needed in between clinics.

### ***The hospital-based viral hepatitis service***

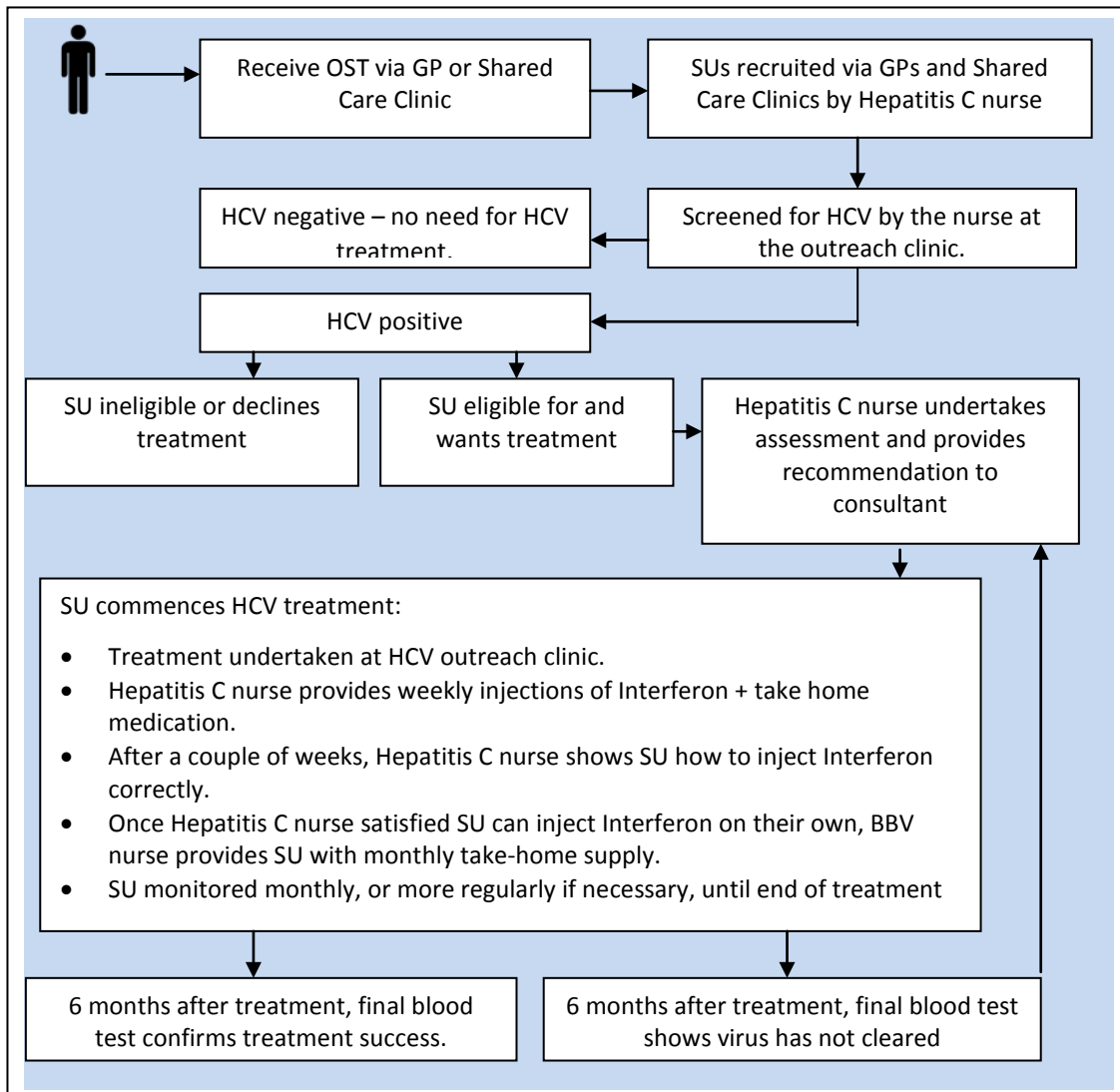
The viral hepatitis service provides treatment for viral hepatitis B and C patients as well as those co-infected with hepatitis D virus (HDV) and HIV. The service is led by a manager, a Physical Health Harm Reduction (PHHR) nurse and a viral hepatitis nurse with overall responsibility held by a consultant hepatologist.

### ***The community-based drug and alcohol service***

The community-based D&A service provides assessment, treatment and advice for adults with drug and/or alcohol related problems living in the local area. The D&A service where site B is located is part of a newly-formed local consortium providing shared care to people with D&A problems. The consortium includes a number of local specialist D&A services as well as many GPs in the area. New clients are triaged, stabilised and assessed for 12 weeks before being designated to either their GP or a specialist site where they will receive their on-going care. All the service users managed under this shared-care system are eligible for consideration for all the services provided by the consortium, including HCV treatment provided at site B.



**Figure 3.3** Services working together to provide HCV treatment at site B



**Figure 3.4** Site B service user's HCV treatment pathway

	Site A	Site B
Location	London, United Kingdom	London, United Kingdom
Commencement of service	2005	2011
Stage of implementation	Established service	Pilot phase service – planned for one year
Availability	Monday – Friday, 9-5	Thursday morning clinic only
Partnerships	<ul style="list-style-type: none"> <li>• hospital hepatology service</li> <li>• specialist D&amp;A service</li> <li>• BBV service providing harm reduction to D&amp;A service users</li> </ul>	<ul style="list-style-type: none"> <li>• hospital viral hepatitis service</li> <li>• community D&amp;A service</li> </ul>
Referral and appointments for HCV treatment	<ul style="list-style-type: none"> <li>• D&amp;A key workers</li> <li>• other D&amp;A and medical services</li> </ul>	<ul style="list-style-type: none"> <li>• D&amp;A key workers at site B</li> <li>• D&amp;A key workers at other sites</li> <li>• Shared care GPs</li> <li>• Local BBV team</li> </ul>
Delivery of HCV outreach service	<ul style="list-style-type: none"> <li>• Coordination and treatment provided by BBV nurse-prescriber located at site A full-time</li> <li>• Eligibility decisions made jointly with hepatology consultant at monthly clinics, with input from D&amp;A key workers and psychiatric lead</li> </ul>	<ul style="list-style-type: none"> <li>• Nurse coordinating HCV treatment based at site B full-time</li> <li>• Treatment provided by hospital based hepatitis nurse at a weekly clinic</li> <li>• Eligibility decisions made by both nurses in consultation with hepatology consultant at hospital, and input from GP or psychiatric lead where deemed necessary.</li> </ul>
Context of HCV treatment	<ul style="list-style-type: none"> <li>• HCV treatment provided alongside other relevant harm reduction interventions including BBV, sexual health and pregnancy testing, safer injecting advice, and wound care.</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment comprises a weekly half-day HCV outreach clinic located at the D&amp;A service and staffed by a hospital-based viral hepatitis nurse.</li> </ul>

	Site A	Site B
D&A service	<ul style="list-style-type: none"> <li>• Multidisciplinary team</li> <li>• Team includes one consultant psychiatrist and two other doctors</li> <li>• All key workers are nurses</li> </ul>	<ul style="list-style-type: none"> <li>• The D&amp;A service is the main service for SUs in the local area.</li> <li>• Shared care (between D&amp;A service and GPs) is managed here.</li> </ul>
Focus of D&A service	<ul style="list-style-type: none"> <li>• Medically orientated – provision of acute mental health care</li> </ul>	<ul style="list-style-type: none"> <li>• Mental health / social care orientated</li> </ul>
After care provision	<ul style="list-style-type: none"> <li>• Blood test at 6 months to see if virus has cleared; If yes, no further action, if no, then depending on treatment options, re-treatment or continued monitoring of liver</li> </ul>	<ul style="list-style-type: none"> <li>• Blood test at 6 months to see if virus has cleared; If yes, no further action, if no, then depending on treatment options, re-treatment or continued monitoring of liver</li> </ul>
(Types of clients served by partnership)	<ul style="list-style-type: none"> <li>• SUs with alcohol or drug dependence and multiple co-morbidities (i.e. mental and/or physical health)</li> <li>• SUs may be homeless or in unstable accommodation</li> <li>• Known for treating the most marginalized of D&amp;A users (“We will treat anything that walks”)</li> </ul>	<ul style="list-style-type: none"> <li>• Service works with service users with a range of drug &amp; alcohol problems</li> <li>• More stable service users transferred to GP shared care from specialist service, under shared-care agreement. Still eligible for HCV treatment at site B.</li> </ul>
Provision of care between appointments	<ul style="list-style-type: none"> <li>• Yes, can telephone for an appointment at short notice or drop in to see the BBV nurse throughout the week</li> </ul>	<ul style="list-style-type: none"> <li>• Yes, can telephone nurse if care is needed in between clinics</li> </ul>
Eligibility / referral criteria	<ul style="list-style-type: none"> <li>• Flexible approach</li> <li>• No rigid restrictions on eligibility</li> <li>• Stability is the primary criterion</li> <li>• Stability is primarily assessed on a case-by-case basis.</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Initially, a conservative approach:</li> <li>• Consume less than 40 units of alcohol a week</li> <li>• Stable injecting drug use (i.e. a couple of times a week)</li> <li>• Ideally, no injecting of crack cocaine</li> <li>• Service user agrees to regularly attend appointments</li> </ul>

	Site A	Site B
		<ul style="list-style-type: none"> <li>• Stable home life with a refrigerator</li> <li>• Stable from a psychological perspective</li> <li>• Agree to enter in to a needle and syringe program</li> <li>• Service users who do not meet the criteria are assessed on a case by case basis.</li> </ul>
Adjunct prescribing of medication	<ul style="list-style-type: none"> <li>• BBV nurse can prescribe medications for many physical side effects;</li> <li>• Medications for depression can be prescribed by psychiatric staff or GP, depending on who is most appropriate.</li> </ul>	<ul style="list-style-type: none"> <li>• Nurses send SUs to a GP for any adjunct medications</li> </ul>
Organizational structure/links	<ul style="list-style-type: none"> <li>• BBV team main office located in same building as specialist D&amp;A service. BBV nurse work remotely at services in the community.</li> </ul>	<ul style="list-style-type: none"> <li>• The HCV clinic is held at site B, where the nurse coordinating the HCV treatment is permanently based.</li> </ul>
Funding for HCV outreach service	<ul style="list-style-type: none"> <li>• Managed within existing funding arrangements for BBV team and for hepatology.</li> </ul>	<ul style="list-style-type: none"> <li>• One full-time nurse funded by a pharmaceutical company for one year to facilitate the setting up of the service and to generate referrals.</li> </ul>

**Table 3.1** Comparison of HCV outreach services at site A and site B

## 4. Methods

This qualitative case study explored the barriers and facilitators to HCV treatment access for PWID. The study – undertaken in 2011 – involved qualitative in-depth interviews with purposively sampled service users and service providers at two different London institutional partnerships.

### Site selection

The two study sites are very different partnerships and are at different stages of their implementation and service delivery. The sites (described in the previous chapter) were selected for the qualitative case study for several reasons. We focused on London sites, given the consistently moderate to high HCV prevalence among PWID in London [6]. We decided to focus on two London sites where organizational partnerships were (a) already established (site A – a community-based partnership seen as a model for ‘best practice’ for HCV treatment delivery and support for PWID) and (b) about to pilot a HCV outreach programme (site B – a nascent partnership).

### Participant inclusion and exclusion criteria

Service user participants were eligible to participate in the study if they had a history of having HCV and a history of illicit drug injecting. We were seeking to include PWID with no experience, recent experience and established experience of HCV treatment. Service users – who were in HCV treatment at the time of the study or had gone through HCV treatment and had cleared the virus – were eligible to participate. We were interested in exploring the experiences of individuals who had a recent history of drug injecting as they are commonly excluded from HCV treatment, because of concerns around treatment adherence and/or HCV re-infection [42, 43]. Those who were engaged in opiate substitution therapy (OST), such as methadone maintenance, were also eligible to participate.

Service providers were considered eligible to participate in the study if they had some direct involvement in the delivery of HCV outreach services at each of the study sites. We were interested in interviewing a range of staff, including consultant hepatologists, consultant psychiatrists, nurses, administrative workers and pharmaceutical representatives.

### Recruitment of participants

The initial aim was to purposively sample 30 HCV positive PWID with no experience, recent experience and established experience of HCV treatment (referred to in this report as the service users) and 12 HCV treatment providers and stakeholders such as representatives of hepatology, clinics, procurement and treatment advocacy (referred to in this report as the service providers).

Service user participants meeting the study eligibility criteria (see above) were referred to the research team through the collaborating D&A and HCV treatment service sites. At each site, a member of staff involved in the delivery of the HCV outreach service acted as the key point of contact between the service users and the interviewer. This contact person’s role differed slightly between the sites. At site A, they selected, approached and recruited all service users. At site B, the contact person gave the interviewer each potential service user’s telephone number and with service users’ consent, the interviewer contacted them and arranged the interview by telephone.

Potential service user participants were provided with a participant information sheet by a hepatology nurse, a case worker at the D&A service, or a by a service user network contact. This study information sheet contained a variety of researcher contact details enabling clients to express interest in participating.

Service providers meeting the study eligibility criteria (see above) were identified by the research team and contacted directly (by telephone or email) and asked if they wished to participate in the study.

## **Ethical procedures**

Ethical approval was obtained from the London School of Hygiene and Tropical Medicine (LSHTM) and National Health Services (NHS) Regional Ethics committees. All participants received written information sheets and the interviewer provided a verbal summary of the information sheet before each of the interviews commenced. Service user participants were provided with participant information sheets which clearly explained that their decision to participate would not impact on their treatment in any way. Service users were reimbursed £20 for their time and expenses in attending the interview. Interviews commenced after informed consent was obtained from service users and service providers. All participants were provided with pseudonyms for the purpose of this and other publications. Any quoted extracts from the in-depth interviews avoids identification of individuals.

## **Data collection**

Data collection comprised qualitative in-depth interviews with service users and service providers. The generation of data was facilitated by an interview topic guide and was designed to explore participants' accounts of their experiences. In addition, a brief questionnaire was completed by service users prior to the interview to gather demographic, drug history and HCV information. Interviews with service users took place in private consultation rooms at the participating D&A or hepatology services or at other private and convenient locations. Interviews with service providers took place in their workplaces or in a suitable place of their choosing. Field notes recorded interview dynamics and reflections on interview accounts. The main topics covered in each of the in-depth interviews were as follows:

- Interviews with service users: HCV and substance use background; HCV testing and diagnosis; referral to specialist HCV services; treatment access, experience and engagement; service evaluation and improvement, and future expectations.
- Interviews with specialist service providers: role and background to the HCV outreach service at their site, referral procedures to the outreach service, HCV testing and treatment procedures, D&A treatment, and service evaluation and improvements.

Following participant consent, all interviews were digitally recorded using voice recorders. Interview duration was from 35 to 170 minutes although most interviews lasted between 60 to 90 minutes. Interviews were undertaken by AM.

## **Sample size**

The initial intention was to recruit a purposive sample of 30 service users and 12 service providers evenly across the sites (that is, 15 service users and 6 service providers from each site). The final sample comprised 49 participants: 35 service users (17 from site A and 18 from site B) and 14 service providers (7 from site A and 7 from site B). The larger sample size was chosen in order to obtain a wider range of service user and provider perspectives.



## **Analysis of data**

All in-depth interviews were transcribed verbatim. The interview transcripts were checked for accuracy against the digital recording, with identifying information (of people or places) removed or recoded to pseudonyms. We undertook two stages of coding informed by grounded theory principles [44]. The first stage of coding drew upon a combination of a priori themes reflected in the interview topic guide and inductive or in vivo codes. These were then re-analysed in the second stage to develop concept driven categories. We coded initially for emerging core descriptive content, with coding further refined in an iterative process of data coding, charting and interpretation. We coded the transcripts as we collected the data to inform the direction of subsequent interviews, coding and case selection. We used NVivo 8 Software to code and analyse the data [45].

## 5. The service users and the service providers

This section briefly describes the 35 service users and 14 service providers who participated in the study. The demographic information was collected from the service users at the commencement of each interview, with further detail about their drug injecting history and HCV treatment status gleaned from the interview transcripts.

### The service users

Of the 35 service users we interviewed, 17 were recruited from site A and 18 from site B. Table 5.1, below, shows the demographic information of the service user participants per study site. Overall 6 women were recruited (17%), three from each site. The median age was 44 years, the youngest was 26 years old and the oldest 60 years old. Around half the participants identified themselves as White British, 40% as White Other, 6% as Black British and one participant (3%) identified as mixed race British. Overall, nearly 70% of the service users reported living in independent or supported housing – this varies slightly by site, with about 60% in site A and 80% in site B reporting living in such housing. Three participants at site A (18%) and one at site B (6%) reported living in a hostel, and a further two at site A (12%) and three at site B (17%) reported living in unstable housing – that is staying with friends or in temporary housing. Finally, two participants in site A (12%) and none in site B reported being street homeless at the time of the interview. Overall, three (9%) of participants were employed full time, four were receiving Job Seekers Allowance of Income Support, 27 (77%) were receiving incapacity benefit, and one participant (3%) was a pensioner.

	Site A (n = 17) n (%)	Site B (n = 18) n (%)	Total (n = 35) n (%)
<b>Gender</b>			
Male	14 (82.4%)	15 (83.3%)	29 (82.9%)
Female	3 (17.6%)	3 (16.7%)	6 (17.1%)
<b>Age (years)</b>			
Mean; median	43.1; 44.5	45.0; 44.0	45.3; 44.0
Minimum - maximum	31 - 60	26 - 60	26 - 60
<b>Ethnicity</b>			
White British	8 (47.1%)	10 (55.6%)	18 (51.4%)
White Other	7 (41.2%)	7 (38.9%)	14 (40.0%)
Black British	1 (5.9%)	1 (5.6%)	2 (5.7%)
Mixed race British	1 (5.9%)	0 (0.0%)	1 (2.9%)
<b>Housing</b>			
Independent or supported housing	10 (58.8%)	14 (77.8%)	24 (68.6%)
Hostel	3 (17.6%)	1 (5.6%)	4 (11.4%)
Unstable housing	2 (11.8%)	3 (16.7%)	5 (14.3%)
Street homeless	2 (11.8%)	0 (0.0%)	2 (5.7%)
<b>Income</b>			
Full time employed	1 (5.9%)	2 (11.1%)	3 (8.6%)
Job Seeker's Allowance or income support	2 (11.8%)	2 (11.1%)	4 (11.4%)

	Site A (n = 17)	Site B (n = 18)	Total (n = 35)
Incapacity benefit	14 (82.4%)	13 (72.2%)	27 (77.1%)
Pensioner	0 (0.0%)	1 (5.6%)	1 (2.9%)

**Table 5.1** Demographic information of service user participants

Thirty-two of the service users were currently engaged in opiate substitution therapy (OST). The remaining three were not currently engaged in OST, but had been in the past. Six participants from site A and two from site B were currently injecting illicit drugs (distinct from injecting licit drugs as part of a treatment program). The eight participants currently injecting drugs were all male and currently engaged in OST. Two were currently injecting heroin only, two were injecting heroin and crack cocaine, one was injecting both heroin and heroin and crack cocaine with the remaining three injecting a combination of substances (see Table 4.2)

Eleven of the service users had no experience of treatment, of whom five were contemplating whether or not to have treatment and six were waiting to start treatment. Seven service users were currently receiving treatment, of whom only one had previous treatment experience, having interrupted a previous course. Four further participants had previously interrupted treatment, one was contemplating retreatment and the other three were waiting to start retreatment. The remaining 13 participants had all completed the treatment: ten were successful or waiting for the final results and three were waiting for retreatment, the first experience not having been successful.

	Site A (n = 17)	Site B (n = 18)	Total (n = 35)
	n (%)	n (%)	n (%)
Illicit drug injecting status			
Currently injecting	6 (35.3%)	2 (11.1%)	8 (22.9%)
Stopped injecting	11 (64.7%)	16 (88.9%)	27 (77.1%)
Illicit drugs currently injecting			
Heroin	1 (16.7%)	1 (50%)	2 (25%)
Heroin and crack cocaine in any combination	4 (66.7%)	1 (50%)	5 (62.5%)
Heroin, crack cocaine and meth/amphetamine	1 (16.7%)	0 (0.0%)	1 (12.5%)
Currently in OST			
Yes	17 (100.0%)	15 (83.3%)	32 (91.4%)
No	0 (0.0%)	3 (16.7%)	3 (8.6%)
Experience of HCV treatment prior to at this service			
Yes	4 (23.5%)	2 (11.1%)	6 (17.1%)
No	13 (76.5%)	16 (88.9%)	29 (82.9%)
HCV treatment status			
Contemplating	3 (17.6%)	2 (11.1%)	5 (14.3%)
Waiting	1 (5.9%)	5 (27.7%)	6 (17.1%)
Current	1 (5.9%)	5 (27.7%)	6 (17.1%)
Completed (successful or awaiting results)	6 (35.3%)	4 (22.2%)	10 (28.6%)
Completed (failed and waiting to retreat)	1 (5.9%)	2 (11.1%)	3 (8.6%)
Interrupted (contemplating retreatment)	1 (5.9%)	0 (0.0%)	1 (2.9%)
Interrupted (waiting to retreat)	3 (17.6%)	0 (0.0%)	3 (8.6%)
Interrupted and now current	1 (5.9%)	0 (0.0%)	1 (2.9%)

**Table 5.2** Illicit drug and treatment history information of service user participants

## The service providers

Seven service providers were recruited from each site. At site A interviewees included a consultant hepatologist, a consultant psychiatrist, three members of the BBV nurse-led team including the team leader, a D&A nurse key worker (team leader) and the administrator for the D&A team. At site B interviewees included a consultant hepatologist, a D&A nurse key worker (team leader), two hospital-based hepatology nurses including the team leader, one BBV nurse, a nurse coordinating HCV treatment and a representative of the pharmaceutical company involved in financing the pilot collaboration (see Table 5.3).

	Site A (n = 7)	Site B (n = 7)	Total (n = 14)
<b>Roles</b>			
Consultant hepatologist	1	1	2
Consultant psychiatrist	1	0	1
D&A nurse key worker (team leader)	1	1	2
BBV nurse	3	1	4
Hospital-based hepatitis nurse	0	2	2
Nurse coordinating HCV treatment	0	1	1
Administrator	1	0	1
Pharmaceutical company representative	0	1	1

**Table 5.3** Roles of service provider participants

## 6. Social structural factors

Evidence emphasises that HCV infection and its treatment is situated alongside a hierarchy of competing everyday concerns experienced by PWID, many of which appear more pressing or important. This can especially be the case regarding concerns brought about by structural deficits, such as problems with housing, income, employment and law. Across participant accounts, we identified multiple social and structural factors linked to HCV treatment access and completion, including social stigma, inadequate housing, insufficient social and welfare support, gender, ethnicity and language, and criminalization. Our aim in this section is to provide a thematic description of these social and structural factors, which potentially provide important targets for social and structural change.

