

EXPERIENCES OF INJECTING DRUGS, ALCOHOL USE AND
HEPATITIS C IN MERSEYSIDE: BARRIERS TO HEPATITIS C
SUPPORT

JANE EVELY

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Abstract

Hepatitis C is a blood borne virus affecting the liver. In the UK, approximately 214,000 people are infected with the hepatitis C virus. Hepatitis C disproportionately affects marginalised populations and in the UK sharing equipment used to inject drugs is the main risk factor for hepatitis C infection. Despite there being treatments for hepatitis C, many do not access it or indeed get tested, leading to deaths from complications of hepatitis C such as end stage liver disease or hepatocarcinoma.

The World Health Organization's target to eliminate viral hepatitis as a major public health threat by 2030, has led to calls for action to increase access to hepatitis C testing and treatment. To increase uptake of testing and treatment, an understanding of the current barriers to access is required. Historically, alcohol and injecting drug use have been barriers to receiving treatment.

Alcohol is also regarded as problematic as it expedites the progression of hepatitis C. There is however a paucity of research on experiences of alcohol use in People Who Inject Drugs (PWID) who have hepatitis C.

The aim of this research was to gain an understanding of the experiences, practices and meanings of alcohol for people living with hepatitis C and to understand their needs and support requirements. Being qualitative in nature, this research took an explorative, inductive approach, allowing emerging themes to lead the direction of the research. The starting point was observation of hepatitis C support groups and interviews with people who have/had hepatitis C (services users, n=21), leading onto interviews with professionals (n=12) working in drug, alcohol and hepatitis C services.

A multi-methods approach was used. Service user interviews were life history interviews, using a calendar method, and for the interviews with

professionals, vignettes about hypothetical services users and semi structured interviews were used.

Data were analysed using a combination of approaches. For the interviews using the calendar method, the individual calendars were studied to ascertain the sequence of events in a participant's life. More generally, an ongoing constant comparative approach occurred throughout the various stages of the research and interview transcripts were analysed using thematic analysis.

This research has explored alcohol use in PWID who have hepatitis C, however the methods employed have afforded wider findings, giving an insight into barriers and challenges to hepatitis C support. Barriers/challenges were found at service user, service and strategic levels. For service users, barriers were to accessing support (incorporating, testing, treatment, advice, information and peer support) and for service providers and commissioners, challenges were to providing support services for people with the hepatitis C virus. Alcohol fits in to this picture as a barrier to support from the PWID community, due to the stigma of becoming 'a drinker' and as an exclusion to receiving hepatitis C treatment.

There is a paucity of qualitative research on alcohol use and hepatitis C in PWID. To our knowledge this research is the first study exploring the lived experience of alcohol use for PWID who have hepatitis C in England. The findings from this study therefore contribute to the current limited body of knowledge on this topic. Although on completing this thesis some of the findings are out dated as hepatitis C treatment is now being provided out of the hospital setting, other barriers to providing and accessing hepatitis C support are still relevant. These findings will be of interest to those working both in practice and public health policy who are working towards the elimination of hepatitis C by 2030.

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Dedication

This thesis is dedicated to my mum Ruth Evely who is greatly missed.

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Glossary

AUDIT

Alcohol Use Disorders Identification Test.

Alcohol dependence

A cluster of behavioural, cognitive and physiological factors that typically include a strong desire to drink alcohol and difficulties in controlling its use. Someone who is alcohol-dependent may persist in drinking, despite harmful consequences. They will also give alcohol a higher priority than other activities and obligations.

BBV

Blood-borne virus.

Brief intervention

A technique used to initiate change for an unhealthy or risky lifestyle behaviour.

CAGE

A screening test for problem drinking and potential alcohol problems.

DBS

Dry blood spot testing.

GUM

Genitourinary medicine.

Harmful drinking

A pattern of alcohol consumption that is causing mental or physical damage.

Hazardous drinking

A pattern of alcohol consumption that increases someone's risk of harm. Some would limit this definition to the physical or mental health consequences (as in harmful use). Others would include the social consequences. The term is currently used by WHO to describe this pattern of alcohol consumption. It is not a diagnostic term.

HCV

Hepatitis C Virus.

Hep C

Hepatitis C.

Higher-risk drinking

Regularly consuming over 50 alcohol units per week (adult men) or over 35 units per week (adult women).

Increasing-risk drinking

Regularly consuming between 15 and 50 units per week (adult men) or between 15 and 35 units per week (adult women).

Lower-risk drinking

No more than 14 units a week on a regular basis.

NICE

National Institute for Health and Care Excellence (formerly known as National Institute for Clinical Excellence or National Institute for Health and Clinical Excellence).

ODN

Operational Delivery Network.

OST

Opioid Substitution Therapy (prescribed to reduce heroin use).

PHE

Public Health England.

RCGP

Royal College of General Practitioners.

SIGN

Scottish Intercollegiate Guidelines Network.

WHO

World Health Organization.

Chapter 1 Introduction

1.1 Introduction

This thesis explores the topic of hepatitis C in the Merseyside region of the UK. Hepatitis C is a virus affecting the liver and in the UK the main route of transmission is sharing equipment used to inject drugs, therefore the population of interest for this research is People Who Inject Drugs (PWID) who have hepatitis C.

Despite there being tests and treatments available to diagnose and cure the virus, historically hepatitis C has been under diagnosed and undertreated, meaning many who live with the virus risk further liver deterioration over time. Whilst living with the virus, people are advised to 'look after their livers'. Alcohol and hepatitis C together are considered a double insult to the liver as alcohol can expedite the progression of hepatitis C, therefore people are advised to consider their level of alcohol consumption. There is however a paucity of research on alcohol use among PWID who have hepatitis C. This research used qualitative methods to explore this topic with a view to informing services of service users' needs. The research identified barriers (and to a lesser degree, facilitators) to PWID receiving hepatitis C support.

1.2 Background to the hepatitis C virus

Discovered in 1989, hepatitis C is a virus predominantly affecting the liver. Known as the 'silent epidemic', hepatitis C is largely asymptomatic, meaning many individuals who have the virus do not know they are infected (Hawkes, 2013). Approximately 20% of people exposed to hepatitis C will spontaneously clear the virus within the first 6 months after transmission (Hepatitis C Trust, 2017a) however others will go onto develop chronic

hepatitis C. In this chronic phase individuals can remain asymptomatic for many years (Department of Health, 2002; Athwal and Prince, 2017) or have symptoms that are nonspecific and are thought to be other illnesses such as influenza, fatigue, insomnia, gastrointestinal symptoms, poor concentration (“brain fog”) and pain (Athwal and Prince, 2017; Hepatitis C Trust, 2017c; World Health Organization (WHO), 2017b). Some people with hepatitis C remain undiagnosed until they present late to healthcare services with complications such as cirrhosis, end stage liver disease or hepatocarcinoma, (Lancet, 2013; Athwal and Prince, 2017) which have high mortality rates (Public Health England (PHE), 2017d).