### Stigma

Stigma and social marginalization are evidenced in the literature as having deleterious effects upon the health and wellbeing of people living with HCV [46] and operate as barriers to accessing HCV testing and treatment [37, 47, 48]. The majority of participants in our study described HCV as a stigmatised condition, primarily due to its association with injecting drug use: “hep C, it’s much more of a stigma about injecting and being an injecting drug user and therefore, it’s dirty, you know, you’ve got it yourself, you’ve gone out and got it” (Tommy, site A); and to a lesser extent – HIV: “It’s got a stigma attached to like the family of diseases, hepatitis, AIDS” (Jeff, site A). Misinformation in regard to modes of transmission was another frequently mentioned source of stigma:

*Lots of people, they don’t know anything about hep C... You have people saying ‘oh bloody hell, what, you have hep C, I’ve just shared a glass with you, I’m going to have hep C’.*  
(Stefan, site A)

A number of participants experienced HCV stigma in the form of prejudicial treatment from medical providers. Shane and Gary describe their experiences of dental treatment access:

*I don’t really go round telling people I’ve got hep C ... Its caused problems when I’ve gone to the dentist. She wouldn’t treat me. She said ‘come back when you get treatment’.* (Shane, site B)

*“The receptionist was talking to the dentist, ‘he’s a dirty case’.... That’s how she categorised it, a dirty case... yeah, ‘we’ve got Mr. G, a dirty case, hepatitis C.’* (Gary, site A)

Experiences such as these affected participants’ motivation to attend unfamiliar medical services and could create anxiety about HCV disclosure:

*Everywhere I was going into they said have you got any illnesses and I would say yeah, hepatitis C. Straightaway. But it was getting to the stage where I’d go in and people with forms about illnesses and should I put down hepatitis C? Because I really from that one dentist, that one dentist I saw really put me on edge.”* (Gary, site A)

Discriminatory experiences often had a negative impact on self esteem and confidence, which in turn impacted on participants’ motivation and feelings of deservedness in regard to treatment access. Davey’s experience is illustrative:

*As soon as I told the consultant what drugs, what medication I was on he was like, 'Ooh'. He sort of like recoiled a bit.*

This perceived reaction was described by Davey as impacting on his feelings about HCV treatment entitlement and on his ability to ask for his needs to be met:

*[I am] much less vocal, yeah. Because I just feel like I'm lucky to be getting it [HCV treatment] I think....Yeah, damn lucky that someone is willing to treat us, do you know what I mean? . ... There's a personal judgment on you. And, like I say that consultant proved it at the time ... that judgment's still going on. (Davey, site B)*

Anxiety about being judged meant that some participants, like Davey above, found it difficult to verbalise their concerns and support needs in regard to HCV treatment. At times this anxiety could result in participants missing appointments or acting inappropriately – thus perpetuating stereotypes of PWID as ill-mannered and unreliable. Kaveh, an Italian immigrant, explains:

*I don't think it's a language barrier. I think it's more a question of what I am perceived to be. It's not because I'm homeless ... It's nothing, the mechanism to talk. Sometimes it's very difficult to go through, immediate preconception, 'You come from there. You come from the drug clinic.'... It works both with me and against me because at the same time being aware I try to prepare what to say before, to be clear. But, at the same time, makes me so nervous that when I'm here I do really stupid things. (Kaveh, site A)*

Being strategic about disclosure was one way that participants managed the stigma associated with HCV, by only telling select people that they had the virus:

*Yeah, there is a bit of stigma but I don't really go around telling people that I've got hep C. All my family know, that's the only people that need to know is my family, and a few of my friends know, and that's it. (Gary, site A)*

For participants who did not wish to disclose to family or friends, due to perceived stigma, options for support during the treatment regime were limited: "I have got this and I weren't freely to say it to people ... it's just scary to some people" (Jeff, site A). For some, the stigma associated with the virus was a primary motivator to enter into HCV treatment – overriding health concerns:

*Don't think very much will change there really [physically], in that sense. So I don't think it [HCV treatment] will do that, no. But I just want to be clean, you know what I mean? Just get rid of it ... There's a stigma on you isn't it sort of thing as well, so just want to get rid of it. (Trish, site A)*

Service providers interviewed for this study were aware of the barriers that prior experiences of stigma and discrimination could cause for PWID in accessing HCV treatment and care. Providers stressed the vital role of creating a friendly non-judgemental atmosphere in their services and of building trust with service users prior to treatment commencement:

*A lot of it is personal interaction, if you can bond with the individual, if you can make it clear that actually, you want to help them, you want to support them, and in they're in an environment where there are people they trust. So you're not coming to see some strange consultant in a strange environment, you're on home turf with nursing staff who've looked after you for years, who you've got some degree of trust with. (Hepatologist, site A)*

The majority of participants' experienced HCV treatment outreach provision at the D&A services positively, in particular favouring certain providers who they knew to be non-judgemental and friendly:

*I mean there was none of this, 'Well, that will teach you to fuck with needles.' There was nothing like that, you know. I can imagine you get some like that though. I'm sure there are. But no, there ought to be more like her ...I wouldn't have gone to that [service] if it hadn't been for her, so that's something in itself. (Eric, site A)*

Some providers acted to mitigate experiences of stigma by providing practical supports, such as relocating medication provision. Frank, for example, describes how he is able to collect his HCV treatment medication from the drug and alcohol service, preventing a potential 'outing' at his local pharmacy:

*She'd [nurse] give me 120 tablets. She used to get them all over here and she'd bring them over by herself ... It was better for me that she did it all... Because then I'm not going to meet anybody in the chemist, they're not going to see what I'm getting and all that. I was really paranoid about somebody finding out that I was sick from that [HCV], I didn't want anybody to find out that I was sick. I call it the bug; I didn't want anybody to find out. It was very important to me. (Frank, site A)*

#### **Findings:**

- Felt and experienced HCV stigma impacted on participants' decisions regarding HCV disclosure, health care access and HCV treatment uptake.
- Non-disclosure of HCV incapacitates opportunities for social support, including in relation to accessing treatment.
- The service partnerships acted to mitigate stigma and encourage HCV treatment access by building trusting relationships and providing practical supports.

#### **Recommendations:**

- Provider cognisance of the stigma PWID face in regard to HCV, and steps to work against this in the treatment environment, is vital for encouraging HCV treatment access and uptake.
- Attention to the individual needs of service users enables innovative and personalized stigma reducing interventions – such as the relocation of medication dispensing.
- There is a concomitant need to increase HCV literacy among the partners and families of affected individuals to create an enabling and socially supportive environment for care.

## **Housing**

Scant research exists on the influence of accommodation circumstances on HCV treatment uptake. There is a clear association between homelessness and HCV antibody positivity in the United Kingdom [49], and a majority of the participants interviewed for this study were homeless or living in unstable housing, such as hostels. Homeless PWID tend to have high support needs, yet may face additional barriers when trying to access services [50, 51]. Not having an address can, for example, pose problems when registering for income support or with a general practitioner, which can impact on treatment access and self care more generally. HCV treatment providers generally consider

homelessness or unstable housing to be a signifier for unmanageability and a contraindication for treatment consideration [52]. Yet, notable exceptions exist, in particular site A:

*We've treated street homeless people. We've one chap who lives in a skip who we deliver his drugs to ... So we have treated street homeless but most homeless people in East London have some hostel accommodation of some sort and some tentative access to services. So I think there are worse boroughs to be homeless in. (Hepatologist, site A)*

Participants overwhelmingly spoke of unstable accommodation as a barrier to HCV treatment uptake, yet perceptions of stability differed, with some participants happy to commence treatment in hostel accommodation, whereas others found that the hostel environment was not conducive to an ideal treatment experience:

*I'm stuck exactly in that vicinity, within a hostel that is rife with drugs and drugs around the area ... Since I've been on the [HCV] treatment, there are times when people – I haven't touched anything or whatever and then all of a sudden, I'll be in my room at night and someone will knock on my door ... Before I know it, they're giving me something and I've put it to my lips, you know. (Neil, site A)*

While reducing or ceasing injecting drug use was not a treatment requirement for either of the services studied, a number of participants mentioned the hostel environment as a barrier in this regard. This indicates that for some, a readiness to undergo HCV treatment coincided, followed or precipitated a desire to 'clean oneself up' more generally. Philip's movement out of the hostel system, while on HCV treatment, is indicative of this desire. He started HCV treatment in a hostel, describing this as 'difficult':

*I was on the drugs free unit and there was people using drugs around me. ... Even on the drug free unit, there was a lot of drugs in there. I was trying to keep myself away from it.*

Half way through treatment he was given his own place, which he speaks of with pride and pleasure:

*I got a grant; I managed to get some furniture and that. I've done a lot since then with it. I've got this lovely place now ... It was very important [getting my own place]. I mean I've been homeless for seven years.*

The move to his own home, and the stability and privacy this afforded Philip also enabled him to cease his problematic drug use, something he was unable to accomplish in the hostel environment:

*I just stopped injecting ... [by] not associating with people that were using anymore and keeping away from them. (Philip, site A)*

Other participants appreciated the supportive structure the hostel provided, especially when provided within a framework of integrated care:

*But still, I'm not on my own because I live in a hostel with loads of staff and even nurses and they know what kind of treatment I'm going through and they're advised to go and knock on my door, once or twice a day, sometimes the night even, to see if I'm okay, if I need anything. Yeah, that was very important I think, to them, when they suggested the treatment to me because this kind of treatment can lead you to depression, and that's very important. I learned not to be on your own, like having somebody who will check up on you. That's why this treatment for me now I guess is only possible because I live in a hostel ... When I started it, [HCV treatment nurse] asked for my permission first, she phoned my key worker at the hostel and she was informed of what I was doing and what she should do, I guess, like she*



*was to check up on me. ...they have a special phone number to the X Hospital, in case I feel ill, they shall phone number. Yeah, they know what to do if I'm not well. (Hugo, site B)*

Assistance from key workers and other service providers in securing accommodation was vital for a number of the participants, many of whom had experienced difficulties navigating complex and bureaucratic housing support pathways:

*[I] got a decent key worker who knew my housing situation and that and they managed to get me into a B&B and then from there, I got a flat. (Dillon, site B)*

A nurse specialist from site A describes this process:

*We've had incidences of where people have been on Hep C treatment and there's been concerns of threats of eviction, so again it's liaising with the housing worker just to say look, this person is on this treatment, it's really important that they have stable accommodation, it's important things like having a fridge to be able to store their interferon, things like that. Can we try and work out some way in which the person isn't evicted? And again if we're working with people who are homeless we can do letters of support just to say we're working towards this person undergoing hepatitis C treatment, and just the same issues again, please can this be taken into consideration that they need stable housing, x, y, z to be able to manage the treatment, potential side effects, whilst they're on treatment. (Nurse specialist, site A)*

The intervention of medical providers to help obtain accommodation was not always successful. Here Bibi speaks of the failure of a medical letter to help her homeless partner, Kaveh, secure accommodation. Bibi occasionally lets Kaveh stay, but is unable to on any long term basis as she fears her benefits will be cut. This instability is a barrier to Kaveh's treatment uptake – deemed vital by his medical provider as Kaveh has cirrhosis of the liver:

*I went with him [Kaveh] to the Homeless United with the letter off the consultant saying he has an urgency to start the treatment for hepatitis C. They read the two letters and said you're not sick enough, we don't reckon that you need the house, you lost your house through your own fault, you are ill through your own fault, now pay the consequences. (Bibi, site A)*

Kaveh says of this experience: "That really, really put me down psychologically. I don't even look no more. I just live like that [street homeless]". He – as well as his medical provider – is caught in a dilemma between his urgent need to undergo HCV treatment and the difficulties this treatment would pose in his current homeless situation:

*I don't know what to do. At the same time I want to take care of my health, and at the same time I also need, if I take care of my health I haven't got a place to stay. [If] I have interferon, from what I know is very debilitating ... I don't see myself on the street with the heavy treatment, being debilitated all the time. Where to go? I travel from bench to bench. (Kaveh, site A)*

While Kaveh was adamant that he did not want to commence HCV treatment while homeless, some providers spoke of the need encourage treatment uptake while accommodating these difficulties:

*Well they're always their priorities but a lot of our patients, their life will always be some major thing going on like that. So that will not change for them, they'll always be homeless or in a hostel or whatever. You can't wait until they're more stable, this may never happen, we've got to work with that.... We actually had a patient who was living in a storage*

*container through the winter who we treated. He had no money, he hadn't sorted his benefits out, he's sorted them out now, he had no ID. But he used to walk into the clinic every week to get his treatment and I found a sleeping bag that I'd got at home that I didn't want anymore. We were a bit worried about him when he was in the container over the winter period, and he did treatment and it worked. (BBV team manager, site A)*

One strategy that the BBV team manager mentions to help those who are unstably housed is the provision of fridges for interferon storage. This issue also arose in participant narratives: “they give me one to keep the [interferon in], a little fridge, yeah” (Fabio, site A). Apart from being a practical solution to medication access and storage, the provision of fridges could enhance feelings of self worth for some participants, with this small investment of resources aiding their motivation to see the treatment through. Jake did not appear to have this option. He was in a room in a hostel for a year, where there was no provision for a fridge for him to store his interferon. As he says “it wouldn't have worked out”. After that year he was moved into his own flat within the hostel complex, which provided him access to the supports of the hostel, such as a key worker, as well as privacy and his own fridge. Here he was happy to start HCV treatment, stating that “for all intents and purposes, you're living on your own” (Jake, site A).

#### **Findings:**

- Unstable housing and homelessness do not preclude successful HCV treatment completion, but can be a significant barrier to treatment uptake.
- Tensions can exist between an individual's urgent medical need for HCV treatment and their reluctance to commence treatment due to unstable housing.

#### **Recommendations:**

- Some PWID may need dedicated accommodation assistance before HCV treatment is a possibility. Where possible, resources should be available to enable this.
- For people who feel ready to undertake HCV treatment in unstable accommodation practical supports such as fridges and bedding should be available.

## **Social support**

For many participants family members offered practical as well as emotional support during the treatment regime. Bibi, co-infected with HIV and HCV, experiences debilitating fatigue and panic attacks which can render her housebound. Her daughter and partner provide much needed supports: “[My daughter] goes shopping for me once a week, the big weekly shop. My boyfriend does the everyday tasks for me”. For the past year Bibi's daughter has also accompanied her to all of her medical appointments, and helped her research HCV treatment after she was encouraged to consider it by her medical practitioner. At the time of the interview Bibi was ‘postponing’ her HCV treatment decision.

For participants undergoing treatment, the interferon and ribavirin side effects meant that day to day tasks were more difficult: “You're tired all the time. You're mentally tired, you're physically tired” (Jeff, site A). Jeff negotiated this fatigue by doing all his food shopping once a week and enlisting his father to drive him to the supermarket. Nat lived with his brother during his treatment. At the beginning of treatment Nat's brother would take each Friday off to accompany him to his medical appointments and provided the day to day practical supports:

*[My brother] brought the money in, he went shopping.... Anything I needed him to do, he would do....he would cook, yeah, not very good but he was alright ... and made sure the electricity was always on, the gas. (Nat, site B)*

Peter, whose family lived in a different location, received emotional support from frequent phone calls:

*[my mother] would ring up virtually every day or every other day, just to make sure I was okay, so that was helpful. ... Yeah and my sister, she lives down there as well. ....So they would ring up, not every day but two or three times a week each, so you get mum one day, sister the next day, [my ex] came round with some food. (Peter, site B)*

Others utilized additional supports such as neighbours or medical professionals:

*I will have my phone, I'll call [HCV treatment nurse] or [Viral Hepatitis Nurse], like they told me if you need anything you pick up the phone and we talk, and I've got a couple of neighbours I really can trust them. I'm gonna tell them, I want a leaflet to give them really, that's what I'm going to do, 'and if you don't see me for one or two days, here's my keys, knock the door and see if I'm alive or everything's alright'. (Kyle, site B)*

Some participants negotiated their treatment journey without additional social supports, often due to a stigma-related reluctance to disclose and/or privacy and self sufficiency preferences:

*I did everything by myself. I don't know if that has implications, I don't know. But it's [HCV] always something I kept by myself..... I just spoke with one person about these things; outside of you professionals....I prefer to keep everything to myself. (Mario, site B)*

For Hakki family support felt like a burden while he was on treatment. He was living with his mother during this time and states:

*I've got family support. .... It makes it even worse really because it makes it harder. You feel like it's all like you ain't just bringing yourself down, you're bringing that ship down with you. It's like you're hurting other people as well. I prefer to be on my own. (Hakki, site A)*

Support from service providers during the treatment regime was spoken of as important, especially for participants who had few other social supports:

*She [HCV treatment nurse] is such a nice lady, she phoned me and texted me many times, almost every week to ask me how I am and if I need anything, to reassure me that they're always here. [It is] very important, to me it is very important. I like people contact, relationships, it's very important ... It is nice to know you have people who know what you're going through because they see this day in and day out and try to offer all kinds of support, especially me; I don't have my family around me. Yeah, to me, it's very important. (Hugo, site B)*

Other participants however, did not have such positive experiences; Tommy for example feels that there could have been better practical and emotional supports available during treatment:

*I mean there were definitely people in treatment who had no support at all ... who were living on their own.... Support isn't offered, there's no sort of, it's the medication and I had [nurses] phone number for emergencies but that was it ...Medical emergencies, feeling unwell or anything, that was basically it. (Tommy, site A)*

Tommy spoke of the need for help with practical issues such as housing, finances and organizing repairs, all issues he struggled with on treatment:

*I had some problems with the housing, with the rent. ... when things start to break down, like repairs and things like that and you're not feeling right and you can't – you can make a couple of phone calls but you just get really demotivated by the whole thing. If you start to get any issues, there's no support, it's like you're dealing with everything by yourself. You can mention it to the BBV nurse and they'll say 'well that's terrible, you shouldn't have to be doing that'. (Tommy, site A)*

Participants' offered suggestions for HCV treatment support improvements, such as information provision about HCV treatment side effects for family and friends, and regular social worker checks for isolated individuals:

*I think it would be a really good idea if there was some sort of social worker in the hospital who could check up. If you live on your own, like I do ... There should be a social worker or someone there who's not so much to do with the hospital, more to do with the other side; is this person eating okay, their general wellbeing, as opposed to the specifics of the liver and the hepatitis, how they're getting to and from the hospital, how are they managing at home.... Imagine last winter when the snow was coming in, imagine if someone, who's only on £60 a week, feeding that meter, you know, they wouldn't have managed. (Nat, site B)*

*I think it is about having maybe a bit more support would be better, if someone came round every now and then to see how I was, that I didn't have to go into a service to be seen. There's no sort of home visits, everything is about either phoning or going into [the service]. (Tommy, site A)*

### **Caring responsibilities**

Caring responsibilities – most often for a dependent partner or children – provided a challenge for participants undergoing treatment. At times this challenge could provide the incentive to stick with treatment, but invariably, it made the treatment experience more arduous. Social supports, in the form of help with child care and household duties such as cleaning and shopping, were seldom available for these participants – a lack of support which can provide a barrier to treatment uptake or completion.

Carol went through treatment with sole caring responsibilities for three children. Her partner was in jail, and her mother who used to provide support had recently died. She had no other social supports, and when asked could not remember if the nurse practitioner had asked her about her support system before she started treatment.

*You do feel really sick with it [HCV treatment], you really do... I had the three kids to look after and I was on my own.... my partner is in prison. So yeah, I had to do everything on my own ... I just had to do it, I had nobody else ... My mum died a couple of years ago. She did used to help but I had to do it, you know, even if I was ill. I mean I literally had to get up, take them to school ... I was exhausted. Another thing, when you're on the treatment, it makes you really tired, it really does make you tired. (Carol, site A)*

Frank lived with a partner who had chronic pain and substance dependency issues. He stated that her continued drug use made it difficult for him to stop using crack and heroin while he was on HCV treatment. Due to his partners debilitating chronic pain Frank took care of all the practical household tasks such as cooking, cleaning and shopping. Despite the difficulty of maintaining this during treatment he felt that the imperative to carry on and care for his partner as well as himself provided

him with some impetus to continue the treatment regime. Importantly, Frank states that if it was not for the moral support she gave him he would not have completed treatment:

*She used to say to me, you know, 'you've never ever given up on anything, you've started, I've never seen you give up on anything, if you don't do this now, you've got to finish'. [If it was not for her] I would have just walked the plank, I just would have given up and disappeared.... I thought I might as well go down to the undertakers now and buy a coffin ... that's how bad I felt. (Frank, site A)*

#### **Findings:**

- HCV treatment side effects impacted on participants' ability to carry out day to day tasks such as cooking, cleaning, shopping and getting to appointments.
- These difficulties were exacerbated for people who had additional caring responsibilities such as looking after dependent partners, parents or children.
- Some participants received practical and emotional support from family, partners and/or service providers, supports invaluable for helping them through the treatment regime.
- For participants without these relational supports, there appeared to be few other available supports – or if they were available, participants were unaware of how to access them.

#### **Recommendations**

- Before treatment commencement the individuals support resources and needs should be ascertained and provision made for additional supports where necessary.
- Ideally, people undergoing HCV treatment – especially those with caring responsibilities – should be able to access subsidised home help.
- Support and information about HCV treatment is also necessary for friends, family and carers of those undergoing HCV treatment.

## **Financial issues**

Financial concerns comprised a large part of participants' narratives, with many describing difficulties accessing what they felt to be appropriate benefits, particularly in the current political climate where eligibility for disability living allowance is increasingly restricted. The site A BBV team manager speaks of the impact these restrictions have on HCV testing and treatment uptake:

*Every time that happens, that their benefits are being reviewed, our requests for hep C tests and hep C treatment go up. I always have to say to them, hep C is not going to keep you on incapacity benefit and hep C treatments not going to do that either. 'Can you just write a letter for the benefits office about my hep C treatment?' 'Well you haven't even started it yet', so that's quite interesting. I don't care what motivates them to have treatment, you know, it won't get them any benefits but if they think that it will then, whatever. So I don't care if it motivates them. But yeah, that's quite interesting, when there's a clamp down. (BBV team manger, site A)*

The difficulties that some participants experienced with HCV treatment side effects, and the restrictions these imposed on their ability to carry out day to day tasks, meant that many felt they should be entitled to a disability allowance – at least for the duration of the treatment.

*I mean obviously it would be nice to have access to some sort of extra finances while you're going through that treatment so that you can get a cab, so you can buy slightly better food...there's no allowance made for that and the fact that you're constantly barfing, you're constantly washing your clothes, you're constantly changing your sheets and it all adds up. There's nothing being taken into account for that.... Some sort of help with support over that period, financially, because it is a period where you've got more output financially. You need cabs, you know, you can't walk everywhere when you're feeling like that and just feeling sick. (Tommy, site A)*

*Oh, there's one thing that really would have helped. I could not really go to the shop, there's something called disability living allowance ... I would have loved to have had that because then I could have afforded to get someone to deliver food to me. Not just that, maybe to have done a bit of help because I never cleaned, I never did any cleaning in the whole year, longer than a year. Literally, I used to pick up clumps of dust, I'd walk around and instead of hovering, you'd see a lump of dust, pick it up and put it in the bin, that's how it was....So it would have been nice to have had that bit of extra money to get someone in to do cleaning once a week or once a month and to be able to have your food delivered. It would have made my life easier. (Peter, site B)*

The majority of participants were, however, receiving incapacity benefits at the time of the study. This may be due to the high rate of co-morbidities present in this service user sample, but also because – for many – benefit reviews and restrictions were yet to take effect. The prospect of having benefits cut caused a considerable amount of anxiety for participants, with those who had experienced these cut backs speaking at length about the process:

*[I was on] ESA (Employment and Support Allowance)... Because of hepatitis C, drug addiction, depression ... Then they took it off me in January ... Because I went to one of the government assessments ... I was as honest as I could be with them, I didn't go there acting or thingy, I said 'look, there's a letter from the hospital saying that my treatment's starting next week, I have to be there three times a week for so much and it lasts a year'. ... I gave it to them and then they wrote back saying no and you have to appeal against it and go through the same thing again ... It was a downer because at the time as well, I was offered, the very same week, I was offered my first flat, a chance to move and then all of a sudden, I didn't have any benefits so I couldn't move into a place. (Neil, site A)*

Neil speaks of the letter he had from the hospital in support of his claim for a continued incapacity benefit. Notably this letter, stating that Neil was about to start HCV treatment, did not help Neil in having his benefit renewed. This is likely to be a result of increased restrictions on incapacity support allowances. As articulated by Tommy: “my own GP said you're going to have two legs amputated and your death certificate half completed before you get any DLA at the moment”. A number of participants had previously been supported by GPs and other service providers when applying for incapacity support allowances, often successfully. As Nat explains:

*Well I was on job seekers for a bit and then when I moved it was the doctor that was like 'you should be on income support'. So I made a claim for that and then went to see the social doctor and told him everything I was doing, the treatment and everything and they signed me off sick to do that for two and a half years ... it wasn't even the GP [who arranged it], it was [key worker] that said you should be income support, you shouldn't have to go and sign on while you're doing that treatment ... and that's when I went and made a claim for income support and got it.... Money wise, it's about an extra £50 every two weeks. ... It meant that I didn't go without electricity and food ... but I'm not sure, if I was applying now, I'd get the same, because we're a different government after all. (Nat, site B)*

As Nat articulates obtaining an incapacity benefit process is less straightforward in the current financial climate, potentially creating a Catch 22 situation for people undergoing HCV treatment trying to access benefits:

*I mean I can't understand the logic behind you've got to be on JSA (job seekers allowance), you would not be able to be on JSA and do that treatment, that would be stupid, you're not available for work are you. ... So basically, you'd have to lie to them, you'd have to not tell them you're on the treatment ... Because if you told them the truth, I'm on this treatment where I can't work, they'd sign you off. ... Because you're not available for work, you're not actively seeking, you've got to be actively seeking work, eight hours a day for five days, not just one day, not just a couple of hours a day but five days a week, eight hours, that is the criteria. So you wouldn't be allowed; that is horrible to think that people might not be able to do that treatment, just because of the benefit system, or you're going to have to pay for it yourself... support yourself I meant. (Nat, site B)*

This Catch 22 (whereby people on HCV treatment not entitled to a disability allowance have to go on the Jobseekers benefit – yet being on treatment precludes their ability to work – a fundamental requirement of the Jobseekers benefit) was experienced by others and was a barrier to treatment uptake for some:

*I booked the treatment on 13<sup>th</sup> October, I changed the [treatment] appointment because I couldn't go to the [JSA] interviews and things like that. There's no way, because I was on job seeker's allowance you had to be able to go to interviews and you have to go sign every two weeks, you have to go and get some jobs and there's no way you can do that when you're on the treatment. (Marta, site B)*

One participant brought a medical letter of support for a benefit review to his interview with the study researcher. Gary described how his hepatology nurse had encouraged him to appeal the cessation of his disability allowance benefit, and read out the letter she wrote:

*She gave me this letter here ... so it's got "G has been diagnosed with chronic hepatitis C and is under the joint care of Consultant Hepatologist, XX Hospital and the BBV team. In order to try and eradicate his hepatitis C, he commenced interferon and ribavirin treatment in February 2009. The duration of this treatment is 48 weeks, the treatment has adversely affected G's breathing and he has consequently been referred to Dr X at the London Chest Hospital, he is awaiting review. Other symptoms that are adversely affecting him are a reduction in haemoglobin that makes him lethargic, tired and breathless, flu like symptoms, fever chills, aches, pains, emotional issues, depression, anxiety, memory problems, neutropenia and dry itchy skin. I hope this information is helpful to you". (Gary, site A)*

Gary was not called in for an assessment and his appeal was declined. He says: "they just wrote me back a letter and said you can walk 40 yards, you can cook a meal, don't waste our time, more or less".

Participants' suggestions for improvements with their financial situation while on treatment included the use of tokens or vouchers, to enable them to obtain home help and transport to appointments.

*I don't think I cooked much at all, I was literally living on cheese sandwiches, if I ate. It would have been nice for someone to come round and cook a really nice meal, even if I just took a couple of spoonfuls ... So DLA, even if it's just for the time you're on the medication, I think that would be useful to anyone. It doesn't even have to be DLA, it could be tokens, like to get*

*people to come and do the hepatitis treatment. You could say if you do the hepatitis treatment, you'll also get your flat cleaned, you'll get someone who'll come and cook once a week or twice a week and you'll get someone to do your shopping for you. Just that, that would be a big help ... It doesn't have to be cash; it could be tokens to pay the cab so that it's not being abused, because you've got to be careful with some drug users. But some sort of help with cabs or getting to hospital, food, things like that. (Nat, site B)*

As Nat indicates, the potential availability of home and transport support for the treatment duration could act as an incentive for service users to consider treatment uptake, and may make the difference between treatment completion and non-completion for some.

#### **Findings:**

- The current financial climate negatively impacted on participants' ability to access Disability Support allowances while on treatment, even with the support of their medical providers.
- For some, this created a barrier to treatment uptake.

#### **Recommendations**

- Ideally people undergoing HCV treatment should be automatically entitled to disability support allowances for the duration of HCV treatment **OR**
- Be provided with vouchers or subsidised supports for nutritious food, transport costs and/or home help for the HCV treatment duration.

## **Gender**

Female PWID have been described as a medically underserved population [48] and some studies indicate that gender can significantly affect the acceptance of antiviral treatment, especially among PWID [53, 54]. Women are reported to experience stigma associated with injecting drug use and HCV more keenly than men [54], and the effects of stigma and social exclusion are often compounded in female drug users and PWID from ethnic minorities [37, 55, 56]. This has been, however, scant gendered analysis of the social structural factors that inform HCV treatment uptake and completion. The majority of participant samples in clinical and qualitative studies are over-represented by males, even when taking into account the larger proportion of men in injecting communities. This is also, unfortunately, the case in our study where only six of the 35 participants were women.

Male service users were over-represented at the two study sites, and providers spoke of the difficulty they had in engaging female PWID in treatment – even in a specialized women's service:

*In the women's service, they are really hard to engage, women with hep C, in particular. They're good for coming in for their STI screens and for the pregnancy screens ... They seek help for symptomatic things a lot sooner than men do but [not for HCV] ... I've no idea why the women don't want treatment. They don't say they don't want it, they just don't engage to do it, or they say they want it and then they never start. We definitely have less success with getting women onto treatment than men, I don't know why. (BBV team manager, site A)*



Reasons for this reticence to engage with HCV treatment could include caring demands (as we saw above for Carol) and/or the possible impact that HCV treatment may have on options for money generation. As the BBV team manager (site A) elaborates:

*Why women do drugs is often for very different reasons to why men do. Knowing all those sorts of things, and why women...if you've got a habit and you've got to sex work and you're losing weight because of your hep C treatment ... if you're starting to lose loads of weight and look like you've got HIV, that's not good for business. That is a concern for someone whose income is starting to drop because they can't sex work. So it's all those sorts of things that they might not tell someone who they didn't think would accept it in the right way.*

Providers at site A, in recognizing these issues, were in the process of running and creating programs specifically target marginalized groups of PWID, including female sex workers:

*There are a few initiatives underway ... There's a very good team that look after pimps and some very disadvantaged groups out in the community. And we're trying to set up... [site A Team Manager]'s got a group of prostitutes who are infected that we're trying to get access to treatment. (Hepatologist, site A)*

As Temple-Smith et al. [54] report, women can feel the stigma associated with HCV more acutely than men. For Trish this was her primary reason to enter into treatment, as she says: "I just want to be clean, you know what I mean? Just get rid of it" (Trish, site A). This felt stigma can impact on willingness to engage with services, particularly for women with children who fear the ramifications of being identified as a drug user. Carol, who went through treatment sole caring for three young children, spoke of her difficulties with social services post treatment:

*They actually put my children on child protection. They're going on like I beat them up. All it is, I had a drink problem, you know ... and they obviously know I've got hepatitis C. (Carol, site A)*

A desire to have children can also be an incentive to enter into treatment, particularly for young women: "we've had a few women, young women, who wanted the treatment because they wanted to get it cleared before they had children" (BBV team manager, site A). This is reflected in Ivana's narrative:

*I'm a woman and at a certain point, I'm going to have children and I just wanted to make myself clear [of HCV]. Of course, I'm going to have some problems because of all these years using the drugs but at least I'm going to be clear ... There's no point to have a child when that child is going to suffer afterwards. ... I have to stop [using drugs], I can't continue with it. I'm 26, almost 27. (Ivana, site B)*

For Ivana, and others, going through HCV treatment became synonymous with 'cleaning oneself up' more generally – including the reduction or cessation of problematic drug use. However for women (and men) who are entrenched in the drug using lifestyle other pressing priorities, such as income generation, may preclude treatment access. As the BBV team manager (site A) continues: "we've got a few older women who really, really need to get treatment and they're not doing it ... women are harder to get interested". While our data can point to some possible reasons why women may be reluctant to engage with HCV treatment services, more research is needed to unpack this important issue.

**Findings:**

- Female PWID appear to be more difficult to engage with HCV treatment than male PWID.
- Reasons for this may include: caring and income generation demands, stigma and fear of child removal.

**Recommendations:**

- More research is needed to explore the barriers and facilitators for HCV treatment access and completion for women, particularly female PWID
- Personalized interventions for women, including support with child care and social services, and specific initiatives targeting female sex workers may help treatment uptake among this population.

## Ethnicity and language

The two sites catered to PWID of a range of ethnicities. Immigrants of Italian, Portuguese, eastern European, Pakistani, Chinese and Vietnamese origin accessed services associated with site A, and site B saw immigrants primarily of Portuguese and eastern European origin. The English language ability of service users varied dependent on their length of time in the United Kingdom. As the BBV team manager, site A elaborates:

*Italian and Portuguese come here.... they've been here longer so they do speak English. Then eastern Europeans, half and half; some of them speak English, some of them don't, they're in N. Then we've got a fair few Vietnamese in H, again, not a lot of English at the moment, I think they're quite new so that gets difficult.*

The variability of service user English competency can pose challenges for service providers, especially in regard to treatment decision making discussions.

*It does make it difficult. But it's a fact of working in East London and most of us at any day have got a patient who we don't speak the same language as and we have to find a way of managing to give them a service, and the best that we can really, and do the best that we can. (BBV team manager, site A)*

Interpreters are used by site A to help provide this service, but they are not always at hand, if for example a patient drops in unexpectedly, and while interpreters are valuable they cannot always provide access to the nuances of expression and body language gained in interaction with someone from the same culture. The BBV team manager explains why this is important:

*But even through an interpreter, to ask those sorts of personal questions, you can say through an interpreter 'oh, is it you that wants the treatment or is it your partner that wants it?' Actually that's not translated in the same way as being able to say [this] to someone ...*

*it does make it a lot more formal and more difficult to unpick that. There's nothing we can do about that but you can't read the subtext the same ... You know if you speak the same language, you can tell when a person is saying one thing but means another thing, and the subtext. When you got through an interpreter, it's a lot harder. (BBV team manager, site A)*

The situation that the team manager is referring to is one where culture and gender intersect. She describes how the service sees a number of younger eastern European women who can't speak English. They are brought in, often unexpectedly, by their partners who may be the only ones there able to translate:

*Normally, I would say to a partner, can you wait outside, but if they've come in with the partner and you weren't expecting them and he's the only one that can translate, you know, you're never quite sure what's going on ... I've had concerns about who it [HCV treatment] was most important to, I've had issues about it seemed more important to the male partner than to the female partner ... because there is a lot of coercion and pressure put on women, our patients, from men, you're very aware of that ... but when they come in erratically and you haven't been able to organize that [a translator] and all they've got is their male partner who can translate, then you can be in a difficult position. (BBV team manager, site A)*

In order to counter this difficulty the service makes sure that there is at least one session for the female service user with a translator without the partner present. In this way – despite losing nuances of body language and expression – it is easier to ascertain treatment desire and readiness.

Just as the BBV team manager speaks of the nuances that are lost in translation, Fabio, of Portuguese origin, tells of the benefits of having a medical practitioner who also speaks his first language:

*Sometimes when you explain to the key worker, his job is for help but sometimes they don't understand perfectly what you want or what you need, the doctor sometimes can understand better for me because when I speak to Dr X, he's Portuguese as well and he speaks the same language as me, I can speak in Portuguese ... it's different because you can express more easily. Sometimes one word, one hundred words, you can express very easily. (Fabio, site A)*

While language can pose barrier to effective HCV treatment communication, another barrier that may arise is the legality of the service user's residence in the United Kingdom, and the possibility of swift deportation when they are in the middle of the treatment regime. Illegal residence is not considered a barrier to treatment access at site A. The BBV team manager refers to a particular service user when discussing this issue:

*Well I don't think here's legally, probably, so he'll probably get deported at some point, I don't know, he's Vietnamese ... I suppose he's hoping that he stays here long enough to get his treatment.... it's not my job to police patients and if this regulation is there and someone's going to police it, then I will do what I'm supposed to do. But I'm not investigating whether a patient's entitled for treatment or not, that's not my job ... generally the drug action teams who fund us and public health, take the view that while these patients are in this country with a blood-borne virus, they are actually a risk to the rest of the population. So whether they're here legally or illegally, we would still want to offer them a service from a public health point of view. (BBV team manager, site A)*

A number of immigrants are not able to access welfare benefits – often if they are in the country illegally or for less than two years. Many who accessed site A were described as very motivated to

take up HCV treatment, although this will often coincide with the need to work long hours. Treatment appointments therefore need to be juggled around these working requirements, which the service tries to accommodate as best it can:

*The Vietnamese people, the Chinese people, they do really well on treatment and they tend to have jobs as well and work really long hours, so you have to kind of fit the treatment and [they] often live in rooms with lots and lots of people so can't always keep their medication that safe, work at night and try and sleep in the day and still manage to have the treatment. We've had a few Chinese patients and they're so stoic, working long hours, in horrible conditions and still doing the hep C treatment and managing it. ... Well we try and fit in as much as we can around it ... Sometimes you end up not seeing them as often as you wanted to, you know, because you can't say well I'll see you every week and actually, they're having to do a ten day stretch and if they don't work, they lose their job. So you've got to try and be safe but be a bit flexible with that as well, you know. (BBV team manager, site A)*

#### **Findings:**

- Despite being very motivated to access HCV treatment, challenges faced by immigrant service users, and their providers, include language barriers, the threat of deportation, lack of benefit access, long working hours and potential coercion – especially for women – to enter into treatment by partners and/or relatives.

#### **Recommendations:**

- Providers need to be cognisant of particular issues immigrants may face, such as the need to work long hours, and aim to provide flexible services where possible in order to accommodate this.
- Interpreters are vital. Even if partners or relatives are available to translate, at least one session alone with a skilled interpreter is necessary to ascertain the service users' treatment readiness and eliminate the possibility of treatment coercion.

## **Criminalization and incarceration**

Drug prohibition laws and the inflated prices that illicit drugs of dependency, such as heroin, command mean that many PWID are criminalized because of the substances they consume and/or the practices they undertake in order to fund their dependencies. Marginalized PWID with multiple co-morbidities and/or who are homeless or in unstable housing (the majority of our sample) are particularly vulnerable to police attention and incarceration. This can be a barrier to treatment access and/or completion. As of 2007, a variety of barriers were identified to HCV treatment access for incarcerated PWID in the European Region. These included limited access to diagnostic tests, biopsy requirements and delays, abstinence eligibility requirements, prohibitive HCV treatment costs and a lack of infrastructure and funding [21]. In countries where HCV treatment is available in prisons, such as some areas of the United Kingdom, there can be additional difficulties with taking medications into prison, obtaining consistent clinical monitoring and medical support, treatment interruptions due to prison transfers, intake and release, and limited understanding of HCV treatment by prison staff [37, 57]. For some PWID, however, a lengthy prison sentence can be an opportune time to take up and complete HCV treatment.

While none of the study service user participants reported incarceration during the period of their HCV treatment, the team manager from site A spoke of how this scenario had recently been handled:

*Not only have we got a Vietnamese patient who doesn't really speak any English on treatment, half way into treatment, he got arrested and put in prison. He's in X prison at the minute, he's not been sentenced yet. They agreed to bring him out to our service for his treatment every two weeks. So they shackle him and he wears a grey sweat top and he's fastened to two police officers and he comes into our drug service, which is a bit scary for all the others.... I don't think that always happens. We had a bit of an argy bargee because it was like well [they said] 'can you send the treatment over'. I said 'look I'm not prepared to take responsibility for that patient when you don't know how to do the monitoring and I'm just sending the treatment over. So that's not going to work, either you prescribe the treatment and we can make it available to you, if you can't get hold of it. But your doctor would have to take responsibility and he would have to do the blood and you take responsibility, and if you can't do that, then you need to bring the patient to us'. So that's what they did. (BBV team manager, site A)*

This indicates that the prison did not have a resident doctor with HCV treatment expertise, but that they had been prepared to monitor the service user's treatment there nonetheless. This could have had potential negative repercussions, possibly exacerbated by English language communication difficulties. The prisons acquiescence to site A's demands meant that the service user was able to receive specialized continuity of care – a scenario which may change if he is moved to another prison after sentencing.

Continuity of care is important during the treatment regime and while prison may interrupt this, service providers also viewed frequent spells in custody as indicative of a service users level of [in]stability, and hence [un]suitability for treatment. As the consultant psychiatrist (site A) says:

*My sort of rule of thumb or my eligibility criteria for considering that someone is suitable for hep C treatment is are they stableish, do they generally turn up on time or on the right day ... do they avoid getting nicked by the cops? Often they're in and out of custody every weekend because they got pulled in for failing to appear or something like that ...if someone is in and out [of custody] then it's difficult. The second thing is if someone is in and out, it sort of just says to me well are they still quite busy in that department, which means perhaps they're not as stable as I thought they were. (Consultant psychiatrist, site A)*

Levels of incarceration or involvement with the police are therefore taken into account by service providers when considering treatment eligibility. Apart from acting as a 'rule of thumb' to assess stability, this may be a pragmatic measure when not all prisons are able to facilitate continued HCV treatment:

*Some prisons are set up to continue hep C treatment. So even if someone does get sent down for, you know, two months or whatever, the treatment can continue. But I don't know which prisons they are. ... We don't have any control over which prisons our patients go to. (Consultant psychiatrist, site A)*

**Findings:**

- Incarceration does not preclude successful HCV treatment uptake and/or continuation
- Incarceration can, however, be a barrier to treatment completion if the custodial facility is not equipped to support HCV treatment continuation.
- Frequent custodial periods can be used to assess an individual's stability, and potentially render them ineligible for HCV treatment

**Recommendations:**

- Incarcerated individuals on HCV treatment need to be able to access specialist HCV care, which may involve supervised visits to their treatment service.
- In order to enhance treatment uptake and completion amongst incarcerated individuals, specialist HCV services need to be available in custodial settings.
- Incarcerated individuals on HCV treatment require continuity of care and where possible should not be moved between prisons for the duration of treatment.

By bringing to the fore the various social and structural issues which can impact on the decision of PWID to take up and complete treatment we provide a background to the focus of our study which will be explored in the following section. That is, the way in which drug and alcohol services can work in partnership with hospital settings to provide enhanced access and uptake to HCV treatment for PWID. A primary social structural barrier to HCV treatment access that we have not addressed in this preliminary section is that of the hospital setting. In the following sections we will highlight the way in which aspects of the hospital system can act as a barrier to treatment access, uptake and completion, and the way in which the research partnerships worked to remove some of those barriers.

## 7. System factors

The hospital-based setting is an evidenced barrier to HCV treatment uptake among PWID [21, 36, 37]. In order to counter this barrier, HCV treatment is being increasingly located at sites such as drug and alcohol (D&A) services which may be more amenable to and convenient for PWID. A key focus of our study was the way in which the two partnerships acted to mitigate some of the barriers associated with HCV treatment provision in the hospital setting in order to facilitate HCV treatment access, uptake and completion for PWID. This section focus on system factors in the hospital and D&A environments, and the way in which HCV treatment access is configured and enabled (or discouraged) for PWID within each setting. Two key themes arose when analysing access to treatment in these environments – those of appointments and eligibility.

### Appointments: The hospital setting

#### **Attendance policies**

Non-attendance at a scheduled hospital appointment leads to the application of a 'Did Not Attend', or DNA, label to a patient in NHS hospitals. Although policies differ between hospitals, several successive DNA labels can lead to a patient being excluded from treatment and having to start again from the beginning. Staff at both sites identified PWID as more likely to miss hospital appointments than other groups of clients.

*I think for whatever reason, in hospitals if you DNA appointments and they're quite strict, then it's so many strikes and you're out for a period of time. (HCV outreach nurse, site B)*

However, the reasons why PWID are more likely to miss hospital appointments than other patients receiving HCV treatment are diverse. Starting from the booking of the appointment, through to past experiences and fears, service users recounted a variety of barriers to their attendance at hospital appointments. Service providers themselves recognize many of these barriers and report having tried a number of strategies to improve attendance among this group with various degrees of success.

#### **Making appointments**

Marta, a service user at site B found the telephone system for booking appointments at the hospital both costly and time consuming and eventually gave up on making an appointment at the hospital:

*They keep you waiting, and when you go to ring them – before, they would book for you, now you have to ring them and if you ring from a mobile, all the credit goes because when they answer the phone and keep you holding, by the time they answer the phone, even with the machine where you have to touch to try to get someone, I was £5 on a mobile. I used to go to this place where you call, where they keep you waiting for ages. In the end, you just give in. (Marta, site B)*

Ever her key worker was unable to help her make an appointment through the telephone system:

*She tried to call with me as well and it was the same, they kept sending her here and there, she couldn't get through as well. Yeah, the problem is, when the machine answers, by the time it answers, you pay already. If you call from a phone box, if you call from your mobile,*

*there's no point is there. I think they should have a line or a free number at least. Because if you call, even when you're on hold, you don't feel like you're spending all your credit. Yeah, it put me off because I tried a few times and it just puts you off. So I didn't know they had this treatment. (Marta, site B)*

Not only did the difficulty in making appointments affect engagement with services, but service users who did manage to engage with the hospital service found it hard to make appointments to get information.

*I didn't know what was happening and they didn't know what was happening and I couldn't tell them what they wanted to know and like I couldn't just go into King's and ask like, 'Oh I've got this problem, what's happening?' because I had to make an appointment to see whoever and it never sort of like... it was like took a month of Sunday's to get an appointment by which time I would have probably forgot and they would have... do you know what I mean? And it was just... it was just unsettled, yeah very. (Davey, site B)*

Hospital appointments with a hepatology department are often made on behalf of service users by their GP, D&A key worker or a referring nurse. Several service users reported appointments made on their behalf that they did not want to attend or did not understand the purpose of:

*I was shitting myself, no, no, I just didn't want to go in, you know, there's nothing up with me, as far as I'm concerned, whether I've got hep C, you know, 15 years it takes to kill you whatever, you know, but I just thought I better do it, you know, because, you know, my key worker's just going to hassle me next time I go in, 'Oh, you didn't turn up, I made that appointment for you'. (Dillon, site B)*

Some service users did not feel able to question appointments made by their key worker as they did not want to displease them, especially since they controlled the service users' access to OST:

*My key- just my key worker told me to you know, my key worker told me. It's always been like that, it always will, you know, the person who writes the [methadone] script, they hold the power, you know, you're not going do anything to piss them off. (Dillon, site B)*

Once an appointment was made, they were often confirmed to a patient in writing to the address kept on their hospital file, several months in advance of the appointment. Several service users described the difficulties they faced in remembering events so far in advance when no reminders were sent.

*Oh no, I got my appointment through pretty quick but it was about five months to wait 'til the appointment, yeah. And I don't know how I managed to remember that one actually. (Davey, site B)*

Service providers agreed that setting appointments so far in advance was a problem and could increase the likelihood of a patient missing an appointment:

*A lot of appointments there are set kind of like if you come in this day maybe to see ... have a review with the doctors and things they would just go we'll see you in three months time or six months time or something like that, let's wait for bloods so it's kind of like that so you might have your ultrasound done later on or something like that ... I think if a client misses, if they DNA, then again everything is put back. A long time as well, so they're quite strict in their DNA rates as well. (HCV Outreach nurse, site B)*



Many PWID have unstable housing situations, living in hostels or squats, or frequently moving, and so may miss an appointment letter. Although Stevie received the letter detailing his appointment, he worried that leaving his squatted flat would lead to his eviction, and so he chose to stay in the flat and miss the appointments:

*I've had a couple of letters saying that I've got to go for an appointment at [hospital] but I haven't been able to make the appointments because of having this problem with my housing. I didn't want to go to the hospital for the fear of coming back home and finding that the council had kicked all my stuff out the flat and got rid of the cat... So I'd rather stay in the house than go out and do the appointments. (Stevie, site B)*

Reminders were identified as important for attending, and whilst some hospital clinics were identified as sending text reminders prior to an appointment, this did not appear to be common practice and the onus was on the service user, sometimes supported by their key worker, to remember:

*I find with a lot of clients they may need reminders, they may need talking to again and just to keep them at the front, kind of "this is it, this is when your appointment is, this is what's going to happen", if they just get a letter in the door sometimes they don't open letters either if it's official so they don't open. (HCV outreach nurse, site B)*

### **Appointment timings**

Several service users and providers identified early morning appointments as difficult for PWID to attend. Chaotic lifestyles and competing priorities such as obtaining methadone or drugs meant that early appointments were often inconvenient:

*I missed an appointment today, I had to have a medical at [external psychiatric service], it's was at 9 o'clock in the morning and I missed it...I was too tired. It's my key worker, he's a pain in the arse. All these appointments he wants me to come there at 9 o'clock, I don't know why he's got a thing about 9 o'clock in the morning. I don't do 9 o'clock in the morning... Yeah, sometimes where I don't sleep, in the morning I feel really bad and I can't – I was awake this morning but I just felt terrible, and it takes me a few hours to shake it all off. (Shane, site B)*

Set appointment times associated with hospitals were in themselves identified as a barrier for PWID who may find it difficult to arrive for a particular 15 minute slot:

*They were pretty strict, because they're so busy. Then that's what they explained to me, that you can't just come in, because I got to a point when I was coming in at different times and that, the right day but not at the exact time. I didn't realise how booked up and busy they are and it's one of the busiest departments I think in [hospital]. (Nat, site B)*

### **Waiting times**

Service users described long waiting times in hospitals as a deterrent to attending appointments. Often they would have to visit several parts of the hospital for one appointment and waiting at each stage could add up to a significant amount of time:

*It's a hospital, it's not like you arrive there and you're seen straight away. You need to wait, and nobody likes that, well I don't...it depends how many people are there before you, yeah, but you always need to wait. (Hugo, site B)*

Nat suggests that pharmacy waiting time could be reduced if clinical staff provided the treatment directly, instead of a prescription:

*I mean it wasn't that much of a pain but after sitting in there for an hour, hour and a half and then you just want to go and then you've got to then go queue up and if it was lunch time, it would be quite busy... It would have been good if they already had your pack of needles and that waiting for you. (Nat, site B)*

Service providers used to working with PWID recognized that their clients do not like waiting for hospital appointments. The inconvenience of having to sit around in an unfamiliar environment coupled with the anxiety of the appointment itself could deter service users. For service users who use drugs regularly, a long wait can be physically uncomfortable and they may need to leave to score.