Prior to 1989 hepatitis C was known as ‘non A non B hepatitis’ and since that time further learning about the virus has discovered there are 6 major genetic variations, named genotype 1-6. The virus is further differentiated by subtypes such as genotype 1a and 1b. Different countries have different predominant genotypes and in the UK the majority of hepatitis C is genotype 1 and 3. It is possible to be infected with more than one genotype of the virus at the same time and treatment choices differ based on the genotype (Hepatitis C Trust, 2017a).

Hepatitis C is a blood borne virus (BBV), meaning transmission is through blood to blood contact with a person who has the hepatitis C virus. Approximately 90% (92.3% Department of Health, 2002; 91.1% between 1992-2002, Department of Health, 2004; 92% PHE, 2017e) of hepatitis C cases in England are transmitted through sharing injecting drug paraphernalia (equipment used in preparing and administering drugs for injection, such as needles, syringes, filters and spoons). Therefore in England sharing injecting drug equipment is the biggest risk factor for transmission of hepatitis C, and hepatitis C is the most common blood-borne infection among PWID (PHE, 2017e).

Worldwide other common routes of transmission include reusing unsterilised medical/dental equipment and transfusions of unscreened blood

and blood products (WHO, 2017). Since September 1991 blood and blood products have been screened for hepatitis C in the UK, and UK healthcare standards stipulate sterilisation or single use of medical/dental equipment. Other routes of transmission include sharing razors or toothbrushes with someone who has the virus, tattooing, piercing, acupuncture, electrolysis, clippers, razors, scissors where equipment is unsterile, needlestick injury amongst healthcare staff, sharing straws or rolled notes for snorting drugs such as cocaine, vertical transmission (from mother to baby during birth - 3% risk of transmission) (Athwal and Prince, 2017) and sexual transmission (2% risk of transmission), (Athwal and Prince, 2017) by having sex with someone who has the virus and where exposure to blood occurs (NHS Choices, 2018; Hepatitis C Trust 2017b; WHO, 2017b).

Over recent years, hepatitis has attracted global attention, seeing the WHO produce the first estimates of prevalence both globally and regionally and developing a Global Health Sector Strategy (GHSS) to reduce infections (WHO, 2016; WHO, 2017a). WHO (2017a) estimated in 2015 there was a similar number of deaths from viral hepatitis (1.34 million) as tuberculosis (1.37 million), and a higher number of deaths than HIV (1.06 million) and malaria (0.44 million). Of the viral hepatitis deaths, the majority (96%) were due to hepatitis C and hepatitis B (WHO, 2017a). Furthermore an estimated 71 million people worldwide (1% of global population) were living with chronic hepatitis C in 2015, with 1.75 million new infections that year (WHO, 2017a). However, within the WHO European Region, a higher prevalence of 1.5% of the population was estimated (14 million people), with 565,000 new infections (WHO, 2017a).

In the UK, liver disease is currently the third most common cause of premature death (Williams et al, 2014). Whereas mortality from other diseases (diabetes, cancer, respiratory, road, heart, stroke) has decreased over the last few decades, death rates from liver disease are increasing.

In addition to this, the Chief Medical Officer for England noted, “liver disease...is the only major cause of mortality and morbidity which is on the increase in England whilst decreasing among our European neighbours” (Davies, 2012, p. 11). These deaths are largely preventable, as the main contributors are lifestyle factors; harmful alcohol consumption, obesity (causing non-alcoholic fatty liver disease) and viral hepatitis (hepatitis B and C) (Royal College of Nursing, 2015; PHE, 2017f). Furthermore, of the liver diseases, hepatitis C related deaths are rising the fastest (Hepatitis C Trust, 2013b), seeing deaths from liver disease attributed to hepatitis C double between 2008 to 2014 (PHE, 2016b).

It is estimated that there are approximately 214,000 people living with hepatitis C in the UK (PHE, 2015). Monitoring is conducted yearly in the PWID population of the UK, finding, a prevalence of antibodies to the hepatitis C virus in 53% of survey participants from England, Wales and Northern Ireland in 2016. By individual country, prevalence was 52% for Wales, 22% Northern Ireland and 54% England (PHE, 2017g). Scotland’s prevalence was at 58% for 2015-2016 (Health Protection Scotland, 2017). Within England, the prevalence of hepatitis C among PWID varies between regions, with prevalence in 2016 ranging from 39% in the West Midlands to 67% in the North West (PHE, 2017a). Figures from 2016 showed that prevalence amongst PWID in the North West is consistently higher than England overall (PHE, 2018b). Within the North West there is variation in prevalence. 2013 figures showed prevalence of hepatitis C in PWID at over 60% in Liverpool and Sefton, two local authority areas of Merseyside (PHE, 2013).

Admissions to hospital due to end stage liver disease in Liverpool (as well as Rochdale and Manchester) are higher than the average admission rates for England and the rest of the North West (PHE, 2016a) and deaths from liver disease attributed to hepatitis C are highest in the North West and London.

These statistics show hepatitis C to be a significant health concern within the Merseyside region of the UK, justifying the need for research within this region.

1.3 Explanation of terms used in this thesis

This section explains the key terms used in this thesis, with the intention to bring clarity to the topics discussed and interpretation of findings but also in recognition that 'language shapes beliefs and may influence behaviours' (UNAIDS, 2015, p.3).

People who inject drugs is the preferred terminology for people who inject psychoactive drugs (such as heroin or crack cocaine) into veins (UNAIDS, 2015; PHE, 2017e). Terms such as injecting drug users (IDU) and intravenous drug users (IVDU) are now defunct in favour of 'people who inject drugs' as it places the emphasis on people and not the behaviour (UNAIDS, 2015). UNAIDS (2015) also suggest abbreviations should not be used as they are dehumanising. Whilst this research is in full agreement with this view, as it has a research philosophy that aims to challenge traditional power dynamics and views people who inject drugs as the experts in this research, the acronym PWID has been used for ease of reading and in keeping with current academic literature and UK Government reports. However the term PWID requires clarification. Do we mean people who are currently injecting, have recently injected or have injected at some point in their life but have stopped? Furthermore what time frame is classed as current or recent injecting? 'Lifetime PWID' (people who have injected at some point in their life) is another term used in the literature, however it requires further explanation as to whether this refers to those who have stopped injecting or those who currently inject. Unfortunately criteria of 'PWID' in studies and reports is not always specified (Larney et al, 2015). For this research the term PWID is used to mean both people who were injecting at the time of the research and people who had stopped injecting but had injected at some point in their life. The reason for this criteria was that this research's

focus was predominantly on experiences of living with hepatitis C and not a focus on injecting behaviour.

The term 'service user' is used as a general term throughout discussions in this research, referring to people who attend drug, alcohol or hepatitis C services. Whilst this includes PWID who have hepatitis C, it may also include people attending drug and alcohol services who do not have hepatitis C, or people attending for help with non-injectable drugs such as cannabis or cocaine. However 'service user' interviews were conducted in this research (see Chapter 3 for service user interviews method and Chapter 5 findings). In this context 'service users' refers to people who met the inclusion criteria of the research, which was PWID who have hepatitis C. Interviews were also conducted with 'professionals' which for this research meant people who have a professional interest in the topics of the research, thus they work in drug, alcohol and/or hepatitis C services. Although some people who work in these services may also have hepatitis C and or personal experiences of drug and/or alcohol use, it is their professional experience that is explored in the 'interviews with professionals', as opposed to the lived experience which is explored in the service user interviews. It is important to note that whilst the term 'professional' suggests a qualified and therefore not amateur understanding of alcohol, drugs and hepatitis C, the term is not intended to place the views of those working in services above those who use services, as it is the service users that are viewed as the experts in this research, which ultimately seeks to understand their experiences in order to inform services.