*So there is an anxiety around all that but there's an anxiety about going into another environment, about waiting. They hate waiting because they're always busy, they're always – very often, their addiction plays a part in that. They're also, I think it's about – I mean I have anxiety going to my doctor or anybody but I think there's an increased anxiety because they are socially less – more inept when it comes to dealing with professionals. (BBV nurse specialist, site A)*

The service providers recounted trying to prepare their clients for attending hospital appointments by encouraging them to mentally prepare and even to obtain any drugs beforehand if necessary:

*A lot of what we do with patients when they do have to go into hospital for a procedure, we say 'look, don't kick off, you are going to have to wait, you need to prepare yourself'. If they're using and we know they're going to have a lengthy wait in hospital, we say 'go and sort yourself out, if you need some heroin before you go, go and get it, you know you're going to be sat in A&E for four hours, that's what everyone has to do'. (BBV team manager, site A)*

Peter, a service user in site B developed his own strategy to avoid waiting at the hospital and for dealing with the bureaucracy and stress. He describes the process of determining the days the clinic was most busy and orchestrating his appointment to occur on less busy days. Preparing the documents he needed for the appointments in advance reinforced the importance of attending and removed the temptation to skip the appointment:

*Sometimes it could be a pain. It depended on who you were seeing, how busy they were and I slowly worked out which were the busy days. So I managed to sort that out as time went on. I learnt that Thursdays were the busiest days so I never had an appointment on Thursdays because it was packed then. Slowly you got to know, and then you would sort of book at different times, you'd know when to book...I got through it because you'd sort of prepare for it three or four days before, on Tuesday or Friday, you've got to go to the hospital. So if it was a Friday, on Monday you'd start preparing for it. Mentally, everything, just saying right, on Friday, I've got to go to the hospital, so you'd talk to yourself on Monday; 'right, what do I need, what have I got to take with me?' Got to take the papers, get the papers out and put them on the table. 'What else do I need?' You know, it's just generally little bits like that, just getting yourself ready so that you wouldn't put it off and say 'oh, I can't go'. So it was reinforcing yourself, building yourself up 'I've got to go, I've got to go, I've got to go'. (Peter, site B)*

Prior to initiating the community based treatment, the D&A services had experimented with other strategies to improve attendance at hospital appointments. One strategy considered for improving attendance was for nurses to accompany service users to their appointments, in the hope that this could eliminate the stress of going to an unknown environment and ensure they arrived in time. However, this strategy was found to be too resource intensive to be cost effective:

*We tried bringing patients to the clinic with one of [BBV Manager, site A]'s nurses and we had a brief period when a nurse would come with a patient. And that was terribly resource intensive and didn't achieve very much because we might have got them to the clinic for the first assessment but they never followed through for biopsies or anything else. (Hepatology consultant, site A)*

*I think, from my experience, it was that I think they really appreciated us, you know, me going basically to support them and to explain and even to find where it is in the hospital, sit with them you know it took that stress out of going to hospital so reduced it in a big way, yeah. So yeah most of our clients, yeah, clients who are very unwell, reluctant we would go with them. So and it did, did work. Unfortunately you don't have time always to go, so. (HCV outreach nurse, site B)*

### **Discrimination**

Although waiting is perceived as part of the normal hospital experience, there is a suggestion that PWID in particular may be left to wait by discriminatory service providers. Charlie recalled an occasion where despite turning up to his hospital appointment and waiting for two hours, the consultant left without having seen him:

*He just disappeared and marked me down as not being there, I think he did that a couple of times and if you don't turn up a couple of times, they can knock you off or something...I was sat there an hour and then it was into the second hour when they were 'oh, are you still here?' 'Yeah'. 'Oh, he's gone'. (Charlie, site B)*

Charlie felt this treatment was due to his status as a drug user: "I haven't got a voice have I?" (Charlie, site B)

Service providers accustomed to working with PWID acknowledged that the staff response to PWID attending hospital clinics can be a big factor in whether they return:

*And, of course, in the general hospital you've got all these motivated directed patients who are extremely keen on treatment, and then you get our patients in who probably might not have had a bath for six months or something like that and they walk in at ten past ten and their appointment was at 9.30 and they're a bit rank and the receptionist maybe doesn't quite understand about patients with drug problems so bites their head off and they say, 'Well, fuck off, then,' and you never see them again. (Consultant psychiatrist, site A)*

A service provider from site A describes how the first impression of a clinic can be key in shaping an individual's impression and determining whether or not they return.

*The first experience of a clinic is so important. To make it as non-judgmental and non-stigmatising as possible ... I think what it means is being a bit flexible, a bit less rigid, a bit more accommodating ... We can get fairly brisk with them if they repetitively turn up at five to five on a Friday afternoon, but it's that initial contact. Is it welcoming? ... do they look as if they're pleased to see you? Do they have some sort of understanding that if they make an appointment for that patient in the hepatology clinic at 9.30 and the patient's on methadone*

*and their pharmacy doesn't start dishing out methadone until ten, when the patient turns up, they will be a bit shaky and sweaty and clammy in opiate withdrawal, and are they prepared to accommodate that? Or do they give the patient a look? (Consultant psychiatrist, site A)*

**Key findings:**

- PWID experience multiple barriers to attending hospital appointments. Hospitals that enforce strict DNA policies can create an additional barrier to treatment access.
- Barriers to appointment attendance in the hospital setting include: complex or expensive hospital phone lines, appointment reminders sent by post, early morning appointment times, inflexible appointment windows, unfamiliarity with the hospital setting, perceived discriminatory treatment and lack of understanding about the purpose of appointments.

**Recommendations:**

- Phone lines for service users to schedule appointments should be free and uncomplicated.
- Service providers making appointments on behalf of service users must ensure that they are acting with the full agreement and understanding of the service user and that they clearly communicate that services such as OST are not dependent on attending additional health care services.
- Appointments need to be scheduled with the input of the service user, to ensure that time is available for other commitments to be met.
- Hospital clinics that are able to instigate flexible appointment times, or windows of time, will encourage access. Overbooking appointments and liaising with other staff who have contact with the service user can ensure that as many service users as possible can be seen.
- Non attendance of appointments should not be used to remove a service user from the system. DNA policies should be removed where possible.
- Where possible, provision should be made for a service provider (from the D&A service for example) to accompany service users to hospital appointments.
- Phone or text reminders for appointments are vital. Postal reminders may not reach the desired recipient.
- Where possible, training for hospital staff in drug and alcohol related concerns should be available. It is imperative that staff attitudes not preclude PWID attendance.

## **Appointments: The drug and alcohol service setting**

### ***Rationale for community based treatment***

Service providers from both sites discussed the community-based partnerships as having been developed as a response to the high DNA rates recorded among PWID in hospital settings. They were cognizant of many of the barriers preventing service users from successfully accessing treatment in the hospital setting and felt that a community-based service may address many of these issues:

*Service users tended to DNA the clinics ... [BBV Manager, site A] felt it was an issue with timing and we wanted to be as flexible as we could. She seemed to know issues, things, barriers that we might be able to remove so we said we would go with that. We tried that and it didn't work, people still didn't turn up ... So after probably about a year, we recognized that we were just getting nowhere so we said okay, let's try something different, let's try and move out into the community and try treating at (site A) (Hepatology consultant, site A)*

*We had a very high DNA rate anyway for the first appointment ...across the board, it's about 25% or I think if drug users did come, you know, they would sort of fall off the radar very quickly and because our appointments into our big multidisciplinary clinic were morning appointments. So, you know, that maybe coincided with them picking up scripts or seeing their key worker or they didn't get the letter through or they'd changed their address, there was always something that meant that they didn't come. So I think that's more the case, that, you know, if they did come initially, that next appointment, they didn't come and so, you know, it's easier for us to take the service to them. (Senior nurse for viral hepatitis, site B)*

From the outset both sites identified increased flexibility as key to addressing barriers to hospital-based treatment access for PWID.

### **Making appointments: flexibility**

Irregular appointment attendance by PWID was recognized as a major obstacle to hospital-based HCV treatment access. The community-based treatment partnerships worked to improve access and attendance by co-locating hepatitis services in the same building as the D&A services. Service users are likely to attend D&A services on a regular basis to receive their OST script, thus making it easier to attend HCV related appointments. Service providers from site A discuss the flexible nature of their clinic as key to their success. Set appointments alongside a drop-in clinic mean that even if service users miss their set time, they are usually still able to see staff:

*We're quite flexible about seeing patients, we don't necessarily have an appointment system ... so for instance, in the drop in, people literally drop in and they may want to see the nurse or we may want to see them so we have mechanisms to try and get them into our clinical room ... I'll go through the diary every day and say I need to see this, that and the other or they may say I want to see the nurse. So we have recall systems and I work very flexibly. Sometimes I'll run appointments but usually, I will see patients as and when they come in and I'll pick them out of the waiting area or they'll ask to see me ... It's probably our model of care which is the most effective, is about being flexible with patients and you set an appointment with a patient and if they don't turn up, that they can still see us. I mean some might argue that that sets up bad behaviour but that's just the way it is and that's the way that we work and that's the way that it works successfully with us. (BBV nurse specialist, site A)*

*I'd always come in fortnightly ... To see my key worker for the methadone ... When I came in for like killing two birds with one stone. When I came in on my fortnight thingy, I'd see my key worker [and] I'd always see [Nurse practitioner]. So I'd deal with that and then I'd deal with that at the same time. (Jeff, site A)*

site B operated a different organizational structure. The nurse specializing in HCV treatment outreach was available most of the time, however the HCV clinic was scheduled on Thursday morning, for which appointments were set in advance. The service providers at site B also discussed flexibility as key to the service structure:

*There are [appointments at site B] because we have to measure the activity ... There's a nursing assessment, there's a medical assessment and there's treatment but we're not absolutely rigid, we're not absolutely rigid with those appointments ... the two patients that have started treatment, [Clinical nurse specialist, HCV treatment outreach] has agreed a time with them for the next few weeks that's good for them but again, it's about juggling around and making it fit really. (Senior nurse for viral hepatitis, site B)*

Service users at site B were provided with a mobile phone number for the nurse coordinating HCV treatment outreach and were able to contact her during working hours if they were unable to attend the service. As well as arranging appointments, this allowed her to encourage drop-ins where necessary:

*So yeah, I think that is really important, that they know that there is just someone there that they can see as frequently as they like really, and they do know that they can call us as well and do call [HCV treatment outreach nurse] on her mobile number that she provides. So they can just call and say look, I'm struggling, can I come in, and we'll just add them to the list for the next week ... We try and keep it to the Thursday, so it's very specific for the treatment clinics, but if someone does need to drop in, then I think she's quite happy just to see them, if they do need to drop in. (Clinical nurse specialist, viral hepatitis, site B)*

In contrast with her experience of trying to arrange a hospital appointment, Marta found the HCV treatment partnership at site B much more accessible, especially as the nurse specialist coordinating HCV treatment outreach was able to arrange Marta's appointments directly:

*She did everything for me. She booked everything, she sent me the dates, she was really, really good. Yeah, she booked everything and she wrote it down, she sent the letters and all the tests, she would call me, send a text to remember about the appointment. Yeah, she was really good. If it wasn't for her, I wouldn't be doing it. (Marta, site B)*

Service providers discussed adapting the way clinic appointments were arranged to meet the characteristics of the service users. Staff overbooked appointments, knowing that many service users would not attend, and instead of applying a DNA label, rebooked an appointment automatically, with no punishment for having missed the first clinic:

*We configured the clinic so we accepted a lot of DNAs, so we just pushed people into the clinics and we would book three or four people at the same time, accepting that 75% won't turn up, and if they don't turn up, we send them another appointment, it doesn't matter. (Hepatology consultant, site A)*

Where appointment times were necessary, service providers with experience of working with PWID described how they made allowances for the needs of the service users and adjusted their working arrangements to ensure the service they were providing was appropriate.

*If someone's injecting heroin, three or four times a day, they've got to score in the morning, why give them a 9 o'clock appointment when you know they're not going to make it. That's like 'well everyone else manages to fit in'. Well that's good that they can fit into that regime but these patients can't. So, you know, there's no point expecting a group of patients to do something that you know they're not going to be able to manage and then complaining when they don't do it... it's not any different to having to get interpreters in for a group of patients who've got different needs, you know, the different groups of patients. (BBV team manager, site A)*

*So they don't fit the box, so, you know, if you accept that and try and work with it, you're more likely to be able to pull them through the system. (Specialist BBV nurse, site B)*

The side effects of HCV treatment were described by service users as sometimes being so debilitating that they were unable to attend services to pick up their medication or seek help. Bibi who attend services at site A and suffered from serious dizziness described how the service

providers were flexible in her appointment times and how they knew her daughter and allowed her to occasionally pick up her mother's medication on her behalf:

*I feel so sick right now, you see, this is what happens to me. Dizziness, the room is spinning ... If this happens when I am by myself at home and I know that I have to leave the house to get out, you can imagine my, you know, resistance is like saying oh no, I do everything possible not to go, if I have to come here, I change the appointment, if it's possible to move the appointment and say can I come tomorrow. If I send my daughter, two or three times, they allow me to send my daughter here to get the prescription on my behalf and go to the chemist and pick up the methadone for me because I was really so bad. (Bibi, site A)*

### **Fewer appointments**

Service providers at site A discussed reducing the number of appointments a service user had to attend prior to starting treatment as an important modification to the hospital system. Instead of several separate appointments, the hepatitis consultant and the BBV nurse would meet with the service user at the same time, bringing together all of the necessary information to make the decision on whether or not to start treatment. The removal of the lead-in period and making decisions instantly meant treatment could be expedited for those who chose it and removed the likelihood of the service user disengaging prior to starting treatment:

*So there's a lead-in period for non injectors when they get to know the nurse and the nurse gets to know them, and that's when issues start to come up that we weren't aware of. So I think with injectors that's slightly more difficult because if you keep putting those hurdles in place, they don't come... they give in. So if you say you've got to have four clinic appointments before you can start treatment, they drift away by the end of the second one, and then... why the hell should you bother keep coming back, if you're not getting anywhere?... So seeing them together with [BBV team manager] meant that all the background information we needed was there and if [BBV team manager] didn't have it, she could get it from one of her nurses at their group meetings, they have regular group meetings ... So they would come and see me and they would then get a decision; we think treatment is right for you, or we think treatment isn't because ... (Hepatology consultant, site A)*

*What historically seems to have happened with patients in the past at some other kind of specialist services, it's almost like they're given a set of appointments to jump through, to make sure, in some way, that if they keep turning up and turning up, that eventually that means they're committed and then you can start treatment. I don't actually think that works for this group of patients, they perceive that as nothing happening and it's a pointless exercise. What you need to do, as soon as a patient says that they're interested in treatment, is you need to start them then. You need to start them as soon as you can, while they're interested because once you start them on treatment, you've got that opportunity then to try and get them committed to doing it as you go along, rather than keep setting appointment dates or the future. I think you need to lower the threshold that you let these patients into treatment, and it's worked with us because we don't have any more numbers dropping out of treatment than any other service. (BBV team manager, site A)*

Service providers at site B described a similar compression of services, describing how they conducted all aspects of an appointment themselves, rather than sending service users to different providers, one of the causes of increased waiting times in hospital settings.

*Well, at the hospital, they would see the liver outpatient's nurse and have their blood pressure and their weight and all of that checked. Then they'd see one of us and then they'd go and have their bloods done by the phlebotomist. Here, we do the weight, blood pressure and all the rest of that, we see them, do the consult and then quite often, [HCV treatment outreach nurse] will take the bloods. (Clinical nurse specialist, viral hepatitis, site B).*

#### **Key findings:**

- Co-location of services and flexible appointment schedules improves appointment attendance by PWID.
- PWID can perceive a series of appointments prior to commencing treatment as a futile exercise and may disengage. The integration of lead in appointments into one or as few as possible, aids service user engagement.
- HCV treatment side effects can make attending appointments or picking up medication difficult.
- Services removed DNA policies, in that service users were not penalised for appointment non-attendance.

#### **Recommendations:**

- Where possible, flexible appointment schedules or windows of time, should be made available
- Clinic appointments should be integrated to include as many components as possible, to reduce the lead-in time to treatment.
- Extra support to service users receiving HCV treatment may be necessary to reflect the problems they may face in attending services. Extra transport support, flexible appointments and allowing trusted relatives to pick up medication when monitoring is not necessary are among the strategies that can be used to encourage adherence.

#### **Reminders**

As with the hospital based service, reminders were identified as key to ensuring service users attend their appointments. Reminders are important not only to remind clients of the time of their appointment, but also to provide encouragement to patients who may be having problems with their treatment or side effects and may not otherwise seek help:

*We don't have very many DNAs, I think we might have had two DNAs that I can think of, which is really good, and I think that comes down to the role [HCV treatment outreach nurse] plays .... because without those reminders and someone there to be a little bit more in touch with the clients ... I think a lot more people might forget that they've got their appointment, or just not turn up because they are struggling and they perhaps haven't had that person to talk to a couple of day earlier, to say come on, you can do it, you've got an appointment in two days, get to the appointment, we can talk about it then and take it from there. (Clinical nurse specialist, viral hepatitis, site B)*

Service users agreed that such reminders were useful and many spoke of having poor memories:

*The importance was for somebody to have made the appointment for me, definitely, it was very important ... All the appointments I have here, they remind me ... They text ... when people do drugs, their memory goes ... I always need reminding...it doesn't matter how it's done, the important thing to me is having a reminder. (Hugo, service user)*



Service providers from both sites talked about strategies to improve appointment attendance that went beyond text and phone reminders:

*I mean one of my nurses... she had a patient on treatment who never used to turn up for his appointments. She knew where he would be, in which doorway on the High Road. So if he didn't come, she'd go and get him, it's that kind of thing really ... Again, in N, they've got an outreach team, so they'll help us, they'll help go and get patients or, you know, patients that they know are homeless and living in a bus shelter or whatever. They will get messages to them or, you know, if they're worried about them, they'll ask us to go out to see the patient. (BBV manager, site A)*

Service providers from both sites talk about obtaining permission from service users up front about how to contact them if they disengage from services or cannot be contacted through the regular channels:

*If they agree as well, if they haven't got a contact number, again it's like if they're on the methadone prescription, then we can just leave a message, a reminder with their pharmacist, not obviously informing the pharmacist what the appointment is about but that they've got an appointment ... it can be a letter or if we need to see the person, can you ask the person to come and see us when they collect their prescription. And if the clients agree I'll just say look, right, we've arranged, for example, if it's a liver ultrasound, are you okay if I let your pharmacist, just to remind you about your appointment? ... We would seek the person's consent to do that. (BBV nurse, site A)*

*If you do an assessment on somebody, asking people if you do disengage, 'how would you like to be contacted, so that, if you did, how would you like us to [contact you]'. (HCV outreach nurse, site B)*

As well as providing reminders, service providers can help prepare service users for appointments in practical respects. Kaveh describes his fear of hospitals and how after missing several appointments, the nurse at site A provided him with medication to deal with the stress of his next scheduled appointment:

*Sometimes I'm frustrated. I know it's a bit childish but sometimes I just ignore the appointment ... [The service provider] the day before I go gave me a couple of valium because I don't go ... He's given me a couple for the morning for the day I go... Only because I was very skittish ... He looked at me and said it will be very bad. I know he dramatises with me, but I think it's party strategy to be sure... but the moment I go in a hospital it's the classic, just mad ... The moment I feel this mad, I start to get ... I'm a reluctant patient sometimes. (Kaveh, site A)*

### **Waiting times**

Flexibility was also seen as key in regard to appointment waiting times. Staff accepted that service users may have a number of competing priorities and by communicating with them and understanding these priorities, made allowances for lateness.

*Up at the hospital...we have 15 minute time...If someone doesn't turn up for their clinic appointment, or they're too late...you need to rebook. Whereas here, because of these clients having a lot of other stuff going on in their life and things perhaps being still a little chaotic for them, them having other appointments, either with Job Centre or with key workers here, we are a little bit more lenient in that we'll hang around a little bit longer or*

*give them a call. If they're on their way, then we'll wait; if they need more time to see us, then we'll give them more time. It's just a little bit more relaxed in that regard I suppose. (Clinical nurse specialist, viral hepatitis, site B)*

A service provider at site A acknowledged the problems for the service users when facing lengthy waiting times and described how he and other staff tried hard to keep waiting times as short as possible to ensure no one left the clinic without being seen.

*We tried desperately hard to see people within a few minutes of their attendance, people don't hang around waiting. So we wouldn't keep them waiting to the appointment time, if they turned up, we would see them. And we would try to run the clinic ... if there were three people waiting, we would try and speed through. One always tries to accelerate a little bit if there are people waiting but people in the non drug user clinic will wait for three quarters of an hour, will wait for an hour, they'll go and have a coffee and come back. Nobody likes waiting, we don't like letting people wait but they generally stay put. Whereas drug users would disappear, if you keep them waiting for ten minutes and they're not seen, they're running out. (Hepatology consultant, site A)*

Service providers at D&A services recognize that even if service users have not made the exact time of their appointment, penalties are unlikely to improve the situation, and maintaining any level of engagement is key.

*We shouldn't let the perfect be the enemy of the just about good enough. So say, for example, a patient is here for a psychiatric review with myself for 2 o'clock and they turn up at five to three, I would much rather pop in and see them for those five minutes than say, 'Oh, I'm sorry, you're late. You'll have to rebook. That's that...So I must say I think we're a lot more flexible, certainly in the initial treatment period when we're trying to engage them.'" (Consultant psychiatrist, site A)*

### **Appointment utility**

Service providers discussed ways they used appointments as a tool to facilitate their work. Key workers in site A carefully coincided OST appointment bookings with the requirements of the nurse specialist running the hepatitis treatment:

*We try to kind of link both appointments on the same day... like I have two clients who have liver decompensation. I used to see them every fortnight, he [Nurse practitioner] needs to see them every week because of the treatment and he spoke to me 'can you please make sure you see these people come every week because I need to see them every week'. So instead of me giving 14 days prescription, if I give 14 days' prescription and then [Nurse practitioner] books his appointment every week, there's a chance that they won't turn up anyway because they've got several more days prescription. So I change their prescription to seven days ... So we work together in a way because if I need to change my appointments or the scripting pattern or I don't want to see this client every fortnight anymore, I will speak to [Nurse practitioner] and see how that would affect treatment. (Acting team leader SAU, site A)*

Stability is an important concept discussed by many service providers and users as key to successful HCV treatment. However, it can be hard to gauge and there are few concrete tools available to service providers who instead rely on their experience and personal knowledge of an individual's situation to make important decisions. The consultant psychiatrist at site A explained how he used an individual's attitude to appointments to gauge their stability:

*I think because it's a reflection of a level of organization in their minds, that they're able to say to themselves, 'Right, Thursday, 2 o'clock, I go there.' To do that, you've got to know when Thursdays happen. You've got to know when 2 o'clock is. You've got to know all sorts of things about where to go, when to go and all that sort of thing. You've got to think that you're getting to get something from turning up at 2 o'clock on a Thursday. If you think it's pointless, you're not going to come. And I think it reflects some sort of commitment to some sort of order in their life, and the commitment being around not wanting to die. Being able to think a little bit further along than the next syringe, the next drink and the next whatever. (Consultant psychiatrist, site A)*

#### **Key findings:**

- Appointments scheduled far in advance are likely to be forgotten and a variety of personalized reminders are important to ensure service users can attend.
- Service providers sought consent from service users about where they could be contacted, and would locate service users in known abodes or leave messages with pharmacists if necessary.
- Additional supports to help service users attend appointments were provided, such as medication.
- Service providers aimed to see service users as soon as they arrived and provide leniency for those who were late.
- Appointments were used as a tool by service providers to help gauge stability and – by coinciding with other appointments – to encourage attendance.

#### **Recommendations:**

- A variety of strategies can be used by service providers to remind service users about appointments, including letters, telephone calls, and contacting them through pre-agreed strategies, such as mutual contacts like community pharmacists.
- If service users are not attending appointments it is necessary to discuss with them their fears/barriers to attendance and provide personalized interventions – such as medication – where feasible.
- Reduction in clinic waiting times and leniency regarding lateness facilitates service user engagement: where possible, services should aim to be as flexible as possible.
- Collaboration between service providers in regard to making appointments can aid PWID attendance.

## **Eligibility criteria: The hospital setting**

In 2004 the UK National Institute for Clinical Excellence (NICE) updated their clinical guidance to recommend that injecting drug use alone is not a reason to preclude an individual from HCV treatment. A service provider at site B described how the guidelines were intended to improve equity of access to HCV treatment, regardless of drug using status, thus removing the potential for consultants to discriminate against drug users:

*The NICE guidelines say that basically, everybody should be offered hep C treatment, regardless and that was a very positive step to actually sort of trying to counterbalance the influence that some of these sort of consultants have around their opinion and their attitude to our client groups. (BBV nurse, site B)*

Although the guidelines aimed to standardise the ability of PWID across the country to access treatment, the individual level treatment decision-making remains the responsibility of hospital consultants, who may have varying opinions about who can and cannot be successfully treated. The view among many service providers who work with PWID is that many hospital consultants consider their clients as unsuitable candidates for treatment, despite limited evidence to support such a view:

*I think the rationale isn't correct. It's the belief that patients who are using or drinking are more chaotic and therefore they will not comply and they're more likely to have failed treatment. (BBV nurse, site A)*

A service provider at site B described the attitude of many hospital consultants as a mixture of judgement and evidence; in that the withholding of treatment until a service user reduces their substance use may be a way of ensuring better outcomes for those patients.

*Anybody that's drinking over a certain amount of units a week, of alcohol, there's no point in them actually pursuing treatment until they've got that more under control. That's why you've got some arbitrary sort of guidelines or ways of thinking or attitudes within certain hepatology services. So some consultants wouldn't treat anybody that's drinking and it's not necessarily a judgement, some of it is judgement, I'm sure, if they're honest, some of it is judgement but there is a strong argument for the fact that alcohol reduces the efficacy of the medication. So if someone's going to go through six months or 12 months worth of treatment, why set them off to fail, why set them off with a reduced percentage of chance of it actually working, when actually, if you wait a year, when they've actually got themselves a bit more organized and drinking less, they could have like 10%, 15% more chance of it actually working. (BBV nurse, site B)*

However, the same service provider also went on to stress the importance of pragmatism when working with this client group. Many service users will never be completely abstinent from alcohol or drugs and therefore achieving a level of intake where they can live stable lives may be the best situation service providers can hope for. A consultant psychiatrist from site A described this viewpoint as: “we shouldn't let the perfect be the enemy of the just about good enough”.

*Is this person in the right place, at the right time and going to give it their best shot? Because if delaying it a year means they will be in a better place, fine, that's a good argument. If they're stable but still sort of doing a little bit of this, that and the other, which you might not like as a clinician, you might not like it that your client injects with heroin once a week and drinks two cans of Special Brew at the weekend or whatever...this is the best place they're ever going to be, this is the person that they are, they're going to be that person forever. (BBV nurse, site B)*

The reasons hospitals gave for refusing treatment to PWID varied considerably. A hospital-based hepatitis nurse recalls clinic letters on file that required service users to lower their alcohol intake before they could begin treatment. Often such clients would not return to hepatology services:

*Looking at the letters, they were still using, they were told they needed to get their alcohol down below a certain level and then they didn't come again. (Senior hepatitis nurse, site B)*

Service users report being refused HCV treatment from hospital providers on the basis that they could re-infect themselves if they were still injecting. Prior to the NICE guidelines changing, Shane was told in 2000 that he couldn't access treatment for this reason:

*I think their exact words were 'it's an expensive drug, you're using on top and we're not treating people who are using, because you could get re-infected couldn't you?'. (Shane, site B)*

Not everyone was given a reason for not being able to start treatment and some reasons given are not supported by the clinical evidence. Ben was told that he must be abstinent from all drugs and alcohol for between six months and a year before they could provide treatment. The doctor told Ben that the treatment may be less successful in a patient still using drugs or alcohol and he had to wait for his body to be clear for several months before he could start treatment.

*She [hospital doctor] said I'd have to stop doing everything, you know, because I was still using occasionally. She said I'd have to stop using, both the crack and the heroin, I'd have to stop drinking, you know, for at least a year, six months to a year, for my body to be clear before they could start the treatment. So I went away thinking, 'Well I don't know how I'm going to, it's going to be harder than I thought'... I thought once that I knew I had hep C, that I could have treatment...she just said if I'm still using, then the treatment won't be as successful as if, I was clean, that's how she put it. (Ben, site B)*

Some service users reported experiences with hospital doctors who based their decisions around the notion of stability, and whether they perceived the service users as able to adhere to the treatment regimen. Kyle was going through a period of heavy drug use when his doctor first broached the issue of HCV treatment. The hospital team monitored him at regular intervals to see if his drug use stabilised. Kyle agrees that it probably wasn't a good time to start the treatment, although he feels the decision was also based on financial considerations:

*Because [hospital doctor] was supposed to do the hepatitis C treatment because I was injecting heroin and they're 'oh let's give six months to see if you stop to use', then I stopped to use but I was smoking ... then 'I'll let you another three months, let's give another six months'...It wasn't the right time probably to do it but well, they don't waste money." Kyle, service user, site B*

Recognizing his history of depression, service providers at another hospital told Shane, no longer drug injecting, that they needed to discuss his mental health with his GP before they could offer him treatment. They recognized that his long term service provider was better placed to make a judgement call about the appropriateness of the HCV medication, given his history of mental health problems, and liaised with the GP to make a joint judgement call:

*They said that one of the side effects of Interferon is depression, severe depression and they wanted to talk to my GP to make sure I'd be stable enough to have the treatment. (Shane, site B)*

Several service users reported being given conflicting information about whether or not they could access treatment by different providers, and few service users spoke of being able to discuss or question the criteria presented to them. Jed described how having met the hospital's initial eligibility requirements, he found that threshold increased to once again exclude him from treatment. Initially Jed was told that he must stop injecting, because of the potential for re-infection. Once he had done so he was told he should be abstinent from all drugs, even those he smoked, a requirement he felt was too much to expect. He discussed the situation with the key worker at his D&A service who raised the problem to the hospital, who then agreed to provide him with treatment.

*The words were 'we don't want you injecting drugs. It's as simple as that. It affects your treatment, you can re-infect yourself, what's the point?' sort of thing. So I give up injecting*

*drugs. And then, because I was smoking it 'you've got to stop doing that'. You know. So it just ... it went on like that and then it just ... I kept on being put off three months, three months, three months. And then eventually I went down to the doctor, my key worker...I said 'look I've had enough of this' do you know what I mean 'I've been doing my best, I've done my best to give up injecting which I've done, I haven't injected since, I still haven't, right, and I'm not stupid. I know when I'm on the treatment that if I take other drugs it's going to affect me. (Jed, site B)*

Service users' experiences with eligibility criteria perceived to be unreasonable or unattainable, such as abstinence from all alcohol and drugs, led many to disengage from services and from hope of managing their hepatitis:

*I wanted to do something about it [HCV] and it was as though, you know, they [hospital] were like stopping me or just, you know, putting walls in my way to get treatment and it's like oh, you know, 'I don't want treatment then' you know, 'Have your treatment. Fuck you' sort of thing. (Dillon, site B)*

#### Key findings:

- Even after NICE recommendations changed in 2004 to include current substance users as eligible for HCV treatment, some hospitals refused PWID from treatment on those grounds
- For many service users requirements for complete abstinence are unrealistic and can result in disengagement from services.

#### Recommendations:

- All services should adhere to NICE guidelines. Current substance use alone should not be a treatment contra-indication.

## Eligibility criteria: The drug and alcohol service setting

### ***Eligibility criteria development***

In the early stages of developing the eligibility criteria for site A, service providers described deliberately picking patients who *were going to be fairly 'straightforward'*. These straightforward patients were defined as those who were not drinking large volumes of alcohol (i.e. 100 units of alcohol per week), and those with relatively good blood counts and low drug use. Given that the main principle behind the service at site A is that *"drug use was no barrier, period"* (Consultant hepatologist, site A), ongoing psychiatric, alcohol and co-medical issues were more cause for concern than ongoing illicit drug use. In the early stages of eligibility criteria development, stability was seen to be key factor in determining eligibility:

*Don't care if they're injecting or not injecting. Don't care if they're on methadone and injecting. Don't care about any of that as long as they're stable.' So if they're on 70 of methadone and two bags of heroin a day, fine, as long as they're stable we can treat them. And, lo and behold, you can. (Consultant psychiatrist, site A)*

The eligibility criteria for site B was developed by a multidisciplinary group of service providers from the hospital, some who had experience in D&A settings, and was informed by research published by site A service providers. The criteria were then discussed with D&A staff based at site B and agreed.

In late 2011, the HCV treatment eligibility criteria required service users to: consume less than 40 units of alcohol per week, be engaged in stable drug use (i.e. a couple of times of week – ideally no injecting of crack cocaine), regularly attend treatment appointments, have a stable home life with access to a refrigerator to store their interferon and agree to enter in to a needle and syringe program. The senior viral hepatitis nurse describes this process:

*We were very mindful of we'd never done an outreach service and we'd never treated drug users so ... tried to come up with sort of sensible criteria of no more than 40 units of alcohol a week, stable injecting drug use, a couple of times a week. Daily, we worried that perhaps they wouldn't cope on treatment and that perhaps we could extend our criteria later on. Obviously stable sort of home life, they needed a fridge and things like that. So we then met the multidisciplinary team, one of the consultants said I don't want any injecting of crack so they felt that it made patients more vulnerable from his past experience at another centre. So that's how the referral criteria came about. (Senior viral hepatitis nurse, site B)*

### **Evolution/ current state of affairs**

Rather than a fixed list of requirements, eligibility criteria at site A are now framed as guidelines only with individuals assessed for stability on a case by case basis. In addition to the emphasis on flexibility, service providers at both sites described eligibility criteria development as an evolving process. As site A has been operational for several years, the eligibility criteria has evolved, and the threshold lowered to admit more complex patients to HCV treatment. site A had no HCV treatment eligibility restrictions at the time of conducting the interviews (2011) and service providers discussed the importance of flexibility in their approach to treating service users. 'Stability' was frequently described as the decisive factor in determining whether someone was physically and mentally prepared to undertake what could be an arduous HCV treatment process, as iterated by one service provider:

*The problem with [eligibility criteria], you know, 'mustn't be doing this, mustn't be doing that, must be doing this, must be doing that' is that you can get into terrible, pointless and fruitless discussions with the patients and withholding treatment when actually, it is worth a go ... My sort of rule of thumb or my eligibility criteria for considering that someone is suitable for hep C treatment is are they stableish, do they generally turn up on time or on the right day, do they generally take most of their prescribed methadone or are they someone who actually only goes three or four days a week to the pharmacy and the rest of the time, they're off doing goodness knows what. Generally, do they avoid getting nicked by the cops? (Consultant psychiatrist, site A)*

Service providers at site A discussed how some people were deemed ineligible to commence HCV treatment immediately as they were not considered stable. This may be due to a number of factors, be it because of their volatile illicit drug use, unstable accommodation arrangements or mental health issues. However, as explained by a service provider, it was important to explain the reasons why HCV treatment was being postponed. The service provider below describes explaining the reasons behind decisions to service users as a way of keeping them engaged with the service.

*So for instance, we may have somebody who isn't eligible but we'd talk about treatment with them and allow them to understand why it isn't suitable at the moment ... we have patients who are very mentally unwell, and have been recently, not that we exclude them forever but they may have only had a hospital admission within the last six to 12 months and it isn't suitable for them to consider treatment at the moment. (BBV nurse, site A)*

Despite the differences between the two sites, stability was considered by both to be an important criterion for HCV treatment. The concept of stability was largely assessed on a case by case basis for

service users of both sites – a “blanket rule” was impracticable as individual circumstances needed to be factored in. This transcended not just service users’ licit and illicit drug use, but whether the service users’ behaviour was relatively predictable in other facets of life. The importance of looking “at the whole picture, what’s going on for [service users]” was suggested by the clinical nurse specialist at site B as a contributing factor in assessing a person’s stability and whether “they have things as under control as possible” (Clinical nurse specialist, site B)

Staff at site A discussed treating patients of many different nationalities, some of whom may be illegal immigrants or otherwise not entitled to free medical care from the NHS. However, staff felt that it was not their responsibility to determine an individual’s eligibility for healthcare, and rationalised providing treatment to everyone in need, due to the public health importance of constraining the infection:

*The drug action teams who fund us and public health, take the view that while these patients are in this country with a blood-borne virus, they are actually a risk to the rest of the population. So whether they’re here legally or illegally, we would still want to offer them a service from a public health point of view. (BBV team manager, site A)*

### **‘The future’**

The eligibility criteria continue to evolve: at site A where staff have been providing HCV treatment to PWID for several years, service providers discussed their plans for the future of the service. These include lowering the boundaries of treatment access to treat the most marginalized:

*We want to be getting to the stage where quite a large proportion of people are dropping out of treatment and then we know that actually we’ve hit the bottom, we’ve treated to the level that is reasonable. So once we start seeing more and more people who are really failing and really not up for it, then we haven’t gone low enough, we haven’t dropped the barriers. So clearly there’s a way to go because everyone we’re treating at the moment gets through” (Hepatology Consultant, site A)*

#### **Key findings**

- Developing eligibility criteria for a service is a constantly evolving process, drawing on service provider experience and lessons learned from similar services
- Clear communication with service users regarding eligibility decisions is vital for maintaining their engagement with the service, even if they cannot be treated straight away.
- The absolute ‘limit’ of who can be treated successfully has not yet been found. Services with adequate experience and resources can continue to lower the eligibility criteria as long as they continue to treat patients successfully.

#### **Recommendations**

- Services planning on offering HCV treatment to PWID should develop eligibility criteria in consultation with experienced staff and national and international evidence.
- The criteria can be adapted and change over time, as service providers attain confidence and the local evidence base grows.



## 8. Integration

A diverse set of skills and resources are required to adequately address the variety of health and social issues faced by PWID. Traditionally these resources were provided separately, organized by the type of service provided: health and social, and even within those: mental health versus physical health, or (un)employment support versus housing or social care. There is a growing realisation among service providers that these issues are interlinked and that integrating services in to one or fewer contacts and can benefit individuals accessing these services. This section explores the way in which the two HCV treatment partnerships worked to integrate care. Specific areas addressed include multidisciplinary care, continuity of care, service co-location, prescription access, information sharing, formal partnerships and funding.

### Multidisciplinary and specialized care

Service providers acknowledged that HCV was often not a priority for PWID, many of whom face a number of other health and social problems. site A caters for clients with multiple morbidities. They receive referrals from local GPs and community drug teams (CDTs) of the most 'complex' cases, often service users with psychiatric and physical health issues interacting with their drug and alcohol use:

*It's more for your service users with complex needs. So yes, so that can range from mental health, maybe women who are pregnant ... There is a whole lot of factors, complex needs may be people who are groin injecting, more chaotic in their use, have other drug, alcohol issues ... People who have got a history of mental health. (BBV nurse, site A)*

The chronic nature of the virus and a possible lack of symptoms for many years can mean that PWID may postpone HCV treatment uptake. There are benefits for treating HCV early, including increased treatment efficacy and, in recognizing this, service providers attempted to engage PWID in conversations about HCV treatment uptake. It was felt that an effective way of engaging PWID in these conversations was through other services, which PWID were more likely to attend: such as needle and syringe exchanges and acute health care:

*Well obviously methadone and drug treatment, needle exchange, and then will access us if they've got acute problems. So if they're in pain, if they're feeling unwell, so if they've got cellulitis or injecting related infection or any of those things, then they will access us for that because we can treat that. But HCV doesn't cause any of those things and so you're already trying to get patients who find it difficult to address their health issues, because they've so much else going on, tend to only address health issues when they become problematic, with a condition that, at the moment, isn't causing them any problems. (BBV team manager, site A)*

*We do have a needle exchange which we use as well here and with the needle exchange, we also see people who not actually engaging with the service. That's another way for us getting them in treatment and referring them to the BBV nurse... So it's a good way to attract new clients as well and getting help. (Key worker, site A)*

While attending services for other reasons, service users are provided with information about HCV and the opportunity to test for this and other blood-borne viruses. Service providers spoke of the importance of offering individuals an integrated and tailored package of services:

*People will come and see us just for general health problems... we will offer everybody blood borne virus testing, who we see. Some people will see themselves as having no risk, some people won't want to have the testing. So that's respected. But it's something that's offered, and it's also just talking to people. Because it's very much like the harm minimization model, it's just about looking at people's practices ... I think it's very hard to separate the person off and say well we're only going to be addressing this, because you've got to look at treating the person as a whole really. (BBV nurse, site A)*

Both sites offered a variety of services, including harm reduction services and acute health care. Many of the BBV nurses who provide HCV treatment at site A are nurse prescribers which means they can complete prescriptions within their area of competency, without input from a doctor:

*We do the testing for things like hepatitis B, HCV, HIV, treatments for Hep C, monitoring...In addition to that we also do primary healthcare, so that can range from leg ulcer dressings, we do sexual health testing ... And just any health problem that walks in the door... And then also we do things like working in harm minimization as well, so that can range from safe injecting practices, looking at someone's injecting practices, are they sharing? Also again addressing alcohol and also it's looking at managing liver disease as well. So anybody drinking, we'll do alcohol review, blood tests, but also that's incorporated in a physical assessment...any patients who are here and if they're wanting their Hep C treatment, or if we're monitoring for their liver disease, then we can arrange for them to see [Hepatology consultant] at the liver clinic, and then we'll follow up the person here. (BBV nurse, site A)*

The BBV nurses who run clinics at site B also provide a wide range of services, although unlike those at site A, they do not prescribe medication themselves and HCV treatment is provided through a separate clinic:

*We'll do a general health screen in respect of doing someone's blood pressure, height, weight, do their BMI ... we screen for the blood-borne viruses and that includes HIV, hep B and hep C, we check for hep A in case there's any need for hep A vaccine. We tag on syphilis because syphilis is a blood-borne bacteria but can be treated easily with antibiotics ... we do general health blood tests; one, generally speaking, a lot of the clients are alcohol dependent as well so it's to sort of assess the health of their liver and their general health. And, of course, if any of the tests come back positive, then we want to have an idea of what their health status anyway. (BBV nurse, site B)*

Such an integrated service is ideally provided by nurses with a wide range of experience, and both sites recruit experienced staff above NHS grade 7. As well as nursing experience, experience of working with PWID is important and understanding the issues they face, not only medically, but socially, is key to delivering effective services. Working with this client group can be challenging for service providers, especially when delivering outreach:

*It's a fairly specialist nursing set ... you've got to have a lot of experience, you've got to be willing to go and work out in the community, on your own, with people who can be challenging and have a tendency to violence and misbehave ... You've got to have a fair amount of experience and self confidence to take that role on; it's not an easy role. There is a good support network, etc, [BBV manager, site A] does a fantastic training but it's not trivial, and it's not for everybody. (Hepatology consultant, site A)*

Training and on the job experience is important for nurses in this role, as is learning from colleagues with relevant experience:

*I've done my mental, I spent two years as a key worker in a drug treatment clinic, and then worked for quite a number of years now in blood borne viruses... I think with the blood borne virus team the lovely thing is we've got nurses who've come from different backgrounds and it's about sharing each other's knowledge and experience, which just enthuses your own knowledge. So it's like we've had people who have come from midwifery in the past and it's lovely. I think with this client group...even if you've not had that background, I think just being able to develop trust and rapport. I've had experiences in the past, but we're going back absolutely years, working on a general ward where some nurses didn't know how to speak or how to approach people with drug and alcohol problems. (BBV nurse, site A)*

Understanding drug use issues is key to build rapport with PWID and to addressing and treating HCV, especially when co-existing with other morbidities. Often there are contraindications to HCV treatment – both mental and physical health – that may prevent a client from being eligible. Understanding these issues, particularly in regard to co-morbidity, is important:

*You do constantly work out whether hep C treatment is a priority. For example, what's happened is patients who inject, the big push, either their venous access becomes such they can't inject anymore or part of drug treatment, and harm reduction has been to get them onto smoking their drugs. So that's fine, but now, of course, what you're finding is that people who've been smoking the drugs for years have got COPD ... So you've got a 45 year old guy, a 50 year old guy who's got hep C and he's got COPD. So do you give them interferon, do you give them hep C treatment because interferon can increase lung fibrosis. If you've already got COPD and you're going to make that worse, you've got to make a judgement then; which is going to kill them first? Is it their liver disease from their hep C or is it their COPD? (BBV Manager, site A)*

While it is important for nurses delivering HCV treatment to have an understanding of D&A issues, it is also necessary for key workers have an understanding of HCV treatment, at least at a basic level. The D&A key workers at site A are mental health nurses responsible for drug treatment and the psychiatric health of the patients. They describe not having much physical health training, however in their first meeting with a new client they ask basic questions about the clients' health and offer a meeting with the BBV nurse on site who can generally see them straight away. The D&A nurses generally have more contact with clients than the BBV team and so it is important that they understand important aspects of HCV treatment so that they can monitor for problems:

*We capture a bit of that in our assessment, i.e., you ask have you ever had a hepatitis infection, this is something that you would need to look into... As I said, staff are now being booked into training because I think it's very important ... to be able to have such knowledge to pass onto the client because if they commence treatment, some of the side effects, it's just recently that the majority of the staff, especially new staff, junior staff like band 5 are starting to know that people can also have depression following treatment. It's something that we need to talk about in our key sessions, although [BBV nurse] is covering that, I think the main key worker who sees them more frequently than [BBV nurse] does, to have good knowledge to be able to pass onto the client. (Key worker, site A)*

As well as multiple physical health problems and drug use issues, service providers are aware of the importance of broader social issues for service users. Obtaining suitable housing and welfare benefits top the list of priorities for many service users and are linked to their ability to seek help for their health. Service users and providers describe a holistic health care approach as including social

care support access. Many service providers realise that in order for health interventions to be successful, social issues, such as housing, may need to be addressed first:

*I think that's where [HCV treatment outreach nurse]'s role is really important as well because she gets the opportunity to build up a bit more of a relationship with our clients because she seems them more frequently, or is involved in the referral process...she helps them out with filling out forms for their benefits or things like that. So she's seeing them for more than just their treatment I suppose, or more of that holistic approach than just the clinic on Thursday and what their side effects are. (Specialist liver nurse, site B)*

#### Key findings:

- PWID are more likely to attend services that attend to their immediate and pragmatic needs, such as NSP and acute health care. Engaging PWID in conversations about HCV treatment at these services can aid HCV treatment interest and uptake.
- Delivering effective integrated care requires a multidisciplinary team, who are able to share knowledge across disciplines.

#### Recommendations

- Training should be available for BBV nurses in D&A issues, and vice versa.
- Where possible, services should be available that respond to the immediate and pragmatic needs of PWID. It is recommended that information about HCV testing and treatment is incorporated into these services.

## Continuity of care

Service users described receiving continuity of care from service providers as very important to their treatment experience:

*A doctor can do their job better if they know your past, obviously ...I think it's important to keep seeing the same person. When you keep getting shoved from pillar to post all the time and you're having to explain everything all over again, it's much better to see the same person all the time and then they know where you're up to and you haven't got to keep saying it all. (Johnny, site B)*

Nat preferred seeing only one or two nurses for the duration of his treatment, not only because of the discomfort of sharing his story with many people, but he also felt that his psychiatric state could be better monitored by staff who knew him well.

*When you finally open up and tell somebody one thing, you don't want to then have to say the same thing to somebody else, which you may not have the same sort of rapport with. Or you may not be feeling the same that day and you may be very shut off. I think that was the point of the same people seeing you, so they'd get to know you and they'd know if you were acting a bit different, so they could actually see how you were getting on maybe better than you could yourself ... whereas if you see a different person every week, or ever two weeks, they wouldn't know that. They wouldn't know that normally, you're actually quite happy and*

*funny and today, you're a bit withdrawn, they could just think 'oh that's your normal personality and it could go by'. (Nat, service user, site B)*

Service users discussed a high turnover of D&A key workers in both sites. This was felt to be an inconvenience in terms of having to continuously start new relationships and a worry in that the new provider may not take their past history into account:

*When you got a new worker or, you know, just with your ordinary key worker and they open up the folder, you know, they're supposed to read what happened the last time but I know what a lot of my key workers did, they just didn't and they would just start afresh. So like I had a file that size with, you know, and my key worker will have no clue what's ... they'd read none of it so each key worker would just start afresh. (Dillon, site B)*

Many service users described their relationships with key workers as important support. They felt that it was important to build a level of trust with their key workers in order to honestly share their story and discuss personal issues. A high turnover of D&A staff undermines the ability of services users to commit to a service in the medium and long term:

*I didn't feel that where I was with this key worker, I wasn't 100% secure with him ... I was still using quite a bit and, you know, I was messing around a lot and I was going through depression and, you know, I just didn't have a real connection with anyone up there, you know, like the workers or anything ... I think it's pretty invasive sort of treatment, you know, you go through quite a lot of crap. So yeah, I think that you should definitely ... it helps a lot a lot to be able to talk to someone properly. (Davey, site B)*

*Only the last month, I see the same key worker for a month more than once. And she's saying now she's my key worker. In the last worker I didn't see the same key worker more than two consecutive times. How are you going to be a relationship? I don't feel comfortable telling my own personal relationship story between every month to a new person. Now, why do I have to trust you? I see you today, I never see you again. I have to come to give you my confidence. No. (Kaveh, service user)*

#### **Key findings:**

- Continuity of care is very important for service users. Services with high staff turnover or policies of staff rotation are likely to experience higher rates of service user disengagement than those where service users are allowed to build rapport and trust with staff over time.

#### **Recommendations:**

- Efforts should be made to ensure continuity of care at both D&A and HCV services. When staff turnover is unavoidable, good notes and thorough 'hand-over' procedures are important.

## **Co-located services: "one-stop shop"**

When specialist skill sets are not encompassed by one person, services can be co-located to ensure clients have access to as many skills as possible with minimal effort. At site A the hepatology consultant holds monthly clinics where he meets patients ready to commence treatment at the D&A service. The BBV nurse who is permanently stationed at site A provides the treatment and

monitoring to the clients as a nurse practitioner. D&A services are provided by the nurse key workers and overseen by the psychiatrists who run site A.

The complexity of the health and psychological problems faced by the clients attending site A is discussed by service providers as an important factor in having specialist on hand who understand their issues and can deal effectively with problems that naturally arise from complex cases.

*The reason why they'll be referred here is because we pick up more complex cases and we have it all, so to speak, here because we have a one stop shop; psychiatrists, you know, in house, we have nurses, we have the BBV team. So that treatment journey for the clients, when they actually come in for hep C treatment, will be monitored by more qualified people so to speak. (Key worker, site A)*

The concept of site A being a one-stop-shop is iterated by a number of service providers and users. Staff discussed the benefits for themselves in terms of support and efficiency, but also for clients in terms of ease of access.

*If you've got a walk-in clinic, it's like having a one stop clinic in a sense...And it has definite benefits for us...it's a mental health trust, so as the doctors are psychiatrists. (BBV nurse, site A)*

*I don't need to refer a client or do a referral form or maybe [BBV nurse] can walk into the duty room and grab some notes and have a read. So that's how easy it is. (Key worker, site A)*

*[Co-located services] would be fabulous, that's a dream because you've got - you don't have to worry about the couriers, the IT systems, the information if someone turns up. (Senior hepatitis nurse, site B)*

Service users discussed preferring to be treated at the specialist services, rather than in the community drug team (for site A) or the GP's surgery, as the one-stop-shop was more convenient and the other clients preferable to be around:

*I found it much better to stay here [site A rather than the CDT], it's quieter here...When I was undergoing the hep C treatment, the CDT give you a letter to take to your doctor, this is another day you have to go. One day is gone to get the letter and another day is gone to go to your GP to get the letter. Then the next day, you have to go down to the chemist to get your methadone and there's three days gone. Here, you come here, you just get your script, chemist and that's it. So instead of all this running around, the doctor does that here, straight here and see your key worker, explain if you're okay, have your tests, get your script, go home and take it down to the chemist. (Frank, site A)*

*I think it's got everything in the one place...you're in the building with like minded people whatever and it's easier. When you're sitting in the [GP's] surgery, I'm like I just want to get out of there sort of thing but in [site B] I'm a lot more relaxed...Well as far as I know, I can do virtually everything at [site B], other than probably just speaking with the consultant beforehand. (Dillon, site B)*

With the addition of the HCV treatment outreach nurse to the team at site B, D&A key workers are now able to refer their HCV positive clients to her for advice and information, progressing to treatment where appropriate. Making her presence known and informing key workers of what she can do for their clients is important, as is making contact with the clients so they know who she is and understand her role at site B.