Participants in the service user interviews were PWID who 'have hepatitis C'. The term 'have hepatitis C' included people who had hepatitis C at the time of the interviews and people who previously had hepatitis C, thus they had the virus at some point in their lives. Previous infection includes people who had cleared the virus via treatment, or who had spontaneously cleared the virus. People with either current or previous hepatitis C infections were

included in the interviews as both experiences of hepatitis C were of interest in this study.

Throughout the thesis, the term 'support' is used. This term is used in a general sense and for people with hepatitis C this support could include: advice, information, getting tested, being referred to a hepatitis C specialist, management of their hepatitis C virus, receiving hepatitis C treatment and receiving peer support.

Language on alcohol use is inconsistent throughout the literature, with researchers using terms such as 'heavy drinkers', 'high risk drinkers', 'alcohol excess', 'problem drinkers' 'addicted' to describe people who drink above government recommendations. Often explanations are provided on the amount of alcohol the used terminology refers to, but this is not always the case, making findings and comparisons between studies difficult to interpret. The preferred terminology of use in this thesis is in line with the National Institute for Health and Care Excellence (NICE, 2010b) and the Department of Health's Chief Medical Officers recommendations (Department of Health, 2016) (see glossary for definition of terms).

1.4 What is not covered in this research

Prevention of hepatitis C, along with increasing testing and treatment, is a key area of focus to reach the WHO (2016) target of eliminating viral hepatitis as a public health threat (defined as achieving a 90% reduction in new chronic infections and a 65% reduction in mortality) before 2030. Whilst understanding the importance of preventing new infections, this thesis does not focus on hepatitis C prevention, but rather focuses on those who have the virus.

Due to the route of transmission for hepatitis C, PWID are at risk of contracting other blood borne viruses such as hepatitis B and HIV. Being co-

infected with these other viruses as well as hepatitis C, complicates management of the hepatitis C virus and increases the risk of cirrhosis and hepatocarcinoma (Lim, 2001). Whilst research into co-infection is important, this research focuses on hepatitis C only, as it is possible that the lived experience of having co-infections will be different to that of having hepatitis C alone.

1.5 Personal reasons for doing this research

My reasons for undertaking this PhD have come from a professional not personal position, thus it is my career in health that has driven me to pursue this topic and not one of personal experience of myself, friends or family having hepatitis C. I qualified as a nurse 18 years ago and have continued to work as a nurse on a part time basis throughout the course of this PhD. My current role is a clinical research nurse, which has led to my decision to conduct my own research and to undertake a PhD.

By definition of being 'a nurse', my interests lie in health and helping people who are sick or injured. Although I have not worked specifically in drug, alcohol or hepatitis services, I have worked in acute settings (an accident and emergency department and Glastonbury Music Festival) with people who have taken or are withdrawing from alcohol and/or drugs and on general hospital wards where there has been patients with a variety of health issues including for some patients alcohol and/or drug dependencies. I have also worked on a research studies that considered whether genetics impacted on the amount of methadone (opioid substitution therapy (OST)) a person required. This involved attending drug services to recruit participants (people on methadone) onto the research. I also have a long term professional interest in infectious diseases, leading me to study tropical medicine and work in South Sudan where the majority of the work was to prevent or treat infectious diseases.

Outside of nursing, I have previously volunteered for a local Merseyside HIV charity. My role there, was not to work as a nurse but to provide support such as gardening or driving people to hospital appointments. From this volunteering, I learnt some of the ‘social’ issues rather than the ‘medical’ issues, of living with HIV, a disease that like hepatitis C, is highly stigmatised. Clearly this volunteering experience has also influenced my choice of PhD topic.

1.6 Capturing the lived experience

This research considers the lived experience of people who have hepatitis C. ‘Lived experience’ refers to understanding the experience of a phenomenon from those who have lived it, exploring not only the experience but also how people respond, live through and perceive the experience (Given, 2008). As someone who does not have first-hand experience of hepatitis C, it was important for me to attempt to capture the experiences of those with the virus, in order to access their knowledge of living with the disease and gain an understanding of issues they faced. Capturing the lived experience of service users is valuable as it aims to seek understanding of a topic from the service users point of view, which could be of value to those working at all levels within that field, such as researchers, policy makers, commissioners and front line staff. The Department of Health and National Institute of Health Research value the lived experience and recommend the involvement of service users, patients and public in health research. Patient and public involvement (PPI) differs from ‘participation’ in research. ‘Involvement’ refers to patients, service users and the public being involved in every step of the research process including the design, management, conduct and dissemination of the research (Health Research Authority, 2017; National Institute for Health Research, 2019). Thus “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (National Institute of Health Research, 2019).

The original vision for the research undertaken in this thesis was to have service user involvement throughout the research. Service user involvement occurred to some degree but proved to be challenging and is discussed in more detail in section 3.5.3. Despite service user involvement being to a lesser degree than hoped, the lived experience of people with hepatitis C was explored in depth. Also in contrast to capturing the lived experience of service users, the 'professional experiences' of people working in the field of drug, alcohol and hepatitis C were obtained. Their professional experiences of working within services as opposed to their personal experiences and views was captured and provided data to compare and contrast with the lived experiences of service users.

1.7 Conceptual Framework

A conceptual framework has been developed for this research (Figure 1). This framework was informed by existing research and my own experiences and knowledge prior to data collection. The framework provides a visual representation of the key concepts with further points discussed in more detail in the literature review Chapter 2.

1.7.1 Experiential knowledge

From my nursing and volunteering experiences I have gained an awareness of some of the difficulties that people with infectious diseases and/or drug and alcohol use face when accessing and receiving healthcare. One such issue is stigmatisation and discrimination.

I have heard accounts from people who are HIV positive about their experiences of discrimination from healthcare staff, such as staff wearing two pairs of gloves when they would wear one pair to see patients without HIV. These experiences led to ongoing fear and reluctance when seeking healthcare in the future.

I have also unfortunately witnessed staff expressing negative attitudes towards patients who use alcohol or drugs. Terminology such as ‘druggies’ or ‘junkies’ was used to discuss patients who used drugs and some staff would also expect patients to act in a certain way because they used drugs, such as noncompliance with medical advice. This grouping together of people based on lifestyle behaviours rather than treating patients as individuals is stereotyping and discriminatory. Similar experiences of stigmatisation and discrimination in healthcare are also evident in the existing literature on hepatitis C.