*A lot of key workers you know, I reminded them, look I'm going to be here if the client comes in for their one-to-one session, I'm here, I've popped out to say hello, can we book a time for them to see me ... I put flyers and leaflets around ... I've written to clients as well, just we're doing awareness morning, coffee mornings, we've got world hepatitis, we do coffee mornings, next Thursday we'll be doing two more just to kind of keep raising, keep that in the forefront that people, key workers will remember ... it's going to depend on the individual, some people respond better if you are more direct, you know, invitations, others might be kind of building up sort of slowly and asking around their health and other health issues. (HCV treatment outreach nurse, site B)*

Consultant-level involvement is important for making difficult judgement calls about the suitability of treatment for complex patients such as PWID with co-morbidities. site A is run by a consultant psychiatrist who has overall responsibility for the D&A services and psychiatric health of the clients. A monthly liver clinic at the site is run by a consultant hepatologist from a neighbouring hospital with one of the BBV nurses in attendance. Here the two meet clients considering treatment and work with them to provide advice and help make treatment uptake decisions. As well as contributing important information about the service user's recent history, the presence of the BBV nurse can help alleviate any stress the service user may feel about the meeting with the consultant:

*It will be one of us [BBV nurse] and it will be the hepatology consultant and the patient ... We're familiar with the patient, the hepatology consultant may only see them once and that's it ... although our records are very clear, we will have much greater understanding of the background ... of crucial information about the patient, of how the system works really, as far as our perspective is concerned. So, you know, we can discuss and often guide the hepatology consultant around certain things. So for instance, if they've had mental health problems recently, we'll pinpoint that or we'll say 'I don't know if you realise...' or they've had a biopsy in the past, we know all those sort of things. Or this is a difficult to handle patient ... there's a familiar face, the fact that I say to patients, you know, [BBV Manager, site A] or I will be here, alleviates a lot of anxiety. (BBV nurse, site A)*

Clients with complex psychiatric and physical health issues require input from both physical and mental health services to decide if treatment is appropriate for them. The BBV nurse coordinating treatment can liaise with both consultants to ensure all aspects of the individual's health are taken in to account.

*[Consultant hepatologist] doesn't necessarily get involved in the mental health side of it. So a patient comes to clinic, he assumes we've already assessed the patient in some way that we think well we know they've got mental health but they might be suitable for treatment. So he'll see them from a physical point of view and then we'll get the psychiatrist to see them and assess them from a mental health point of view. (BBV team manager, site A)*

This level of support is important not only for the clients to receive optimal care, but also for the nurses delivering the treatment at site A to feel confident and supported. Liaison and communication with specialist providers means that they can be confident in the decisions they are making. The likelihood of interferon triggering psychosis in a service user is rare, but an important factor in decision making. Community based treatment must be safe, and expert monitoring is important to ensure clients are responding well to treatment.

*In terms of support for the patient, I don't think it's any more support necessarily, it's support for us...because if we're pushing a patient on treatment, they're starting to say they're getting depressed and they're starting to maybe get paranoid and maybe they're starting to carry a knife, I need the psychiatrist to say 'well actually, let's change your medication, I'll*

*keep my eye on him for two weeks and we'll see how he goes'. Or 'actually, no, I am going to get him sectioned to the hospital' or 'no, he's getting where you need to stop his interferon'... it's support for us around managing the safety of it, which we wouldn't get in the community if we were at a drugs service and the patient turned up paranoid and carrying a knife and they were living in a hostel. (BBV team manager, site A)*

In addition to the hepatology and psychiatric consultants, there are other resources the BBV nurses can call on in difficult times:

*We've use the Assertive Outreach Team, which is the mental health team that will go round to people's homes and see them that way...we use GPs, ...if we're really worried about someone, we'd do a home visit... So we kind of look around, which is probably easier for us than a hospital based service; we know what services are out there, we know at that hostel, okay, yeah, they're not nurses but they're really good at looking after the patients. They'll go knock on the patient's door and they're sensible and they'll say yeah, they're alright. We know where those services are and it's about knowing where your patient is and who you can call on for support. (BBV team manager, site A)*

At site B, D&A key workers make referrals to psychiatrists, however, the timing of these referrals was often after treatment had commenced, and earlier contact may have been useful for clients in need. Although Jed didn't experience any severe problems while on treatment, he did feel that he could have benefited from earlier intervention:

*My key worker, she's often said to me, if you want to see anybody I've got access through here, I can come here and see a psychiatrist... I was told that I would be seen by one but they just didn't say when. .. and then I got the appointment through and ... it's a bit daft, why have it that late?...I'm not saying it would be useful for me particularly to see him earlier, but thinking about it logically it's quite a long time isn't it into your treatment. You would think they would make it a little bit closer to the beginning of the treatment. (Jed, site B)*

While the co-location of HCV and D&A services was generally described positively, some service providers described possible tensions – particularly when providers offering different services had different ideologies or goals around drug use, for example:

*I do think that there's something about all their contact with healthcare being about their drug use ... we'll treat them like anybody else would be who's going through a course of treatment. So we don't focus on their drug use particularly at all and I think it does work better that way...I don't see why drug workers couldn't do it but there may be some conflict around patients trying to address their drug use and actually, you saying no, I want you to keep that the same while you're on treatment, I don't know. Even nowadays, I think there are still some drug workers reluctant to give patients needle exchanges because they feel that it's a bit of a conflict there, you're trying to address people's drug use but you're giving them a needle exchange. (BBV manager, site A)*



**Key findings:**

- HCV treatment decision-making for complex patients requires input from a wide variety of specialist service providers. Timely input regarding an individual's physical and mental health as well as their social and living arrangements are key to making good decisions and effective monitoring of patients throughout their treatment.
- Co-locating physical and mental health services on one site can be beneficial for both staff and patients, reducing referral and waiting times, cutting down on administration, improving communication and generally being more efficient and convenient.
- Many PWID prefer to attend services specifically designed for their needs, away from general services where they may feel discriminated against or services may not cater for their needs and issues that affect them. However, this is not universal, and some people, those who no longer inject, for example, may prefer to avoid places designed specifically for PWID.

**Recommendations:**

- Services providing comprehensive physical health care services alongside mental health services are extremely well placed to integrate HCV treatment in to the repertoire of services they offer at little additional cost. Establishing regular HCV clinics supported by nursing staff who have regular contact with the service users is an efficient way to reach a wide number of clients.
- Services providing integrated mental and physical health services should move to integrate some level of social support, or a liaison with social support services, to improve the social well-being of the service user, reduce stress associated with dealing with housing or financial issues and improve uptake and adherence to treatment
- Where a number of options for treatment location exist, service user preference should be taken in to account when deciding where to treat.

## Phlebotomy, prescriptions and opiate substitution therapy

### **Phlebotomy**

Key to successful treatment engagement is the co-location of a skilled and non-judgemental phlebotomist with the D&A and HCV treatment services. PWID often have difficult venous access, and many describe harrowing and stigmatising experiences having blood taken in the hospital setting:

*I kept on saying to [hospital phlebotomist], 'Look, you know, my veins are a nightmare, you know, let me do it'. [She said] 'Oh you people, you think you know about your veins and all that, when you know nothing'. (Dillon, site B)*

Hospital phlebotomists may not have experience drawing blood from PWID and/or be limited to which veins they are allowed to take blood from:

*The [hospital] phlebotomist is only trained to – 'allowed' to take blood from the arm, nowhere else, that's the first place that in PWID that the veins are shot. So they'll stick them six or seven times in a hopeless attempt to get blood out of them and then they won't turn up again. It is*

*traumatic ... I think they need to trust you somewhat before they allow you to stick pins in them. (BBV nurse, site A)*

The partnerships, in contrast, provided on-site phlebotomy services with relaxed protocols, in which blood was able to be taken from sites such as the groin and neck, and in some cases by the service users themselves. Key to developing trusting relationships was the ability of the phlebotomist to listen to and work with the service user around the often fraught issue of venous access:

*I've had clients come that immediately say "you're not testing me because nobody can get blood off me, I'm not having you poke around and stab me". Then I'll just have to get through that barrier and ... listen to them because very often, they do know where the vein is because they use their veins to inject so they know which veins. (BBV nurse, site B)*

In addition, flexibility was negotiated not only around the sites of venous access, but the amount of blood to be taken:

*You're only doing what is absolutely crucial. I've researched the minimum volumes for each test so we have that information. (Senior hepatitis nurse, site B)*

### **Prescription access**

While a number of the site A BBV nurses delivering HCV treatment are able to prescribe medications, not all medicines are available from the same site. In site B the nurses delivering HCV treatment are unable to prescribe treatment for side effects and so refer clients back to their GPs to receive medication support. Financial constraints also play a part in who prescribes what as some services, such as GPs, are more able to prescribe expensive medications than others: "The weight loss, again, Ensures, we can't prescribe them. Do you know how expensive they are?" (Consultant psychiatrist, site A). Service users also suspect a financial motivation for the separation of services:

*I'm on antidepressants...Metazapine...they used to do it here but now I go to the GP because for some reason, they're not getting paid or something, I don't understand. But no, I have to go to the GP to get them. (Carol, site A)*

Although the hepatitis nurses in site B have experience of useful medications for side effect control they can only make suggestions, not prescribe themselves. Good communication with GPs who write prescriptions can help ensure service users receive appropriate care:

*We might suggest something, but that's all, that's all we can really do because we're not prescribers ourselves, but just suggest perhaps something that might help. But then, ultimately, it's up to the GP because they're the one that is prescribing it. But try and use that clinic letter to give as much information as possible so that then the GP can make a decision quite easily with all that information. (Specialist liver nurse, site B)*

At site A service users may be referred to either to the attending psychiatrists or their GP for depression medication access, depending on which is most appropriate.

*It might be the psychiatrist here [site A] who advises that they go on to antidepressants and they'll ask the GP to do that. But that's a dialogue that they'll have between the psychiatrist and that usually happens before we even start treatment... Some services deal with a lot more drug users than other services, whereas some GP services only have one or two patients on methadone and therefore, they may not be that familiar with our service. Whereas others, you know, have a lot of patients with drug and alcohol problems, who are*

*very familiar with our type of work and work that much more closely because of that, work much more closely with us. (BBV nurse, site A)*

Some service providers felt that referral to a GP for side effect medications was not sufficient and that medication known to help deal with common side effects should be automatically given to clients receiving HCV treatment, by the treatment providers. Immediate provision of medications in anticipation of likely side effects was described as important in maintaining service user adherence:

*We had antiemetics, had antihistamines for the skin, topical antihistamine for the skin, pain relief obviously, simple pain relief for headaches ... If they come and they've got an irritating rash from the treatment, you give them cream and you give them an antihistamine, that helps them get through the treatment ... I think that's really key in keeping clients- I mean I think everybody should have that standard, everybody that's having treatment, not say 'right, okay, you need to go to your GP and ask for an antihistamine or go to the counter and buy a £6 box of Piriton', it's not going to happen ... No, and, you know, antiemetics, you know, because ribavirin makes you very nauseous and you have to take it twice a day, 12 hourly, so the morning and the evening. So the morning's your breakfast, you know, so you're taking this medication, you feel nauseous, you don't eat. So you've got a real problem there in that, you know, suddenly if you have an antiemetic that you can take prior to having your breakfast, you're just more likely to get through the treatment. (BBV nurse, site B)*

Some service users who received side effect medications through their GP were happy with the situation. Jed described being able to discuss the options of anti-depressants with his GP and make a decision based on his needs, rather than taking the standard medication recommended by the HCV treatment providers:

*They [HCV treatment team] wanted me to take for a certain type anti-depressant but I actually chose another type through my doctor and done it that way...they suggested this particular type but I actually discovered one which I found was quite helpful for me. (Jed, site B)*

Regardless of what the prescription is for, service providers at both sites are clear that communication with the prescribing GPs is vital to ensuring clients receive the appropriate medication to manage the HCV treatment side effects. Despite clear communication, GPs may not be willing to prescribe anything strong enough to deal with the severe pain experienced by some service users whilst receiving treatment. This may reflect a reluctance to prescribe strong opiates to clients with a history of opiate dependence.

*Pain relief can be something that we require the GP to help out with ... I can't even give you any specific examples, just some people have been prescribed naproxen or something like that, just another anti-inflammatory that isn't available over the counter. Not that we expect GPs to be prescribing morphine or anything like that for pain relief, but yeah, just something that isn't available over the counter, or that perhaps needs more careful monitoring, the use of it or setting up guidelines for how often they should be taking it, rather than just going to the chemist and picking something up. (Specialist liver nurse, site B)*

Consultants with little understanding of PWID and no experience in a D&A setting may not understand the needs of these patients and the importance of pain control. This can lead to unintended consequences such as patients self-medicating by injecting heroin for pain relief. Charlie had not used opiates for seven years when he made the conscious decision to control the side effects of the HCV treatment by injecting opiates as the hospital services would not support him with the pain control he needed:

*I started using again because I'd never felt so ill as the interferon made me feel. This was six months after I started using it, I started using again and that was a conscious decision I made to control the way I felt because it was unbearable. I couldn't live like that really, it was that bad, and it wasn't getting any better. I was told by the consultant, last time I saw him, was told I was talking a load of rubbish, that I was feeling ill ... I think I was advised the paracetamol, I think that might have been about it but no, I wasn't given anything, prescribed anything ... Nobody listened to me over there, not once you start feeling ill, they don't want to hear that, they didn't want to hear that. So it's important that someone hears what you're saying (Charlie, site B).*

### **Opiate substitution therapy**

Engagement with drug treatment, especially OST, has been shown to enhance HCV treatment access, uptake and adherence among PWID [22]. For some service users the side effects associated with HCV treatment may be ameliorated somewhat by an increase in their OST prescription for the treatment duration. Service providers recognized this, and also discouraged OST reduction while the service user was on HCV treatment:

*Whilst you're having this treatment for Hep C, everything else should remain more or less steady. Because the Hep C treatment can be quite destabilising, we don't want to add in another factor that might also destabilise you. ... [HCV treatment can be ] exhausting, fatiguing, depressing, might make you psychotic. So what we don't want to do is add another psychological or physiological stress by reducing the methadone. (Consultant psychologist, site A)*

From the service user perspective, the most common concern was restrictions around OST pickups. For those who were experiencing side effects from the HCV treatment, having to attend the chemist every day to access their OST could be difficult:

*Since I've been on the [HCV] treatment I've been very, sometimes I just don't want to go out, just want to be left alone ... I just don't want to go into the chemist every day ... me taking it [methadone] supervised ain't helping me. (Hakki, site A)*

An additional concern was the way that receiving supervised consumption was perceived by many service users. It was experienced as sending messages about the service provider's level of trust in them, which could lead to anger and disengagement. Hakki who was halfway through his HCV treatment regime at the time of the interview, said:

*I've been on the [methadone] script for about 8 months now and they still supervise. I don't know what they think I'm going to do ... I'm too angry with the system at the moment. I don't really engage ... what pisses me off is why don't they trust me? (Hakki, site A)*

In contrast, service users who received OST takeaways (only having to attend the chemist one to three times a week) spoke of the freedom this provided them, also making a clear association between OST takeaways and trust. Jeff who picked his methadone up once a week said:

*Knowing that I've got it [methadone] there, to wake up to in the morning. I haven't got to rush out to get it at the chemist before I've even had a wash ... I get it weekly, I've been trusted for a long time. (Jeff, site A)*

This was experienced as particularly beneficial while he was on HCV treatment:

*Yes, because not only you had the hepatitis [treatment], you had - the last thing you want is to run out to the chemist and get your medicine and come back. Knowing that it [methadone] was there, it was one more thing off your list that you had to do. So it is a great help having it there. (Jeff, site A)*

OST access arrangements were found to be interpreted in terms of trust by many service users. Positive messages regarding trust instantiated in the provision of OST takeaways were also drawn on by service users to inform personal notions of agency, responsibility and self worth:

*I had a stage when I was supervised and after I was unsupervised. And now I'm still unsupervised. So take that [OST] home, and in that way, I can deal with my bits what I need to do daily. If you don't do it, who's going to do it? ... You're not a kid no more. If you don't care about yourself, then that's when you'll stop doing what you're supposed to do. (Mick, site A)*

#### **Key findings:**

- PWID often have difficult venous access and can experience having blood taken as stressful and potentially stigmatising. This can be a barrier to treatment uptake and completion.
- Service users often require a variety of medications to manage the side effects associated with HCV treatment. They report finding it most convenient when the medications are provided by the staff providing HCV treatment, or from the same location. When this is not possible, clear communication between the HCV treatment service provider and the prescribing service provider is important.
- OST access arrangements were found to be interpreted in terms of trust by many service users. Takeaway provision was found to be extremely beneficial especially for those experiencing HCV treatment side effects.

#### **Recommendations:**

- Services need to provide access to a non-judgemental skilled phlebotomist (preferably onsite) who has a remit to access veins such as the femoral and jugular and is open to letting service users draw their own blood.
- Medication used to control common side-effects should be provided to patients embarking on treatment to prevent simple problems that can affect adherence, without the need for additional visits to services. Pain relief and anti-depressants are two of the most important medications prescribed by this group and serious considerations must be given to the most appropriate medications to deal with these issues, involving consultation with the service user.
- Appropriate and sufficient pain control should be prescribed to prevent service users self-medicating with street drugs.
- Where possible allowance should be made for people on HCV treatment to have access to OST takeaways. Increasing OST dose while on HCV treatment can help with side effects, OST dose reductions while on HCV treatment are generally not recommended.

## **Information sharing**

Because of the often complex networks of service providers looking after clients, communication between them needs to be clear to ensure everyone understands the required treatment regime.

Just as there are many ways that services providers communicate together, there are many barriers that can prevent this communication being effective.

Joint meetings between service providers and the clients was seen as an important way for bringing different types of information together and making well considered decisions:

*The other difference, which was actually terribly helpful, was [BBV Manager, site A] was in the clinic where we saw them together... [BBV Manager] would give me the lowdown on their past medical history, drug taking etc., other medical issues and we would then make a joint decision on whether or not we thought we could treat them ... [BBV Manager, site A] would chip in with things that I tended to forget about in the early days, like have you got a partner, have you got anywhere to sleep, the sort of minor things that I don't normally think about or worry about. [BBV Manager] would invariably have background knowledge about previous problems so if that individual had had psychosocial problems in the past, [BBV Manager] would know about them from their meeting... So that in depth knowledge of that person as an individual, rather than a HCV infection brought a very important dimension to that. (Hepatology consultant, site A)*

*If somebody came up...and they're saying they're struggling for whatever reasons and started using it would be probably a three way, we'd sit down together, key worker, client sit together and say 'look what is the way forward', for the doctor or whatever and say if it's a possibility let's increase it [methadone] for now, especially if they're using. (HCV treatment outreach nurse, site B)*

In this situation it is important that more junior staff are able to share their expertise, which is often a detailed understanding of the individual client, with more senior staff such as consultants. The hepatology consultant at site A describes the value of having a non-hierarchical team delivering HCV treatment, especially when problems arise:

*We see it is a team approach and it's never been an issue, we've never seen the nurses as nursing staff, they're part of the team that sort the patients out. So again, there aren't barriers, it's a very non hierarchical approach. [BBV Manager] will phone and if she thinks I've got it wrong, she'll tell me, and rightly so and that cascades down so other nurses will phone me...Any member of the team has got my number and they'll phone me if they've got a problem and they'll email me with issues so there aren't any concerns about people will pick up the phone if they're worried about a patient at any time. And I think that's very important, to have those contacts and those pathways, and that people know that if they're struggling, they can get hold of someone. (Hepatology consultant, site A)*

As well as ensuring good clinical decisions are made for the patients, this type of communication were able to trust that they would receive support from the consultant if anything went seriously wrong with the treatment:

*You have to recognize that their [service provider] heads are way above the parapet ... There is a judgement call about is this person sufficiently depressed to make it safe to carry on, is that low white blood count worrisome or not, is that little infection they've got something I should be worried about. So they are exposed and if it goes wrong, people are going to poke fingers. So they need to know that if it all goes belly up, I'll go to the coroner's court and hold their hand. (Hepatology consultant, site A)*

Service providers who work in the same building can share important information in general and clinical meetings. At site A the BBV nurse attends the regular D&A clinical meetings both to learn and share information about clients and their physical health care, including HCV treatment.

*We run a clinical meeting once every Tuesday morning ... [BBV nurse] attends our clinical meeting once every month ... [BBV nurse] will then capture those people who've started HCV treatment and people that we're planning, or their team are planning to start on HCV treatment or people who may have HIV and he may have done tests and if there's anything he needs to feedback to the team, he would then take that to the clinical team meeting and present it ... Before the day that he would attend, he would have sent an email round; 'I'm attending your clinical team meeting on this day, is there any client that you may need to discuss about?'. (Key worker, site A)*

Outside of the clinics located at the D&A sites, service providers use clinic letters to communicate with other relevant service providers. As GPs often provide support for side effects and the mild depression that accompanies HCV treatment, it is important that they have up to date information about the status of a client's treatment and current health. Service providers at both sites describe writing clinic letters after each appointment.

*We inform GPs, that's the least we do...usually they receive a clinic letter to say that the patient's being offered treatment ... then we send out a letter to say that we've started treatment, that we've stopped treatment and sometimes, in between treatment, we may update GPs about patients, if they've got particularly complex needs, so for instance, they do have mental health ... If there are events that happen during that procedure, we usually inform the GPs as well. (BBV nurse, site A)*

Service providers at site B describe how clinic letters appear to be working well as a medium for communicating with GPs, although there may be situations where a telephone conversation may be necessary.

*I haven't noticed any problems at all or haven't come across anything. I don't know, some service users perhaps come in and say that they do have difficulty with their GP, perhaps prescribing them extra things for their side effects, or just a difficult relationship ... I haven't had any problems at all, and as a team, we're quite open to any of the GPs calling for any extra information that they might want, or just to ask us questions. (Specialist hepatitis nurse, site B)*

Unlike site A where the BBV nurse is on hand, the hepatitis nurses at site B visit only once a week and relies on the HCV treatment outreach nurse to provide a link to clients at other times. The hospital is not near site B, so it is important that communication is clear and effective so as not to undermine the treatment.

*Because [site B] is so far away, if they [miss the clinic], you couldn't deal with them, but [HCV treatment outreach nurse] could deal with them because she's there ... for support, to act as a liaison and as a link to us because she would be able to access me directly, she'd just phone me on my mobile, she'd pretty much know my movements so she would be able to phone me and say 'this person is absolute crisis, what shall I do?' Or 'this person has run out of meds, is there a script there ready for them, can you arrange it?' Or 'this person's turned up, they're really itching, what antihistamines would I recommend?' so very simple things. So she's there to sort of be a trouble shooter there, which she's very good at... because it's no use going over there once a week 'there's your treatment', you know, being as sort of helpful and friendly and informative and then not being there for four and a half days, five days a week,*

*they need to know that, and especially during the early phases of treatment, that there is someone there. (Senior hepatitis nurse, site B)*

For Davey at site B, the HCV treatment outreach nurse's good working relationship with other service providers and her understanding of the service was a key benefit to receiving treatment there. Her knowledge meant she knew who to communicate with and did so efficiently. This was a stark contrast to the communication problems he had previously experienced between the hospital and his D&A service:

*[HCV treatment outreach nurse] ... where she's good, she knows all the people there, where she's worked there, she sent a message to my key worker ... about what's happening and they've got that sort of like connection anyway because they've worked together and, you know, it all just feels friendlier and nicer and everyone knows what's happening and they've gotten in touch with my doctor and he knows what's happening and what to expect ... So they're doing a lot of work behind the scenes as well, you know. And that I just feel like everything's a bit more secure with it all, you know, rather than going to the hospital and no-one knows ... nothing's being talked about, no communication between the two [hospital and D&A services]. (Davey, site B)*

Although Davey understood and appreciated service providers discussing his case, Neil was unhappy about the letters between service providers communicating his issues. After having experienced sensory hallucinations while taking interferon, Neil had been removed from treatment as providers were concerned that he had had a psychotic reaction. He did not agree with their diagnosis and felt it undermined the difficult experiences he had while on treatment. While this may be attributed to poor communication between the service providers and Neil, he now feels disconnected from the services and feels unable to be honest about his experiences:

*When I came here and I started it [treatment] here and they were writing reports and letters about me and saying that I had some kind of psychotic episode or reaction to it... This is the psychiatrist, [BBV nurse] and [key worker] ... I don't really understand what psychotic is or the birth of it and what actually determines what you call something that's a psychotic thing or whatever. What happened to me, it wasn't fabricated, I wasn't deluded out of my mind, I know what I felt, I was totally honest, it was an experience that I felt. I don't think I'm mad or that I've got what they say, a psychotic problem. When they do actually suggest and tell me that, I feel quite offended inside. I still come back here for treatment but between me and you, half the time, I don't tell anything to them, I just grin and bear it. (Neil, site A)*

Ethical considerations arise in the sharing of confidential information between separate medical teams. D&A service providers at site A describe obtaining oral consent from service users to discuss their case with the BBV nurse, and vice versa.

*How that works is if the patient's happy, then it's alright for us to know everything that's going on with the blood-borne virus team, and vice versa. Although the protocol for vice versa is, I'm not sure, but I usually ask the patients, is it alright for me to copy the letter to your key worker, [BBV nurse] ... So it's never been an issue. Now from [BBV nurse]'s point of view, if we've asked the patient and the patient is happy, then he's happy to disclose whatever. So no, that's a non issue. Whenever I ask the patient, sometimes they say 'oh I assume that you were doing that anyway' because we're all, you know, in together. (Consultant psychiatrist, site A)*

Service providers acknowledged that although few service users raised concerns about sharing their information with other service providers, some were reluctant for certain information – such as drug



use – to be shared. The BBV nurses may be more aware of an individual's drug use behaviour than the D&A nurses, but instead of breaking confidence they will discuss the benefits of honest communication with the client and encourage them to talk about their drug use.

*There are sometimes confidential issues, for example, a client comes in and maybe has been saying to the key worker that 'listen, I'm not using anymore, I'm not injecting anymore'. He'll go to see [BBV nurse] and say 'I need needle exchange but I don't want my key worker to know', that kind of thing... He'll give them talks like, you know, 'if you're withholding information like this, how is your key worker going to be able to help you' and all this kind of thing. But he would then give information about safety injecting ...but other than that, somebody might come in and say 'okay, I've got HIV, don't tell my key worker'. [BBV nurse] will say 'okay, I'm going to keep it to myself'. (Key worker, site A)*

At site B governance issues were identified as making communication difficult when hospital hepatitis staff were working out in the community, such as at site B. Staff have developed innovative ways of sharing data that do not breach ethical codes, although they may be more time consuming and less efficient.

*It's been difficult ... going back to [site B], we have a [D&A services] laptop and initially, it was set up so that we would be able to access [hospital] systems. Because you cannot transfer records on paper between the two sites ... So we've had to find all sorts of ways around, we've had to send information via NHS net, we've had to sort of make notes with just initials on so that confidential information isn't identifiable. I had to actually hire a car last week, World Hepatitis Day, and get the receipt for it, for the transportation of the samples back with all of the patients' information on. (Senior hepatitis nurse, site B)*

### **IT systems**

Formal communication procedures between NHS service providers generally rely on a number of IT systems that store patient data for clinical and statistical purposes. However, as no database is NHS wide, most services and locations have their own systems which cannot be accessed from other locations or collaborating teams for ethical and logistical purposes. At site A where the D&A and BBV teams are co-located and work very closely together, the two teams still have separate IT systems. Because the BBV nurse cannot access the D&A database, he refers to the paper files maintained by the team to access information about clients.

*We've got two completely separate systems... We deal with their substance misuse, it's like their key working, their motivational work, urine testing...whereas [BBV nurse] deals with the more medical side, the hep C, the hep B, the blood investigation and stuff like that... I guess it is two completely different services that are about the same clients...The addictions unit doesn't have access to [BBV IT database], the BBV doesn't have access to [D&A IT database]. So while we may work together, we work on two completely separate systems on the computer... [BBV nurse] has access to all the [paper] files, he can go and help himself to the files, that's fine. (SAU Administrator, site A)*

The administrator of the D&A service at site B describes how compartmentalised the system is and how duplication of effort can occur between the two co-located teams as well as between D&A teams in different sites.

*When it comes down to it...he doesn't need my system and I don't need his system so it's just kind of a bit weird really...It's like service compartmentalised...I mean the [D&A service at neighbouring location] can't access my caseloads, I can't access their caseloads. Like if I wanted to see if one of our clients was known to them, I'd actually need to ring them and say*

*'hey, is this person known to you?' ... But the only thing that'll ever show up to me is like it'll give me a warning saying this client has the same name as somebody else. But if it doesn't have the same date of birth or anything like that then no, no worries...It would be nice to have wider access across the three specialist addiction services. (SAU Administrator, site A)*

Similar problems arise in site B, where the hospital hepatitis and the D&A IT systems are incompatible. The D&A service database does not hold, or easily retrieve, information about the service users HCV status. This has proved frustrating for the HCV treatment outreach nurse at the service, in that she does not have this aid to locate HCV positive clients with whom she can discuss HCV management and treatment:

*Unfortunately the database they have here [site B], that's [D&A IT database], that should have people who are hep C whatever on [D&A IT database] assessment form...there's still not a system that you can just type in and bring up who's HCV positive, so the computer system is no good, sadly, but this is what you're up against ... which would make life ... fabulously easy and then you could say what the percentage of people who are hep C positive and work with them but the way I have to do it is go through each key worker and see who they've got on their caseloads and they kind of try and refer to me. (HCV treatment outreach nurse, site B).*

Service providers discussed how important collecting indicators of services provided are for determining future healthcare commissioning priorities. In addition to the studies suggested by the service provider below, IT data bases systems are key in collecting such information, although it seems they are not currently collecting such data at site B.

*Well, the outcomes will be, well, it would be number of tests, number of patients that are assessed, number of patients commenced on therapy and outcomes from therapy. So I think there are some very clear endpoints from that ...The education, the understanding, the widespread client and key worker view of what blood-borne viruses are and to raise the agenda ... raise blood-borne viruses on the agenda of commissioning. (Consultant hepatologist, site B)*

A nurse at site B described how closer collaboration between IT services at the hospital and D&A services at an early stage in the planning process could have made life easier for service providers using the systems.

*I think sort of perhaps a bit more sort of talking between the two IT teams at an earlier stage because it's almost as though you're sort of pushing and pushing and pushing and nothing's happening. (Senior hepatitis nurse, site B)*

**Key findings:**

- Clear communication between service providers involved in an individual's care is important for ensuring that the correct decisions are made and optimal care is provided. Modes of communication can vary depending on the service location and the provider skills, but can include patient appointments attended by multiple service providers, clinical meetings between service providers, shared access to IT databases and clinical letters
- Ethical considerations should be given to how information is shared between teams and locations. The sharing and storing of data is a sensitive matter and it is important to have protocols in place that ensure patient confidentiality is respected, while allowing service providers to fulfil their roles as efficiently as possible.
- Many IT systems are designed with the needs of funding bodies in mind and are inadequate for the needs of multiple teams working together.

**Recommendations:**

- Clear communication pathways are needed for service providers involved in an individual's care, with specified routes of contact for routine and urgent information.
- Patient consent should be sought as early as possible with regards to sharing relevant treatment information between teams.
- IT systems need to be designed with the needs of the staff accessing them in mind from the very set-up of a service so they record sufficient information for the right purposes, and avoid duplication.

## Formal partnerships and funding

Although service co-location and good communication is important across all services, formal partnerships between services can be a way of ensuring the continuum of care and the standard of services offered across communities. Shared care agreements formalise the relationship between primary care providers such as GPs who in this case would provide D&A services with support from specialist providers, such as those at sites A or B.

At site A, formal shared care with GP services is limited to a service that specializes in homeless clients. This has led to much closer working with that service than others in the area. The D&A service at site B is part of a consortium of D&A organizations working with local GPs that provide shared care facilities in that borough. The politics are complex, but this service user who has some involvement with service provision summarises the pros and cons of merging services.

*"[site B] and [other D&A organizations in the area] have now formed a consortium. So if you were to turn up, say at [D&A service] you should get the same treatments as you get at [site B] or at [other D&A service]... it's worked out good because...there's so much stuff there, like legal clinics, benefit clinics, you know, complementary therapies, then there's all the pre-detox, relapse, all that sort of stuff. That's been really good but the crappy thing has been that it's kind of merged all the staff so workers from [D&A service] have been moved in because when they formed the consortium, that's shone a light on what they do at the service ... and the rest of the consortium got to see the numbers, they were full of shit ...and the service users were noticing, wait a minute, this person knows nothing about drug*

*treatment, you know, and it's really kind of shone a light on- on, you know, the working practices down there. (Dillon, site B)*

The integrated client pathway was described by a service provider, below. He explains how following an initial triage and 12 weeks assessment, clients are either assigned to GP shared care – with support from specialist services – or receive direct specialist support at the D&A services. Again, the complexity surrounding the clients' situations described at site A is used here to distinguish between clients who can be managed by GPs and those who need to remain under more specialist supervision:

*If you have a drug or alcohol problem you can either present here or to one of the other hubs and have a triage assessment. Or you can go to your GP and more than likely they'll be a worker based there so the GP just books you in. Either way you'll have the triage assessment. If a client comes here and is assessed for a drug problem, they will be allocated a key worker from the assessment and treatment team whose job will be to work with that client up to 12 weeks. So within that 12 weeks they should have dose assessed them, stabilised them on some substitute, opiate replacement, like methadone. So within that 12 weeks there should be a good idea of what's going on with the client... And then either before the 12 weeks or about the 12th week mark, it'll be discussed to see what's more suitable for that client. If they've achieved a certain level of stability, and they've no other major issues going on around housing, mental health issues, physical health issues, where they're injecting, if they've got abscesses, things like that, if we see them as being quite stable, we'll then transfer them out to the shared care team... Now if there are more complex issues going on, be it physical or mental health, they'll be deemed as kind of too complex to be managed in primary care. So then they'll go to the central care team who are based here in [site B] and there's some over there [D&A site]... So we'll just stay here until such times as they may be suitable for GP prescribing. Some of them might not be, some of them might never be. And it could just be that they never, ever stabilize to a main optimum in a sense, so they carry on injecting or they have schizophrenia, things like that. So they'll just remain here. So that is for the more complex client. ( Clinical lead shared care, site B)*

This service provider described the consortium working in more detail and how the shared care aspect of it works. He considers the success of the model down to careful planning and involvement of staff and service user representatives from the beginning. Staff are managed matrix style, with formal management remaining within their organizations, but clinical oversight from the relevant team leader which can help ensure consistency across the consortium:

*It was really bringing sort of the best heads and teams and all of the teams within the borough together and now they're work amalgamated and split into these three teams of assessment and treatment, central care team and shared care team, with a kind of a recovery focus team all over each of the teams ... It's integrated in such that there's no - each of the three teams are made up of all the staff from the other organizations. We're not their line managers, they still have a manager representative to the organization that employs them ... They have clinical supervision with me and they'd have some form of line management supervision from the others. So when I meet them it's purely around the case load and any clinical issues that they have ... The thing is when we developed a consortium we involved the staff and we involved the service users. And we had awaydays to present the model. And we really sold it to people, to the staff, and I think they could see the benefit, certainly for clients in the borough. (Clinical lead shared care, site B)*

Ben is a service user at site B who described being moved from being managed by site B to a GP surgery under the new scheme. He wasn't consulted about the move, but was persuaded that his

needs would be better served by the new system. He expressed being happy with the current situation.

*They were the ones who changed it [to GP shared care]. It was the system, their system was changing so they told me, it wasn't my choice, they told me I would have to move. That was the system they were coming up with now, they thought it would be easier for me if everything was under one roof so I don't have to come here and go there for something, you know ... So I prefer it ... it was a thing that was just happening, the system was changing, yeah. I think it just freed up more space here, maybe they were getting more people coming in, so it's, you know, people that didn't really need to come here, just to pick up a letter and see a key worker, you know, once every two weeks, they thought it would be better to move some. (Ben, service user, site B)*

Despite site B delivering shared care as part of a consortium, the funding stream for the D&A services and the GPs remains separate, and service users may consider that staff have financial motivations for switching them from specialist care to GP-led care, which often entails less contact – a fear for some service users:

*But they aim to move, you know, most of us out into the surgeries because it's a different pot of money, totally different. You know, and we're cheaper to them to have us in the surgery than to have us there ... well the consortium and you know, the commissioners ... they see there's enough capacity in GP surgeries for 800 odd service users, you know, but that's on the condition that a lot of them are only seen, say, you know, once a month or once every three months, which is- it's no good. Once every three months, a lot can happen. (Dillon, site B)*

Resources do not allow all services to be everywhere, so commissioners must ensure they are located strategically. Shared care between GPs and D&A services is an important tool for maximising the coverage of services within an area through collaborating and pooling skills. Finances are a huge restraint to expanding such important collaborations within communities.

*We do treatment in one GP surgery ... GP service for homeless people and there's a blood borne virus nurse in there so they run a blood borne virus service and they treat in the practice, but it's the same model as the community care. We've got a separate scheme treating in GP surgeries which is going to be nurse led and that's a slightly different approach ... We'd love to put a nurse into GP surgeries and provide them with, replicate the system we've got, hire another half a dozen nurses and treat all the injectors in every GP practice. [BBV Manager] could supervise it, we can prescribe, don't see it being a problem at all but the GPs have got to cough up and they've got to provide space, rooms, support and the PCT consortia at the moment haven't provided the cash. (Consultant hepatologist, site A)*

The emphasis on value-for-money and obtaining wide coverage may come at the expense of quality of care for clients. There is concern from some service providers that the HCV service model at site B isn't client-centred enough and doesn't support those clients who are not eligible for treatment, but still require attention for their HCV:

*I don't think it's been done from client focussed perspective, I think it's been done from we need to go, we need to be seen to be going into the community, we've got this money, we've got a year's worth of band 7 money, let's do this... That's the thing with hep C, it's an insipid, chronic, damaging virus to the liver so clients that are not ready for treatment, still need input, still need to be monitored... I mean if you go into an outpatients clinic for hep C, not everybody there is going to be on hep C treatment, they're going to be there for monitoring and reviewing of the condition, where our clients don't get that... our clients come and, you*

*know, I ask them who's looking after your hep C? 'No one, I don't see anybody'. (BBV nurse, site B)*

This lack of service user engagement was felt to be key in poor hepatitis outcomes for PWID, and a culture of service users having to be assertive to access treatment was blamed for unassertive service users not being able to access care:

*They may have been referred initially by their GP or someone like that but they've not engaged so nobody's looking out, the GP doesn't regularly take their bloods ... Unless someone is proactively trying to ensure that they engage, then who's going to be encouraging them to have their bloods checked every few months or whatever ... GP surgeries don't have protocols in place so that, you know, they're getting recalled for blood tests, liver reviews and things like that ... Healthcare, the way our healthcare system works is if you're not assertive and have enough intelligence to know how the system works, then chances are, you'll fall in the gaps. You know, I've heard 'well the hospital didn't tell me so it must be alright' type scenario, 'they didn't get back in contact with me so it must be alright'. It's like well actually, that's not necessarily so, you know, you actually sort of need to make sure that actually, everything is okay, you need to know what the results were. (BBV nurse, site B)*

The service provider suggests that GPs should be taking the lead in following up their patients with HCV who are not receiving hospital treatment. An incentive system such as that in place for managing other chronic diseases could encourage them to take more responsibility for such cases:

*I think the GP should pick it up, if you see what I mean. If somebody's registered and you've got blood results to that say they're hep C positive, they should be on recall every six months to have a liver function test, at least every year, at the very least, every year, just a full blood profile, just to see how they're getting on. Then every five years, a liver ultrasound. I mean that's what a good gastroenterologist would want to do for his hep C clients or her hep C clients so why is a GP not mirroring that ... I mean in this country, GPs get enhanced care monies for things like heart disease, diabetes, they don't get it for hep C so it's off the agenda ... if they manage to screen a certain percentage of their registered clients over 40, they will get extra enhanced payments ... there have been a lot of campaigns to encourage testing, you know, hep C awareness stuff ... But as I say, if there's no incentive to it, very often it just falls by the wayside. (BBV nurse, site B)*

**Key Findings**

- Formal partnerships can lead to better services available throughout an area, with everyone able to access a wider variety of health and social services. However, there is some evidence that more 'stable' PWID who receive care in non-specialist settings may not be able to access the same level of care and that important functions, such as HCV case management, may fall by the wayside.
- While obtaining value for money and widening coverage are important service goals, they should not come at the expense of quality of care for individual service users and attention must be given to maintaining standard while expanding services to reach a greater number of service users.

**Recommendations:**

- Formal shared care partnerships between specialist services and GPs in an area can promote better access to services to a wider number of people, although maintaining a high level of quality over the whole network is key to achieving good results for every individual accessing services.

## 9. Summary and recommendations

We summarise here the key findings of the study and our recommendations for action based on these.

### Study context and methods

Current injectors are not precluded from HCV treatment access in a number of European countries, yet uptake rates are substandard. This qualitative study aimed to assess the barriers and facilitators to HCV treatment access and completion for PWID in drug and alcohol (D&A) settings in two sites in London, United Kingdom. We sought to examine the barriers and facilitators to HCV treatment by describing pathways to hepatitis C treatment, including referral, as well as factors mediating treatment access in the D&A setting.

Accordingly, in 2011, we undertook a qualitative study to explore the barriers and facilitators to HCV treatment access for PWID in D&A settings. Two London-based partnerships were selected: site A (an established community-based partnership offering HCV treatment delivery and support for PWID); and site B (a nascent partnership about to pilot a HCV outreach programme). In-depth interviews were conducted with service users (n = 35) and service providers (n = 14) from both sites. Through a thematic analysis of these qualitative interviews we describe the experience of HCV treatment access in order to develop recommendations to enhance the accessibility and quality of delivery of HCV treatment.

### Key findings

Our thematic analysis identified three key domains affecting HCV treatment access for PWID: social structural factors; system factors; and the integration of care. We summarise key findings relating to these below.

#### *Social structural factors*

Multiple social and structural factors affect HCV treatment access, including: felt stigma; housing; access to social and welfare supports; access to employment and income; family and caring responsibilities; language and ethnicity; gender; and criminalization. These then, are also important domains for social and structural change.

**HCV stigma**, for example in the form of prejudicial treatment from medical providers, could negatively impact on participants' decisions regarding HCV disclosure, health care access and HCV treatment uptake. We found that the service partnerships acted to mitigate stigma and encourage HCV treatment access by fostering a welcoming non-judgemental environment, the development of trusting relationships and provision of practical supports. Individualised stigma interventions, such as the re-location of medication provision, acted as facilitators to treatment access.

The majority of participants were in unstable **housing**, such as hostel accommodation. While unstable housing and homelessness do not preclude successful HCV treatment completion, they can be a significant barrier to treatment uptake. Many participants prioritised the obtainment of adequate housing over HCV treatment commencement; this could create a tension between an individual's urgent medical need for HCV treatment and their reluctance to commence treatment until they were appropriately housed. Some service providers played a vital role in helping



participants' access housing and hostel accommodation. The provision of practical supports, such as fridges, acted as facilitators to treatment access and uptake for those in unstable accommodation.

Participants with HCV treatment experience reported a variety of **treatment side effects**. Fatigue and depression were the most commonly mentioned. For many, HCV treatment side effects impacted on their ability to carry out day to day tasks such as cooking, cleaning, shopping and getting to appointments. Caring responsibilities, such as sole parenting, could exacerbate these difficulties. For many participants family members and partners provided invaluable emotional **and practical supports**. Reported adequacy of supports received by services were mixed – some participants spoke favourably of support received from service providers, others less so. Recommendations from participants regarding needed **social supports** included home visits and voucher provision for transport, home help and nutritious food.

**Financial concerns** formed a large part of the participant data. The current financial climate negatively impacted on participants' ability to access disability support allowances while on treatment, even when recommended and supported by their medical providers. Treatment was perceived to increase daily living costs, for example in regard to public transport access. For some, this created a barrier to treatment uptake. Income generation demands also impacted on HCV treatment decision making. The need to maintain appearance and stamina arose as an issue for women engaged in sex work and acted as a barrier to treatment uptake. Service providers reported that **women drug users** were more difficult to engage with HCV treatment than their male counterparts, possibly due to income generation demands, caring responsibilities, stigma and fear of child removal.

Employment demands were not always a barrier to treatment access. Immigrants with HCV, for example, were described by service providers as very motivated to access HCV treatment. A number of these immigrants were not entitled to **welfare benefits**, and worked long hours while on HCV treatment. Additional challenges faced by providers and immigrant service users included **language barriers**, the threat of deportation, lack of benefit access and potential coercion – especially for women – to enter into treatment by partners and/or relatives. Services acted to mitigate these issues, by fitting appointments around working hours and ensuring clients were seen with translators to ensure treatment readiness.

**Incarceration** was not found to preclude successful HCV treatment uptake and/or continuation. It can, however, be a barrier to treatment completion if the custodial facility is not equipped to support HCV treatment continuation. Service providers reported assessing clients as unstable and therefore not suitable for treatment if they were experiencing frequent custodial periods.

### ***System factors***

The two HCV treatment partnerships acted to facilitate HCV treatment uptake and completion among PWID by making modifications to aspects of more traditional treatment regimes, such as those operating within many hospital settings. Key system modifications that were found to encourage HCV treatment access involved appointment policies and HCV treatment eligibility criteria.

Regarding **appointment procedures**, a number of HCV treatment hospitals in the United Kingdom enforce 'did not attend' policies, whereby a patient who fails to attend successive appointments is removed from the treatment process, until they are re-referred. High levels of hospital appointment non-attendance by PWID were reported by service providers at both sites. Interviews with providers and service users uncovered a number of barriers to appointment attendance in the hospital setting. Complex or expensive hospital phone lines for patients to schedule appointments acted as a

deterrent, as were appointments scheduled for the early morning. Many PWID are late risers, and/or have to prioritise picking up methadone or obtaining drugs before appointment attendance. Appointments made by service providers on behalf of service users were at times experienced as coercive, especially if the service user had not fully engaged with or understood this process. Typically, hospitals will schedule a number of pre-HCV treatment appointments in order to assess treatment 'readiness' and undertake required tests. Service users could experience multiple pre-treatment appointments as futile and fail to attend, especially if each appointment involved a considerable waiting time. For service users on treatment, the side effects of treatment could act as a barrier to appointment attendance, particularly if the hospital was difficult to get to, and/or funds for transportation were lacking. Prior stigmatising experiences at hospital settings were also a barrier to appointment attendance.

The two HCV treatment partnerships worked to mitigate a number of these barriers by making the appointment processes more flexible and streamlined. Appointments were often made with cognisance of the service users' daily schedule, for example allowing for time to pick up methadone or arranged around the long work hours of some immigrant service users. Flexible appointment policies were common, whereby service providers were given a large window of time in which to attend, and 'did not attend' policies were not in practice. Services acted to streamline the treatment process, reducing the number of pre-treatment appointments in order to hold service users interest. In this way services were tailored to meet the service users' needs, resulting in increased engagement and uptake of treatment.

Regarding **eligibility criteria**, hospital based restrictions in regard to HCV treatment eligibility were also found to be a barrier to treatment uptake in this setting. Despite NICE guidelines changing in 2004 to include current injectors as eligible for HCV treatment access, some hospitals still used this as an exclusion criterion. Participants described being refused access to treatment in the hospital setting due to their drug use, even if reduced. Eligibility criteria adopted by the two treatment partnerships included provision for ongoing drug and alcohol use, with varying degrees of flexibility. Stability arose as a key in assessing eligibility criteria at both sites, which was assessed on a case by case basis. As the services gained experience of successfully treating more marginalized individuals (those with co-morbidities, unstably housed etc) definitions of 'stability' were increasingly relaxed. In this way the development and implementation of eligibility criteria operated as a constantly evolving process, drawing on service provider experience and lessons learned from similar services.

A key facilitator for HCV treatment access and engagement is the provision of **integrated networks of care**. Many PWID have complex health and social needs and may have to access a variety of service providers to address these issues. The service partnerships helped to engage participants in HCV treatment uptake by co-locating HCV treatment services in the same building as OST and harm reduction services. Communication between D&A key workers and HCV treatment providers enabled service user appointments to be coincided, thus facilitating appointment attendance. The service partnerships comprised multi-disciplinary teams, with all D&A key workers at site A also trained as nurses and psychiatry and specialized phlebotomy services were located onsite at both services. Service user engagement was enhanced when individual service providers were able to deal with a broader range of issues, and/or refer the service user to a provider in the same building.

For many PWID, HCV treatment may not be a priority. The provision of holistic care, such as wound and sexual health care, at the services – particularly at site A – was seen as a way of engaging service users and initiating conversations about HCV testing and treatment. Continuity of care was reported as very important by service users and, in some cases, high staff turnover could lead to disengagement. While many PWID prefer to attend services specifically designed for their needs, where they are less likely to feel discriminated against, this is not the case for all – for example people who are transitioning away from drug use may prefer to access generalised services.

Communication between general practitioners and HCV treatment providers was vital – especially in regard to the provision of medications for HCV treatment side effect management. Ideally such medications should be provided onsite but this was not always possible. Adequate pain medication for people experiencing severe HCV treatment side effects is important. An increase in OST dosage may help with side effect management. For many service users the configuration of OST access was a concern. Service users who were on daily supervised OST consumption spoke of the difficulty of visiting a chemist daily when experiencing HCV side effects and feeling that they were not trusted, were more likely to disengage with services. PWID often have difficult venous access and can experience having blood taken as stressful and potentially stigmatising, the co-location of a skilled and non-judgemental phlebotomist at the services aided HCV treatment access and completion

Clear communication between service providers involved in an individual's care is important for ensuring that the correct decisions are made and optimal care is provided. Modes of communication varied depending on the service location and the provider skills, but can include patient appointments attended by multiple service providers, clinical meetings between service providers, shared access to IT databases and clinical letters. Information sharing systems between the partnerships were at times experienced as a barrier to effective communication between teams. The sharing and storing of data is a sensitive matter and it is important to have protocols in place that ensure patient confidentiality is respected, while allowing service providers to fulfil their roles as efficiently as possible. Formal shared care partnerships, incorporating general practitioners for example, can lead to better services available throughout an area, with increased access to a variety of health and social services. However, there is some evidence that more 'stable' PWID who are relocated from specialist to non-specialist settings may not be able to access the same level of care and that important functions, such as HCV case management, may fall by the wayside.

## Recommendations

Following the key findings summarised above, we make recommendations in three domains: social structural interventions; systemic interventions; and integrated care interventions. We draw attention to key evidence

### *Social structural interventions*

Our findings emphasise that access to HCV treatment can be understood as a product of social condition, wherein a combination of systemic and structural factors affect help seeking, treatment engagement and service provision. **Enabling environment interventions** oriented to creating opportunities for stable housing, stigma reduction and systemic changes in policy and health care delivery can play a critical role in enhancing HCV treatment access and uptake for PWID in the European Region.