1.7.2 Existing theory

There are many theories that could be discussed in relation to this thesis, such as models of addiction, behavioural change models, theories on how people perceive and manage risk, theories on access to health care, theoretical approaches to stigma and so on, however as the population being studied, PWID with hepatitis C, are generally a hard to reach group it is not known if these theories are helpful as their efficacy has not been ascertained for this population group. Neale (1997) argues the case for reconsidering theory in homelessness. Although she discusses homelessness and not PWID who have hepatitis C, there is overlap between the groups as both populations are largely marginalised and hard to reach. She suggests theories (feminism, post structuralism, postmodernism, critical theory) are somewhat incompatible and instead draws upon a range of theoretical perspectives to conclude with eight theoretical assumptions, many of which are relevant to the population considered in this thesis. Two notable assumptions are ‘the differences between homeless individuals are multiple and are not adequately explained by theory’ and ‘shared experiences of, and beliefs about, homelessness, are nevertheless common’. These points can be related to PWID who have hepatitis C as although sometimes ‘tarded with the same brush’ people with hepatitis C are not a homogeneous group but are individuals with different experiences and outcomes.

As this research does not conform to any particular theory but is pragmatic in its approach to exploring the topic, a generic qualitative approach is used. This approach gives methodological flexibility, allowing choice of methods which are best placed to explore the perspectives of participants and the topics under consideration (Cooper and Endacott, 2007; Kahlke, 2014). Innovative methods of calendar and vignettes interviews were used. Calendars were used with service users as a visual aid to assist with their narratives of alcohol/drug use and hepatitis C and vignettes with staff to seek their professional actions rather than personal views on services provided. Further to this semi structured interviews were conducted with public health commissioners to explore the system factors involved.

1.7.3 Existing empirical research

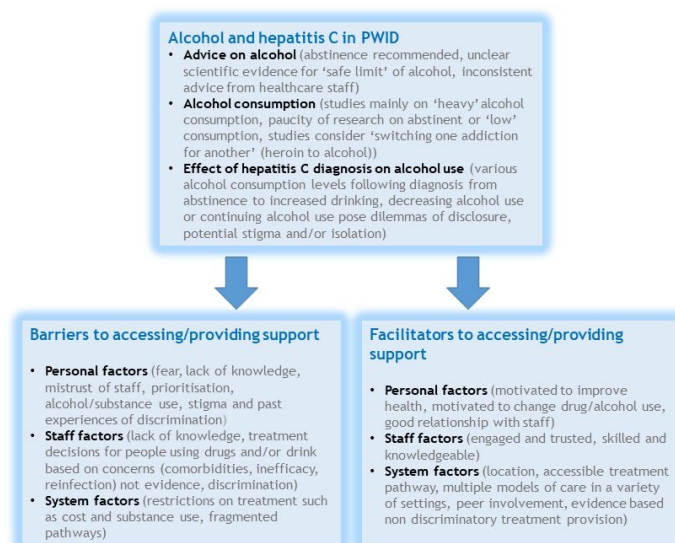
The existing research shows that little is currently known about the lived experience of alcohol and hepatitis C in PWID as there is a paucity of qualitative research on this topic. There has been one study (Harris, 2010) conducted in Australia and New Zealand which found people drank for a variety of reasons but negative judgments could cause people with hepatitis C to hide their drinking, become isolated, and limit their opportunities for receiving appropriate medical care.

Other barriers to accessing care were evident throughout the literature. Barriers were found to getting tested, linking into hepatitis C specialists and getting treated as well as barriers to getting support from peers. Drinking alcohol (at certain levels) was also a barrier to receiving hepatitis C treatment.

The literature also identified facilitators to accessing care, such as having engaged, trusted and knowledgeable staff and the importance of a good patient /staff relationship. Furthermore, there were system factors which impacted on accessing (and providing) care, such as having a pathway to link into specialist hepatitis C care.

Further discussion of the existing literature is in Chapter 2.

Figure 1 Conceptual framework



1.8 Organisation of the thesis

This thesis consists of eight chapters. Chapter 2 is a review of the literature, analysing previous research conducted and providing background to the topics explored in this thesis. Chapter 3 is the methodology, explaining the aims of the research, the theoretical perspectives, the researcher's philosophy underpinning the research, methods used and analytic approach. Methods employed were participant observation of hepatitis C support groups, life history interviews using a calendar approach with service users and semi structured interviews (including the use of vignettes of hypothetical service users) with people working in the field of drug, alcohol and/or hepatitis C. For the observation, the method as well as the researchers role within this method are discussed. For the interviews, the design and application of the calendar and vignettes are explained and analysed. Chapters 4 to 6 present the research findings. Chapter 4 discusses the findings from the period of observation, Chapter 5 presents the service user interview findings, and Chapter 6, the findings from the interviews with professionals. Chapter 7 is the discussion chapter, comparing and contrasting the results from Chapters 4 to 6. Chapter 8, the final chapter, is the conclusion, consisting of a summary of the main findings, the strengths

and limitations of the research, the contribution to knowledge and future recommendations.

Chapter 2 Literature review

2.1 Introduction

This chapter presents background information and analysis of the current literature on hepatitis C support namely, testing, linkage to specialist hepatitis C care, hepatitis C treatment, and peer support. It also reviews the literature on alcohol use for PWID who have hepatitis C and stigma, two issues that can affect people living with hepatitis C, and affect access to support.

2.2 Diagnosis, treatment and linkage to specialist hepatitis C care

Historically, statistics about hepatitis C presented a gloomy picture. Approximately 50% of those with hepatitis C in England knew they had the virus (PHE, 2014a) and of those diagnosed, only 3% received treatment (PHE, 2014b). Thus approximately half of people with chronic hepatitis C were aware of their diagnosis but the majority did not access treatment. Furthermore of those who did access treatment, few cleared the virus (see Section 2.2.2). A similar picture was seen across the whole UK (PHE, 2014b), consequently, the UK deaths of hepatitis C related end stage liver disease and hepatocarcinoma rose year on year, with 98 deaths in 1996 rising to 428 deaths in 2012 (PHE, 2014b). However 2015 saw an upturn, with the first decrease in deaths from hepatitis C in the UK in over a decade (PHE, 2016b); a trend continuing in 2016 (PHE, 2017d). This reduction in hepatitis C related mortality is thought to be due to the increasing availability of new treatments, known as Direct-Acting Antiviral (DAA) drugs (PHE, 2017d; PHE, 2017e). This is discussed in more detail in Section 2.2.2.

2.2.1 Diagnosis

Hepatitis C testing is a two stage process. Firstly a simple, fast and relatively inexpensive (Carlson, 2005; Jefferys, 2017) antibody test is

conducted. If antibodies to the hepatitis C virus are present, this indicates the person has been infected with hepatitis C at some point in their life. As around 20% of people exposed to hepatitis C can spontaneously clear the virus (within the first 6 months of being exposed to the virus), the presence of antibodies therefore does not necessarily indicate a current infection, requiring a second (more expensive) test (Carlson, 2005; Jefferys, 2017) to be conducted. This second test is known as HCV (hepatitis C) RNA test or PCR (polymerase chain reaction) test and confirms if the infection is current, the amount of virus in the blood (viral load) and establishes which genotype of the hepatitis C virus is present (National Institute for Health and Care Excellence (NICE), 2016b; Hepatitis C Trust, 2017d).