Our study, as elsewhere [56-61], highlights the pervasiveness of **social stigma** in the HCV treatment experience. Service providers should understand the impact of stigma on HCV treatment outcomes and work to improve the service environment for PWID to ensure better treatment uptake and outcomes. We recommend that:

- The treatment journey should be tailored with individual service user needs in mind to ensure that contact with services in no way exposes them to potential discrimination or perceived stigma. Relocating medication dispensing and providing personal fridges to keep medication safe are examples of such personalized interventions.

**Housing** can be an important factor in determining how well individuals adhere to HCV treatment and unstable housing can be a reason for low uptake. Many service users may not want or be able to undergo treatment while street homeless or in unstable housing situations. It is important, however,

that unstable housing is not an automatic contraindication to HCV treatment eligibility. We recommend that:

- Individuals are assessed on a case by case basis, with resources available to support service users who wish to undertake HCV treatment while unstably housed.
- A service provider with knowledge of the accommodation system should be available to assess the housing needs of individuals and help them navigate the system.
- Basic resources such as bedding and fridges should be available to service users in unstable accommodation who feel comfortable to commence treatment in such circumstances.

**Social support** is vital for helping PWID to adhere to and complete the HCV treatment regime. We recommend that:

- Before treatment commencement service providers ascertain an individual's support resources and needs and provide links to additional supports where necessary.
- Assistance with obtaining appropriate welfare benefits should be available for service users and, ideally, voucher schemes or subsidised support for home help, child care and travel expenses should be available where necessary.
- Support and information about HCV treatment should be available for friends, family and/or carers of those undergoing HCV treatment.

**Women who inject drugs** face particular challenges accessing treatment [48, 50, 62, 63, 64]. We recommend that:

- Personalized social interventions such as the provision of childcare, respite care and assurances regarding child custody may help to encourage HCV treatment access among women.

**Immigrants** can also face additional challenges in accessing treatment. Communication between service users and providers is pivotal. Relying on family or friends to translate undermines provider-patient confidentiality and may result in inappropriate or incorrect decisions being made. We recommend that:

- Interpreters should be available for service users with poor English
- Even when relatives or friends of the service user are available to translate one session should be scheduled with an impartial interpreter to ascertain treatment readiness.
- Flexible service provision is desirable, especially when service users have to maintain long work hours and have little ability to take leave.

**Imprisonment** may be a barrier to HCV treatment adherence and completion [65, 66]. Enhanced access and funding of HCV testing and treatment in prisons and pre-trial places of detention can reduce HCV transmissions and associated morbidity and mortality as well as provide a valuable opportunity for HCV assessment and treatment [67]. We recommend that:

- Specialist HCV services should be available in custodial settings and relationships between the criminal justice system and D&A and HCV services developed so that continuity of care is facilitated for incarcerated individuals.

### ***Systemic interventions***

Our findings support the notion that HCV treatment delivery may reproduce social stigma in the environment indirectly as well as directly. For instance, HCV treatment eligibility criteria which incorporate demonstrations of 'stability' or 'treatment readiness', which may also involve regular

attendance at appointments or regular urine screens, may be experienced as stigmatising or disempowering, recreating an atmosphere of mutual suspicion and distrust that can permeate relationships between PWID and medical providers. Similarly, attendance requirements at clinic appointments as a demonstration of 'readiness' may be experienced as patronising or disciplining and can be a barrier for individuals who want to commence treatment immediately and/or who find hospital environments problematic.

In relation to **appointment procedures**, we recommend that:

- Non attendance of appointments should not be used to remove a service user from the system. DNA policies should be removed where possible.
- Services that operate appointment based systems should be as flexible as possible to allow service users to choose appointment times that are realistic and do not coincide with other commitments. Where possible, flexible windows of time or drop in periods should be available.
- Service providers making appointments on behalf of service users should be very clear about the purpose of the appointment and ensure that service users are clear that access to D&A services is not dependent on attending healthcare services.
- There should be no service targets around referrals that may encourage coercive referring.
- Where service users make their own appointments, free phone lines should be available.
- Where possible, provision should be made for a service provider (from the D&A service for example) to accompany service users to hospital appointments.

If high rates of missed appointments are normal, service providers can draw on prior experience to overbook clinics to ensure that as many people as possible are seen. We recommend that:

- Service providers should work to structure appointments to be as time-efficient as possible, maximising contact with service users by including multiple components in a single contact, that reducing the number of contacts a service users needs to make and shortening the lead-in time to accessing treatment.
- Phone or text reminders for appointments should be considered vital as postal reminders may not reach the desired recipient.
- Extra support to service users receiving HCV treatment may be necessary to reflect the problems they may face in attending services. Extra transport support, flexible appointments and allowing trusted relatives to pick up medication when monitoring is not necessary are among the strategies that can be used to encourage adherence.
- If service users are not attending appointments it is necessary to discuss with them their fears/barriers to attendance and provide personalized interventions – such as medication – where feasible.

Regarding **eligibility criteria**, national guidelines for HCV treatment should enshrine access to treatment for all, and be clear in their message that injecting drug use alone is no reason to preclude an individual from HCV treatment. We recommend that:

- The criteria used to determine eligibility for HCV treatment at individual services should be developed with consultation between hepatology and D&A staff who can use their complementary experience to draw up guidelines that both are comfortable with and ensure patient safety. Emphasis should be put on moving away from rigid checklist-style guidelines and drawing more on individual circumstances that indicate a level of stability necessary to successfully undertake treatment. Guidelines can be adapted over time to

reflect providers' growing experience and confidence and changes in the social profile of the clients attending services.

- All services should adhere to UK NICE guidelines. Current substance use alone should not be a treatment contra-indication.

### ***Integrated care interventions***

HCV treatment provision for PWID is effective particularly when delivered in an integrated and multidisciplinary framework [32, 68-78]. Evidenced and recommended HCV treatment facilitators for PWID include linked targeted interventions to provide 'low threshold' treatment access, social support, adherence support, and treatment literacy support. A review of the literature indicates that evidenced targeted access supports include: HCV treatment provision in OST services [22, 41, 70]; relaxed eligibility requirements [41]; and flexible opening hours and appointment times [32]. Targeted social supports include: peer support groups [71, 72]; peer-workers integrated into HCV treatment provision [73]; improved psychological services [32]; and assistance with practical problems, such as transportation, accommodation and welfare benefit access [72, 74]. Targeted adherence supports include: electronic reminder systems [74]; co-ordination with pharmacies for medication dispensing [32]; directly observed therapy [33]; respectful client-centred continuity of care [37, 74]; nurse provided interferon injections [37]; improved phlebotomy services [32], including provision to use external jugular venepuncture [75]; and flexible OST provision, including access to take home doses [76]. Targeted treatment literacy supports include: education for PWID [38], as well as training and support for drug and alcohol staff [77] and primary care providers [78, 79], including the use of video conferencing [78].

Our study findings support the notion that **integrating HCV testing, education and treatment into drug and alcohol services** already attended by PWID can prove an efficient way of reaching more clients successfully. Settings such as D&A services that provide OST and clinics that provide acute care to PWID are ideal locations for providing HCV information and testing to those who require it. Physical health care services co-located directly alongside specialist D&A services are in an especially good position to offer HCV treatment to clients. The co-location or availability of specialist psychiatric support in these services can be an important support to service providers making difficult judgement calls about the effects of treatment on potentially unstable clients. We recommend that:

- Delivering effective integrated care requires a multidisciplinary team, who are able to share knowledge across disciplines.
- Training should be available for BBV service providers in D&A issues, and vice versa.
- Where possible, services should be available that respond to the immediate and pragmatic needs of PWID. It is recommended that information about HCV testing and treatment is incorporated into these services.
- Services providing integrated mental and physical health services should move to integrate some level of social support, or a liaison with social support services, to improve the social well-being of the service user, reduce stress associated with dealing with housing or financial issues and improve uptake and adherence to treatment
- Where a number of options for treatment location exist, service user preference should be taken in to account when deciding where to treat.
- Efforts should be made to ensure continuity of care at both D&A and HCV services. When staff turnover is unavoidable, good notes and thorough 'hand-over' procedures are important.

Further, we note that services need to ensure that their services are welcoming and clients are not deterred from attending by discriminatory service features or provider attitudes. Well-trained and

highly experienced service providers, who are familiar with issues faced by PWID, are well-placed to provide non-judgemental services to what can be perceived as a difficult client group.

Our findings suggest that accessible medication provision helps alleviate HCV treatment side effects which can improve HCV treatment adherence. **Reducing multiple contacts with service providers** by cutting out the additional need to visit a GP to prescribe such medications or buying potentially prohibitively expensive **medication directly from a pharmacy** are important tools in improving adherence. PWID often have difficult venous access, which – when not well managed – can be a barrier to testing and treatment uptake. In addition, the important role of OST provision in enhancing HCV treatment access, tolerability and adherence is well evidenced [34, 80, 81]. Taken together, we recommend that:

- Where possible, medications for side effect control should be provided on-site.
- Appropriate and sufficient pain control should be prescribed to prevent service users self-medicating with street drugs.
- Services need to provide access to a non-judgemental skilled phlebotomist (preferably onsite) who has a remit to access veins such as the femoral and jugular and is open to letting service users draw their own blood.
- PWID considering HCV treatment should have access to OST, and where possible – provision for OST takeaways.
- Increasing OST dose while on HCV treatment can help with side effects, OST dose reductions while on HCV treatment are generally not recommended.

Attention to the structural and cultural context of drug and alcohol services, including provider attitudes, is a pivotal component of successful HCV treatment support. For example, ‘one-stop-shop’ models of integrated treatment can run the risk of breaching patient confidentiality regarding their HCV status through **information sharing**, which clients may wish not to disclose [82]. We recommend that:

- Services working closely together should ensure that well considered information sharing protocols are in place and that they obtain patient consent before sharing information with other providers
- IT systems should be designed with the needs of the staff accessing them in mind and aim to avoid duplication where multiple systems exist.

Where **shared-care agreements** exist or are being put in to place, working groups need to ensure that the benefits gained from such arrangements do not compromise the quality and individualisation of care available to service users that can be such an important factor in determining uptake and success of HCV treatment.

## 10. Conclusion

### **Social interventions in a combination intervention approach**

HCV treatment provision is ideally envisaged as a combination intervention, encompassing social as well as biomedical dimensions, wherein the provision of social, welfare and psychological support is critical. Current operating definitions of 'combination intervention' in harm reduction for PWID, such as those promoted by the World Health Organization [83], tend to be narrowly defined primarily around a selected number of biomedical and behavioural interventions. These core interventions include syringe exchange, OST and HIV/HCV treatment, among others, but give little or no emphasis to social support and community action interventions or to wider structural interventions. Combination intervention approaches to HCV treatment ideally should incorporate social and structural change interventions, including those oriented to creating opportunities for stable housing, stigma reduction, de-emphasising criminalization, and systemic changes in health care delivery.

### **Multiple social structural interventions are needed**

Research among PWID highlights the salience of social and material inequalities as overarching structural factors adversely affecting those most marginalized and their access to health care [87-89]. HCV specifically and health generally can be experienced as a relative priority, situated alongside multiple competing and often more immediate concerns. Our study identifies that stigma, housing, the availability of social and welfare support, family and caring demands, income, gender, and criminalization may all impact on HCV treatment access, uptake and completion. These areas are potentially amenable to social structural intervention, and some such interventions have been implemented to varying affect by the two partnerships we researched. Successful interventions included: the provision of fridges to unstably housed PWID; help and support for service users in accessing accommodation and disability benefits; efficient liaison between HCV treatment providers and hostel/housing staff; providing continuity of care to incarcerated service users; the provision of frequent phone contact and emotional support; negotiated flexibility of service provision around the long working hours of immigrant service users; the use of skilled translators; and the relocation of medication dispensing to protect a service users privacy at the chemist.

Enhanced social and welfare supports which our findings suggest could improve HCV treatment uptake and completion among PWID include: the provision of subsidised home and child care help, and transport vouchers or improved access to disability allowances for those undergoing HCV treatment. For many participants undergoing HCV treatment family and partners played a major supportive role and this needs to be acknowledged in the provision of enhanced information and support for family, partners and carers. For individuals without these relational supports access to home visits by a care worker may be of benefit. We acknowledge that these recommendations are not always feasible in a climate of increased budget cuts, and may include interventions that are out of the power or scope of service providers – such as increased restrictions on disability support access. Some examples of best practice – such as personalized stigma interventions, and particular attention to the needs of women PWID and service users from immigrant backgrounds are feasible however, and we hope will be taken into consideration by HCV treatment service partnerships.

### **The importance of service setting**



A barrier to HCV treatment access and uptake identified by both service users and providers was the hospital setting, with high numbers of HCV-related hospital appointments not attended by PWID. Hospital-based HCV treatment is often not ideally suited to PWID due to: geographic distance; referral-associated delays [37] inflexible appointment policies; lengthy waiting times [30, 37]; limited infrastructure and psychosocial supports [21, 84]; abstinence requirements [37]; and prejudicial attitudes of some staff to PWID [37, 85]. Navigating health care systems can be daunting, especially for PWID who may have had previous negative experiences with providers [36, 82]. The highly compartmentalised nature of health care systems can create a barrier to comprehensive care for PWID whose needs are complex and may span multiple disciplines, such as drug dependency treatment, acute health care (wounds and infections), psychiatry and hepatology [55].

### **The potential afforded by community-based partnerships**

The partnerships, by locating treatment access at D&A based settings and attending to the specific requirements of PWID, were able to engage participants in HCV treatment who might not have accessed hospital-based therapy. Providers worked to facilitate service user trust by making modifications to traditional treatment systems. This ‘taming’ of the system was enabled through practices of negotiated flexibility, particularly in regard to appointment and eligibility protocols. Such strategies of taming sought to open up the system to easier navigation on the part of service users, and allowed for ongoing substance use during HCV treatment. Service providers were cognisant of the mistrust many PWID have in expert systems, such as health care, and worked to build trusting relationships with service users. Trust was enabled by the provision of non-judgemental continuity of care, and the provision of help with practical supports and concerns, such as acute health care. Services, such as site A, often engaged service users with the idea of HCV treatment on this basis – after a relationship had been built around the provision of acute needs, such as OST and wound care.

### **The need to tailor care in a client-centred and ‘situated’ approach**

The service users’ experiences of treatment and support needs were diverse. Their experiences of provider support and continuity of care, transport, housing and caring support requirements, OST supervision and access, adjunct prescribing and phlebotomy all highlight the need for HCV treatment to be individually tailored and delivered on a case-by-case basis. Service users concerns and expectations of HCV treatment can be a primary barrier to treatment uptake and completion. Specific study findings include concerns regarding: adverse treatment side effects, negative provider attitudes, access to professional phlebotomy care and OST takeaways, financial pressures and ability to carry out caring and other responsibilities. Providing HCV treatment to PWID, many who may have multiple co-morbidities and competing priorities, is also challenging for service providers. The demands on service providers to constantly ‘do more’ (i.e. work longer and more flexible hours, provide different services, undertake additional training) were evident. Service providers were tasked with making difficult decisions about HCV treatment eligibility and ‘readiness’, including the potential management of co-morbidities, continued substance use and the – at times difficult – disengagement of service users from the treatment relationship.

The HCV treatment decision making process is challenging for both providers and service users. For service users, to trust in a medical regime with uncertain efficacy and variable side effects, in order to rid oneself of an illness that may not be a pressing priority, can be difficult. For providers there is a need to manage a tension between encouraging treatment and commencing individuals on an arduous regime for which they may not be adequately prepared. A tension for both parties can also exist when there is a clinical need to start HCV treatment urgently (for example in cases of advanced fibrosis or cirrhosis) but the service user does not feel ready, due to being unstably housed for example. Some service users might find the drug and alcohol setting less than ideal for HCV treatment, particularly if they fear confidentiality breaches or feel unable to disclose current

substance use due to the co-location of services with their OST prescriber (for example, if receiving OST takeaways on the proviso of abstinence from illicit drug use). While the two services provided an environment tolerant to ongoing drug use during HCV treatment, it is unclear how this affected OST prescribing and access protocols.

### **Developing effective partnerships is likely context dependent**

While a majority of the literature reports favourably on HCV treatment provision in drug and alcohol settings, recommended services generally offer a comprehensive program of multidisciplinary care and support, with provision for service user input and/or peer support. A growing body of Australian-based research identifies the dangers inherent in just ‘adding on’ HCV treatment to D&A services that are ill equipped to offer flexible and multi-disciplinary care. This literature is notable for its theoretically informed critique of the stigmatising and constraining capacity of OST settings, and the potentially detrimental impact of HCV provision in highly regulated and surveillant OST clinics [40, 86]. The Australian OST context, is however, distinct from that in the United Kingdom – in which regional Drug Action Teams are mandated by the UK National Treatment Agency to ensure that the views and experiences of service users are incorporated into the development, delivery and commissioning of those services. The pilot project in particular displayed a commitment to service user input with a service user representative sitting on the interview panel for the BBV nurse appointment and feeding into all stages of the pilot scheme development. Crucially, this involvement provides not only a voice for the priorities and needs of PWID but sends vital messages regarding trust.

### **In conclusion**

PWID face considerable barriers in accessing and completing HCV treatment in hospital settings. These barriers can be overcome and access improved by providing HCV treatment in D&A services. In order for this process to be a success however, institutional partnerships will ideally need to make modifications to traditional treatment protocols in order to provide care tailored to the needs of PWID. Service user involvement in the development of services is an important way to ensure that these needs are met. Successful interventions include increased flexibility around eligibility criteria and appointment schedules and the provision of practical supports, such as fridges. Enhanced support provision for PWID can increase HCV treatment uptake. A successful model of integrated care will ideally incorporate a multidisciplinary team, offer provision for social and psychological supports and take into account the concerns and multiple priorities that face PWID considering HCV treatment.

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## 12. Appendices



## Appendix A: Service users' demographic and treatment information

This table is based on the demographic and treatment information collected at the beginning of each interview (short questionnaire administered to service users). It is also based on information collected during the interviews with service users.

Service user	Site A or B	Gender	Age	Ethnicity	Country of birth	Main language spoken at home	Housing	Income / Employed	Currently on OST	Illicit injecting status	Illicit drugs currently injecting	Number of times tested for HCV	HCV treatment status*	Ever had HCV treatment
2 Dillon	B	Male	43	White Irish	Ireland	English	Independent	Incapacity benefit	yes	still injecting	heroin	2	waiting	no
3 Davey	B	Male	31	White British	England	English	Independent	Incapacity benefit	yes	still injecting	heroin, heroin & crack cocaine	2	waiting	no
5 Kyle	B	Male	41	White Other (Portuguese)	Portugal	English	Independent	Incapacity benefit	yes	stopped	NA	More than 3 times	waiting	no
7 Jed	B	Male	44	White British	England	English	Independent	Incapacity benefit	yes	stopped	NA	3	current	no
8 Rosie	B	Female	60	White British	Czech Republic	English	Independent	Other (pensioner)	yes	stopped	NA	2	completed (failed), waiting	yes

11 Bibi	A	Female	49	White other (Italian)	Italy	Italian	Independent	Incapacity benefit	yes	stopped	NA	Many times	contemplating	no
12 Hakki	A	Male	31	White other (Turkish)	England	English	Living with family or friends	Incapacity benefit	yes	still injecting	heroin & crack cocaine	3	current	no
13 Jeff	A	Male	42	White British	England	English	Independent	Incapacity benefit	yes	stopped	NA	2	completed	no
14 Gary	A	Male	48	Black (Caribbean or African)	England	English	Independent	Incapacity benefit	yes	still injecting	heroin & crack cocaine, meth/amphetamine	3	completed	no
17 Shane	B	Male	39	White Irish	England	English	Independent	Incapacity benefit	yes	stopped	NA	5	waiting	no
19 Neil	A	Male	47	White British	England	English	Hostel	Incapacity benefit	yes	stopped	NA	2-3 times	Interrupted, current	yes
21 Fabio	A	Male	42	White other (Portuguese)	Portugal	Portuguese	Hostel	Income support	yes	still injecting	heroin	5	Completed (failed), waiting	no
23	A	Male	53	White	England	English	Independent	Full time	yes	still	Heroin, heroin &	10	Interrupted	yes

Tommy				British			nt	employed		injecting	crack cocaine, cocaine, crack cocaine		d, waiting	
24 Philip	A	Male	60	White British	England	English	Independent	Incapacity benefit	yes	stopped	NA	1	completed	no
26 Amir	A	Male	52	White other (Iranian)	Iran	English	Hostel	Incapacity benefit	yes	still injecting	heroin & crack cocaine	7	waiting	no
27 Kaveh	A	Male	42	White other (Italian)	Italy	Italian (slang)	Street homeless	Incapacity benefit	yes	stopped	NA	More than once	contemplating	no
28 Trish	A	Female	46	White British	England	English	Independent	Incapacity benefit	yes	stopped	NA	2	Interrupted, waiting	yes
29 Mick	A	Male	43	Other (Mixed race British)	England	English	Independent	Incapacity benefit	yes	stopped	NA	1	completed	no
30 Ben	B	Male	37	Other (Ghanaian)	Ghana	English	'Sofa hopping'	Incapacity benefit	not now, but in the past	stopped	NA	1	current	no

31 Eric	B	Male	55	White British	England	English	Independent	Incapacity benefit	yes	stopped	NA	More than once	waiting	no
33 Carol	A	Female	39	White British	England	English	Temporary housing	Incapacity benefit	yes	stopped	NA	1	Interrupted, contemplating	no
35 Stefan	A	Male	39	White other (Portuguese)	Mozambique	Portuguese	Supported housing	Incapacity benefit	yes	still injecting	heroin, crack cocaine, heroin & crack cocaine	10	contemplating	no
37 Giorgio	A	Male	41	White other (Italian)	Italy	English and Italian	Street homeless and living with family or friends	Job Seeker Allowance	yes	stopped	NA	1	Completed	no
38 Jake	A	Male	46	White British	England	English	Supported housing	Incapacity benefit	yes	stopped	NA	5	Interrupted, waiting	yes
39 Stevie	B	Male	50	White British	Germany	English	Living with family or friends (recently evicted)	Incapacity benefit	not now, but in the past	stopped	NA	1	contemplating	no
40 Ivana	B	Female	26	White other (Bulgaria)	Bulgaria	English, Bulgarian, German,	Independent	Full time employed	yes	stopped	NA	2	completed	no

				n)		Russian								
41 Frank	A	Male	56	White British	New Zealand	English	Indepe nt	Incapacity benefit	yes	stopped	NA	1	completed	no
42 Nat	B	Male	41	White British	England	English	Indepe nt	Job Seeker Allowance	yes	stopped	NA	2	completed	no
43 Mario	B	Male	47	Other (Italian)	Italy	Italian	Indepe nt	Incapacity benefit	yes	stopped	NA	1	Completed (failed), waiting	yes
45 Charlie	B	Male	58	White British	England	English	Indepe nt	Full time employed	yes	stopped	NA	1	completed	no
46 Peter	B	Male	59	White British	England	English	Indepe nt	Incapacity benefit	yes	stopped	NA	1	completed	no
47 Johnny	B	Male	44	White British	England	English	Indepe nt	Incapacity benefit	yes	stopped	NA heroin	2	contempla ting	no
48 Mark	B	Male	42	White British	England	English	Living with family or friends	Incapacity benefit	not now, but in the past	stopped	NA	3	current	no
49	B	Male	46	White other (Portugu	Portugal	English	Hostel	Job Seeker Allowance	yes	stopped	NA	2	current	no

Hugo				ese)										
50 Marta	B	Female	47	White other (Portuguese)	Portugal	Portuguese	Independent	Incapacity benefit	yes	stopped	NA	3	current	no

\* HCV treatment status: waiting; current; completed (virus cleared); completed (failed); interrupted; completed (failed), waiting; interrupted, waiting; interrupted, current.

## Appendix B: About the authors

**The Centre for Research on Drugs and Health Behaviour** at the London School of Hygiene and Tropical Medicine undertakes and promotes high quality research to understand the social and behavioural aspects of drug use in order to inform, design and evaluate interventions and policies designed to reduce the drug-related health harm.

**Tim Rhodes**, PhD, is Professor in Public Health Sociology and Director of the Centre for Research on Drugs and Health Behaviour at the London School of Hygiene and Tropical Medicine (University of London), and Conjoint Professor of the Sociology of Health at the University of New South Wales. He leads a programme of mixed-method qualitative research focused on understanding how social environments shape the health harms linked to drug use.

**Magdalena Harris**, PhD, is a Research Fellow at the Centre for Research on Drugs and Health Behaviour at the London School of Hygiene and Tropical Medicine. She is a qualitative researcher with a background in sociology, whose primary area of research is the social relations of living with, treating and preventing hepatitis C.

**Anthea Martin** is completing her PhD at Middlesex University, and is an Honorary Research Fellow at the Institute of Psychiatry, King's College London. With a focus on qualitative research, her key areas of interest are 'problem' and injecting drug use, harm minimization, and the marginalization of illicit drug users.

**Emma Jolley**, MSc, is a Research Assistant at the Centre for Research on Drugs and Health Behaviour at the London School of Hygiene and Tropical Medicine.

**Helene Wells**, MSc, is a criminologist with a keen interest in researching organized crime and drug-related behaviour in young people. She has worked as a Teaching Fellow and Senior Research Officer at Bond University (Australia), and as a Research Fellow in the Centre for Research on Drugs and Health Behaviour (LSHTM). Helene currently works at the Crime and Misconduct Commission (Australia) as a Senior Research Officer.



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