After exposure to the hepatitis C virus, it takes between 6 and 12 weeks for the immune system to produce the antibodies to the virus. However for some people it could take as long as 6 months (Hepatitis C Trust, 2017d). This time frame is known as the 'window period' and if antibody testing is conducted within this window period it is possible for the person to have the virus but get a negative result. Those testing negative for the antibody test (conducted at the correct time, thus outside of the window period) do not require the second (PCR) test, saving the person being called back for a second sample, and reducing costs by only conducting PCR testing on those who require it.

Whilst some services do conduct the antibody test and then if necessary recommend attending for the second test, Hepatitis C Trust and NICE suggest that the two tests could be taken at the same time reducing the number of times blood samples are required (NICE 2016c; Hepatitis C Trust, 2017d). Further guidance on testing is provided by NICE (NICE, 2012c) who recommend that hepatitis C (and B) testing is offered to all service users attending drug services and that drug services have access to Dried Blood Spot testing (DBS) (finger prick test for antibodies) for those who have difficult venous access. A further recommendation is for drug services to have access to specialist phlebotomy services, with view to enabling

hepatitis C treatment to be provided in the community (NICE, 2012c), thereby reducing the need to attend secondary care for the second test (PCR test) and treatment.

Further recommendations concern staff at drug services, requiring them to have the skills and knowledge to promote testing and treatment for hepatitis C (and hepatitis B) and also to ensure they are trained and competent in performing the DBS test as well as pre and post-test discussions (NICE, 2012c).

To note, generally discussions on ‘testing’ and figures on hepatitis C testing in PWID, in reports and literature, are related to the antibody test; throughout this thesis ‘testing’ is used to mean the antibody test unless otherwise stated.

An annual survey, known as the voluntary Unlinked Anonymous Monitoring (UAM) survey, is conducted with PWID attending specialist agencies (agencies providing a range of services to those who inject illicit drugs, from medical treatment to needle and syringe programmes and outreach work) in England and Northern Ireland. Amongst the data reported, is the prevalence of hepatitis C, as well as the number and proportion (of PWID taking survey) who are aware of their positive hepatitis C status. The proportion of PWID in England that are aware of their hepatitis C antibody positive status has remained relatively stable over the years. In 2003, 47% were aware of their hepatitis C positive status (PHE, 2014a), 52% in 2005, 55% in 2010 and 53% in 2015 (PHE, 2017b). 2016 figures showed that across England, Northern Ireland and Wales, 52% of PWID with hepatitis C were aware of their positive status (PHE 2017e). Thus roughly half of the people surveyed were aware that they have hepatitis C, which evidently means half were unaware they have the virus. Furthermore of those that were unaware of their positive status, many reported they had never been tested or had not received a test recently. 22% said they had never received a test and of those tested 44% said their last test was over 2 years ago (PHE,

2017e). Retesting is recommended once or twice a year when the risk of exposure continues (such as continued sharing of injecting equipment) (NICE 2012a b or c; Scottish Intercollegiate Guidelines Network (SIGN), 2013; NICE, 2016c; PHE, 2017e), indicating current testing is insufficient. However, amongst PWID that are in treatment for their drug use, there has been an increase in hepatitis C testing, from 53% in 2010 to 65% in 2016 (PHE, 2017e). Further data on hepatitis C testing in PWID, showed at the start of treatment for drug use, 96% were offered a hepatitis C test, however only 67% of PWID accepted the offer.

There are a number of studies researching why uptake of testing is low amongst PWID (Craine et al, 2004; Khaw, Stobbart and Murtagh, 2007; Harris, McDonald and Rhodes, 2014). Considering the UK based studies, reasons for low test acceptance include: fear and lack of knowledge on hepatitis C, (Craine et al, 2004; Khaw, Stobbart and Murtagh, 2007; Harris, McDonald and Rhodes, 2014)) including lack of awareness of disease progression and treatment available (Khaw, Stobbart and Murtagh, 2007); concerns about the testing procedure including phlebotomy (Craine et al 2004; Khaw, Stobbart and Murtagh, 2007; Harris, McDonald and Rhodes, 2014); inadequate pre- and post-test discussions (Craine et al, 2004; Khaw, Stobbart and Murtagh, 2007); thinking testing is unnecessary as not at risk of having hepatitis C (Craine et al, 2004; Harris, McDonald and Rhodes, 2014) and concerns around institutional stigma and confidentiality (Khaw, Stobbart and Murtagh, 2007), especially in hospitals (Harris, McDonald and Rhodes, 2014). People feared breaches of confidentiality regarding their positive hepatitis C status, and were fearful of potential discrimination due to this diagnosis (PHE, 2017e).

Considering literature from other countries, (mainly Australia and USA) (Aitken, Kerger and Crofts, 2002; Day et al, 2008; Lally et al, 2008; Strauss et al, 2008; Swan et al, 2010) found the same barriers as the UK, but also found other barriers, namely: lack of knowledge on location of testing centres (Strauss et al, 2008; Swan et al, 2010) and lack of accessible testing (Lally et al, 2008); having not considered testing for hepatitis C (Aitken,

Kerger and Crofts, 2002); hepatitis C not thought to be worth worrying about (Aitken, Kerger and Crofts, 2002; Swan et al, 2010); feeling well (Swan et al, 2010); fear of investigations (Swan et al, 2010); difficulty keeping appointments (Day et al, 2008); prioritisation of obtaining/taking drugs (Lally et al, 2008) and doubt over healthcare staffs' knowledge of hepatitis C (Swan et al, 2010).

The literature also noted some facilitators to getting tested. Service users at drug treatment centres noted that support from staff facilitated testing. Explaining the importance of being tested and helping service users to understand and cope with test results were seen as supportive measures. (Strauss et al, 2008). Lally et al (2008) found a personal facilitator to getting tested, which was an interest from service users to improve their own health.

Whilst the new DAA treatments are providing opportunities to reduce hepatitis C morbidity and mortality, these opportunities are limited if rates of diagnosis are not improved, requiring efforts to increase the offer and uptake of hepatitis C testing (PHE, 2017d; PHE, 2017e).

2.2.2 Treatment

The aim of treatment for hepatitis C is to 'cure' the virus, defined as an undetectable level of the virus (HCV RNA) in the blood and known as sustained virologic response (SVR) (Pearlman and Traub, 2011). Hepatitis C treatments have evolved over the years since the virus was first discovered. Initially chronic hepatitis C was treated with interferon alpha, achieving SVR rates between 6% and 19% (McHutchinson et al, 1998; Poynard et al 1998; Manns et al, 2001). Then in the late 1990's there was 'a major breakthrough for treating HCV' (Franciscus, 2017, p.3) as ribavirin (tablets) were introduced and given in combination with interferon alpha, increasing SVR rates to between 38% and 52% (McHutchinson et al, 1998; Poynard et al 1998; Mannes et al 2001; McHutchinson et al, 2002; Manns et al, 2001).

A further development in early 2000s saw the introduction of pegylated interferon (NICE, 2004). As interferon alpha is metabolised rapidly in the body, the virus could multiply between the thrice weekly injections. Pegylation (attaching a molecule chain to the interferon) meant interferon was metabolised at a slower rate in the body, enabling drug levels to remain more constant and therefore be more effective at treating the virus. This also meant pegylated interferon injections were not required as frequently as the interferon alpha injections, requiring weekly administration only (Hepatitis C Trust, 2018a).

Until recently, ribavirin and pegylated interferon taken for 24 or 48 weeks (depending on genotype) have been the standard treatment for hepatitis C (European Association for the Study of the Liver, 2011; Burstow et al, 2017). These treatments saw a SVR rate of 80% for genotype 2,3,5 and 6, a lower SVR rate for genotype 4 and the lowest SVR rate of approximately 40% for genotype 1 (the main genotype worldwide) (Burstow et al, 2017). In 2012, NICE (2012a; 2012b) approved two further medications (boceprevir and telaprevir) for adults with genotype 1 who had compensated liver disease (earlier stages of liver disease where the liver is still able to perform most of its functions and people do not experience symptoms) (Thornton, 2016; Hepatitis C Trust, 2018b). The addition of either boceprevir or telaprevir to ribavirin and pegalyted interferon saw SVR rates improve to between 64% and 75% (Burstow et al, 2017). It is worth noting that boceprevir and telaprevir, are no longer used in the UK (as newer DAAs have a shorter treatment duration, achieve better SVR and have less side effects; see Section 2.2.2.1) (NICE, 2012a and 2012b).

Despite treatments being available to cure hepatitis C, in 2014 only 3% of people diagnosed with hepatitis C in England accessed treatment (PHE, 2014b). Uptake of treatment is not only a concern for England, but a topic of international concern, with the majority of research to ascertain the

reasons for the low uptake of treatment being conducted in the USA and Australia.

The majority of research considered found fear of side effects (physiological and psychological) to hepatitis C treatment to be a barrier to starting treatment (Doab, Treloar and Dore, 2005; Grebely et al, 2008; Swan et al, 2010; Jordan et al, 2013; Mravčik et al, 2013; Treloar et al, 2014a; Lewis et al, 2016). Side effects reported for interferon based treatments include: flu-like symptoms such as fatigue, headache and pyrexia; gastrointestinal symptoms including nausea, vomiting, constipation, diarrhoea; loss of appetite and weight loss; anaemia; rashes and itchy skin; insomnia and depression (NICE, 2010c; NHS Choices, 2015).

Other commonly noted barriers were concerns over the efficacy of the treatment (Mravčik et al, 2013; Treloar et al 2014a), the length of treatment (Jordan et al, 2013) and not having symptoms from the hepatitis C (Doab, Treloar and Dore, 2005;

et al 2008; Treloar et al 2014a). In Jordan et al's (2013) study there was a common perception amongst participants that the treatment was worse than the disease itself. This was echoed by participants in Treloar et al's (2014a) study, who felt they would only have treatment when they were unwell enough from the hepatitis C, and as one participant (*Gary*) explained, hepatitis C treatment would be the '*last step to take*'. Other barriers included: not wanting a liver biopsy (Doab, Treloar and Dore, 2005); fear of needles (blood tests/interferon) after stopping injecting drug use (Swan et al, 2010); a lack of knowledge about hepatitis C (Grebely et al, 2008) and lack of knowledge of availability of treatment (Grebely et al, 2008; Jordan et al, 2013). Studies also found participants had competing priorities, such as other health concerns, (Doab, Treloar and Dore, 2005), family responsibilities, unstable housing (Treloar et al, 2014a), addiction, education (Swan et al, 2010), employment (Swan et al 2010; Treloar et al, 2014a), as well as an overall sense that hepatitis C was not a priority in their lives at the current time (Treloar et al, 2014a).

Employment affected participants in many ways, including difficulty keeping clinic appointments (Swan et al, 2010), fear of reduced income from being unable to work whilst on treatment (Swan et al 2010; Treloar et al, 2014a), and a reticence to discuss sick pay in fear of the response to disclosing hepatitis C status (Treloar et al, 2014a). The later demonstrates another barrier for people with hepatitis C: reluctance to disclose a positive status, due to fear of discrimination and stigma of the virus (Hopwood, Nakamura and Treloar, 2010).

Some participants in the studies had tried to access treatment but had been declined. The main reasons for this were: that their liver disease was not advanced enough to receive treatment (Doab, Treloar and Dore 2005; Jordan et al, 2013); there were long waiting lists for treatment (Doab, Treloar and Dore, 2005); treatment providers' concerns of the complications due to comorbidities; risk of reinfection post treatment (Harris and Rhodes, 2013a); injecting drug use (Doab, Treloar and Dore 2005; Jordan et al, 2013), adherence to treatment and 'heavy' alcohol use (Doab, Treloar and Dore, 2005, Harris and Rhodes, 2013a). There is however evidence to suggest that drinking may not affect interferon treatment. A study in France considered interferon based treatment with a population of 'alcohol dependent patients with ongoing abuse'. Analysis showed SVR rates of 48% versus 49% in control group (lower-risk drinkers) (Le Lan et al, 2012).

Relationships with healthcare providers also influenced participants' access and engagement with treatment (Swan et al, 2010; Jordan et al 2013, Treloar et al, 2014a). Participants expressed a lack of trust and confidence in healthcare providers motivations and knowledge (Swan et al, 2010; Jordan et al 2013). A study conducted in the USA found participants felt that healthcare providers dissuaded them from pursuing treatment and felt the lack of effective treatment choices was due to the marginalisation and stigmatisation of PWID (Jordan et al, 2013). Stigma and discrimination as a

barrier to hepatitis C support is discussed further in Section 4.2.6 and 5.2.3.3.

A study in Australia interviewed staff and clients at opioid substitution clinics and considered factors that facilitated engagement with hepatitis C treatment, finding there was a ‘crucial interplay between system, provider and personal factors’ (Treloar et al, 2014, p.563). Provider factors were having an engaged and trusted clinician. System factors were having an accessible treatment pathway and associated support structures, which are discussed further in Section 2.2.3, linkage to care.

2.2.2.1 The era of direct acting antivirals

In considering patients’ reasons for not accessing hepatitis C treatment (interferon based), these are largely centred around the treatment itself, namely the efficacy, length of course, route of administration (injection) and side effects of the treatment. However since 2014 hepatitis C treatment entered a new era, seeing the invention of new drugs known as Direct Acting Antivirals (DAAs), such as sofosbuvir, daclatasvir, dasabuvir, ledipasvir, ombitasvir, paritaprevir, ritonavir, elbasvir, grazoprevir and velpatasvir (NICE, 2015a; NICE, 2015b; NICE, 2015c; NICE, 2016a; NICE 2017; Hepatitis C Trust, 2018a).

These drugs are orally administered as opposed to injections, the course of treatment is shorter than interferon therapy (8-12 weeks), they have fewer side effects and are more efficacious at treating hepatitis C (rates of SVR 80-90%) (Harris et al, 2016; PHE, 2017d; PHE, 2017e). Thus these drugs have the potential to transform the treatment landscape for hepatitis C, providing a faster and more effective cure to the majority who receive them, without many of the complications associated with previous interferon based treatments (Innes et al, 2015; Harris et al, 2016). However, initially the new drugs raised ‘real issues of affordability for UK health services’ (PHE, 2015, p.12), seeing delays in access to these

medications for many (Gornall, Hoey and Ozieranski, 2016). The Early Access Programme was set up in 2014 by NHS England, which allowed people with compensated and decompensated cirrhosis to benefit from the drugs whilst they proceeded through the NICE approval and NHS England implementation processes (PHE, 2015), explained by Gornall, Hoey and Ozieranski (2016), as ‘Before the NICE process was complete, NHS England took care to ensure that the sickest patients—people with liver failure who might die before the guidelines were issued—were treated’ (Gornall, Hoey and Ozieranski, 2016, p. 2).

The first drug approved by NICE in February 2015 was Sovaldi (sofosbuvir), however, due to concerns over cost, NHS England delayed access to this medication until August 2015 (Gornall, Hoey and Ozieranski, 2016). Furthermore the next drugs to be considered by NICE in early 2015, Harvoni (combination-ledipasvir-sofosbuvir), Viekirax (ombitasvir-paritaprevir-ritonavir) and Daklinza (daclatasvir), were challenged by NHS England amidst fears of cost effectiveness and the impact on the NHS budget. This led the British Society of Gastroenterology, the British Association for the Study of the Liver, the British Viral Hepatitis Group and the Royal College of Pathologists to provide a joint submission to NICE contesting the budget impact claimed by NHS England. NICE finally recommended these medications in November 2015, to be available for all indicated patients by the end of February 2016. In March 2016 NHS England announced numbers treated would be doubled (to 10,000) in 2016 -2017 through 22 operational delivery networks (main regional sites that would allocate treatment). Gornall, Hoey and Ozieranski (2016) argue that this was actually a way to ration treatment to patients, as clinicians had a maximum number of patients they were allowed to treat each month, and going over this allocation would see the provider paying for treatment. As NHS England had for the first time placed a cap on drugs that NICE recommended to be effective, cost effective and to be available, the Hepatitis C Trust responded, “It is truly ironic that NHS England should chose to start rationing drugs that are so effective they cure almost everyone who is

treated. It feels like people with hepatitis C are being picked on” (Charles Gore, Chief Executive of the Hepatitis C Trust, cited in Hepatitis C Trust, 2016). Since the controversy over these initial drugs NICE have approved further DAAs for use (NICE 2016a; NICE 2017). According to PHE (2017d) ‘while the high price of these new drugs represents a major barrier to access in most countries worldwide, these medicines are now being rolled out, in accordance with national recommendations, in all UK countries’ (PHE, 2017d, p.17).

Globally, the introduction of DAAs has been controversial, raising questions on drug pricing and who should and should not be treated. Whilst the Australian government announced DAAs would be available for every Australian with hepatitis C (Australian Minister for Health, 2015), Grebely et al (2015) noted the USA and ‘other countries’ were excluding people from accessing treatment (interferon or DAAs) based on their alcohol and drug use, despite USA, European and WHO clinical guidelines recommending all people with any stage/severity of the disease receive treatment (European Association for the Study of the Liver, American Association for the Study of Liver diseases / Infectious Diseases Society of America, cited in Grebely et al, 2015; WHO, 2014). The restrictions based on drug and alcohol use were also highlighted in the hep-CORE study which in 2016 asked liver patient groups in 27 countries (26 in WHO European region including United Kingdom, plus Egypt) ‘in practice what restrictions are there on access to direct acting antivirals for the treatment of HCV infection in your country?’ Findings showed 52% of hep-CORE countries restricted DAA treatment for those currently injecting drugs, with restrictions also shown to alcohol use and previous injecting in some countries (Lazarus et al, 2017).

Reasons for excluding PWID, people who use drugs (non-injecting) or people who use alcohol from hepatitis C treatments are: non adherence to treatment regimes; poorer outcomes from the treatment than people with the same stage of the disease who do not use drugs or alcohol; a higher

chance of reinfection (due to ongoing injection risk); and lack of data on the outcomes of DAA treatment in this population (Grebely et al, 2015).

Data available on interferon therapy demonstrated that these exclusions were unfounded (Grebely et al, 2015) and although data on the use of DAAs for PWID was initially limited, a number of studies have now been conducted with this population (Dore et al, 2016; Grebely et al, 2017b; Mazhnaya et al, 2017; Morris et al, 2017; Norton et al, 2017; Read et al, 2017). The first study was the C-EDGE CO-STAR study, which considered the use of DAAs in people receiving OST and included people with ongoing drug use. Over 50% of the study population were using at least one substance: amphetamines, barbiturates, benzodiazepines, cannabinoids, cocaine, opiates, or phencyclidine throughout the study period (numbers of participants injecting was not ascertained). Results showed adherence of over 95% by 96% of participants and SVR12 (SVR at 12 weeks after treatment completion) by 91% of study population (Dore et al, 2016). Other studies (Mazhnaya et al, 2017; Morris et al, 2017; Norton et al, 2017; Read et al, 2017) conducted with PWID (recent and historic injecting) showed treatment completion by 96-100% of the study population and an SVR12 of 80 - 96%. However it is important to note that whilst these studies included people who have injected drugs, the definitions of 'recent' use varied between studies (1 month to 1 year). One study which defines 'recent' as having injected in the last month, with 48% of the study population injecting at least once a week, was the SIMPLIFY study, where 96% of the study population completed the treatment and SVR12 was achieved by 94% (Grebely et al, 2017b). The most important finding from these studies was evidence showing little difference in treatment completion and SVR rates between drug users and non-drug users receiving DAA treatments, giving force to the argument that 'recent' injecting / drug use should not be an exclusion for DAA treatment.

Regarding alcohol consumption and DAAs, Tsui et al's (2016) study considered alcohol consumption in 15,151 patients who were initiating DAAs

for hepatitis C. Using the AUDIT-C tool (Babor, 2001), 68.5% of the study population were abstinent, 22.6% were classified as low-level drinking and 8.9% as ‘unhealthy’ drinking. The study found no significant differences in SVR12 between the groups (SVR 91%, 93% and 91% respectively), concluding that alcohol use should not exclude people from receiving DAAs. And as Grebely et al (2015) argue;

Even if it could be shown that treatment is less effective for people who use drugs and alcohol, it does not follow that it is equitable or just to exclude them. Potential life-saving therapies for the treatment of lung cancer or asthma are not withheld from current smokers. Similarly therapies for type 2 diabetes are not withheld from those who are overweight and do not adhere to dietary recommendations.

(Grebely et al, 2015, p. 781).

It is unclear if the UK was included in Grebely et al’s (2015) ‘other countries’ who were excluding people from DAAs based on their alcohol and drug use. However, as previously discussed, DAAs ‘are now being rolled out, in accordance with national recommendations in all UK countries (PHE, 2017d, p.17) and UK recommendations do not exclude people from treatment based on alcohol and drug use (NICE, 2015a; NICE,2015b; NICE, 2015c; NICE, 2015d; NICE, 2016a; NICE, 2017; Scottish Government, 2017), with the 2015 NICE guidelines stating: ‘..the recommendations do not differentiate between any groups of patients.’ (NICE, 2015d), and the 2017 guidelines agreeing that: ‘The committee noted that its recommendations on sofosbuvir-velpatasvir were irrespective of whether or not the person uses injectable drugs.’ (NICE, 2017). Instead the guidelines highlight the benefits of treating PWID.

It [DAAs] would also allow access to treatment for people who have found it difficult to access treatment before, such as people in prison, **people who use injectable drugs** and migrant populations. The Committee [advisory committee of NICE] recognised the effect of chronic hepatitis C on the lives of people with the virus. It concluded that treatments that give very high levels of sustained virological response (which is considered

equivalent to a cure), and so help reduce the rate of hepatitis C virus (HCV) transmission and the stigma associated with having chronic hepatitis C, are of major importance.

(NICE, 2015a, section 4.1)

However the NICE guidelines on hepatitis C treatment are not enforceable but allow flexibility in implementation, thus allowing for individual healthcare professional's reasoning and decision making.

The application of the recommendations in this guidance is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

(NICE, 2017)

This is explored further in Chapter 6, of this thesis, where healthcare professionals were given vignettes of hypothetical service users and asked to explain what care/treatment they would provide for the service user and their reasoning for these decisions.

To conclude, the new DAA treatments have brought hope to the hepatitis C community, eliminating the barriers associated with interferon based treatments. PHE suggests that since the DAAs have been introduced, the number of people treated has increased (approximately 40% increase in 2015) and there have been fewer hepatitis C related deaths (8% fall in mortality from hepatitis C related hepatocarcinoma and end stage liver disease in 2016) (PHE, 2017d). However the problem still remains that around 50% of people with hepatitis C do not know they have the virus, therefore efforts to increase testing, along with linking those testing positive into specialist hepatitis C services (discussed below) are required to increase the number of people receiving treatment (Grebely et al, 2017c). Without such measures the WHO targets of a reduction in hepatitis

related mortality of 10% by 2020 and 65% reduction by 2030 (WHO, 2016) will not be met (Grebely et al, 2017a).

2.2.3 Linkage to specialist hepatitis C services

The cascade of hepatitis C care (continuum of care) originates from a model used in HIV care (Gardener et al, 2011). In its application for hepatitis C, the cascade includes testing and diagnosis, linkage to hepatitis C specialist care, accessing treatment and achieving a successful treatment outcome (SVR) (Yehia et al, 2014). Not only is consideration required in diagnosis and treatment but also linking the two, keeping those who test positive for hepatitis C in contact with hepatitis C specialists in order to go on to access treatment. The cascade's purpose is a framework to enable monitoring of population level public health and clinical outcomes as well as to identify gaps along the cascade (Bajis et al, 2017).

An example of a cascade of care for hepatitis C in England is demonstrated by PHE (2016c) using data collected on people who use drugs attending specialist services between 2005 and 2014 (i.e. pre DAA era).

1. Of those who tested positive on hepatitis C antibody test, 75% had received the RNA test within 6 months of the antibody test.
2. Of the RNA tests taken, 75% had a positive result (showing they had a current infection).
3. 3.7% of those with a current infection received hepatitis C treatment within a year of being diagnosed.
4. Of those receiving treatment 43.5% achieved SVR.

Whilst this data does not solely include people who inject drugs into veins (as per thesis focus), it does provide an insight into gaps in the pathway of care for people with hepatitis C. There is a large gap between testing positive for a current infection and receiving treatment. Some barriers to treatment are discussed in the previous treatment section of this thesis

(Section 2.2.2), however there are further issues to consider. This cascade does not have data on how many of those testing positive with current infections (chronic hepatitis C) were referred onto hepatitis C specialists (as would be the norm for other illness, such as a referral to a cardiologist for a heart condition).

Specialists are generally understood to be the medical experts in that particular disease. Thus whilst the ultimate goal may be to treat hepatitis C, specialists (as in any other health condition) provide advice, conduct further investigations and monitor and manage the disease. Therefore linkage to care is important for disease assessment and management as well as treatment.

Along with finding the undiagnosed, linkage to specialist hepatitis C care is seen to be an important challenge in reaching WHO GHSS targets on reducing hepatitis C related mortality (WHO, 2016; PHE 2017d). To this end, linkage to care has been suggested as a ‘research priority’ by experts in the field of hepatitis C (Grebely et al, 2017c) with one priority being to identify ‘barriers and facilitators associated with linkage to HCV [hepatitis C] care and treatment at the levels of the patient, provider and system’ (Grebely et al, 2017c, p. 55).

In addition, PHE (2017d) recommend;

Those responsible for commissioning hepatitis C treatment and care services should continue to work with public health agencies, clinicians and other stakeholders to simplify referral pathways; improve the availability, access and uptake of approved hepatitis C treatments in primary and secondary care, drug treatment services, prisons and other settings; and to drive innovative approaches to outreach and patient support. It will be important to consider those individuals who have been diagnosed but subsequently lost to follow-up, as well as those who are newly diagnosed or already engaged with treatment services.

(PHE, 2017d, p. 11)

Numerous interventions to increase linkage to care have been reported in the literature. Use of FibroScan (non-invasive technique used instead of liver biopsy to assess stage of liver fibrosis), is one such intervention (Foucher et al, 2009; Marshall et al, 2015), as PWID have previously identified having to undergo a liver biopsy as a barrier to hepatitis C assessment and treatment (Doab et al, 2005; Swan et al, 2010). Foucher et al's (2009) study used FibroScan on street based outreach with facilitated (guided) referral onto hepatitis C care, resulting in 10% of those who were hepatitis C positive going onto have hepatitis C treatment. Other interventions include patient navigation programmes in the USA, where 'patient navigators' acting as dedicated linkage to care coordinators, helped people with hepatitis C to navigate the pathways to hepatitis specialist services (Trooskin et al, 2015; Falade-Nwulia et al, 2016; Seña et al, 2016), and telemedicine, used by nurses working in prisons in Australia (Lloyd et al, 2013) and clinicians in rural primary care clinics in USA (Arora et al, 2011; Tahan et al, 2016) to get advice in order to treat their patients. Nurse-led educational interventions (Zhou et al, 2016) were also evaluated, along with integrated hepatitis C care (Cullen et al, 2006; Tait et al, 2010; Ho et al, 2015; Zhou et al, 2016). In these studies, hepatitis C services were integrated with mental health services, substance misuse services, prisons and GP practices, examples of the interventions are explained in more detail below.

In the study by Cullen et al, (2006), 26 GP practices in Ireland had nurse facilitated referral to hepatitis C specialists. The intervention consisted of a liaison nurse whose role was to providing training and support around hepatitis C to GP practices who had patients on methadone, and to liaise with hepatology and addiction treatment services. The nurse also held consultations with patients, provided testing for hepatitis C and facilitated further investigations as required. An increase in hepatitis C testing was seen, as was referrals to hepatitis C specialists, although increase in referrals were not statistically significant.

A 2010 study conducted in Scotland by Tait et al focused on referrals into hepatitis C specialist care from prisons, drug and alcohol services and general practice. The intervention consisted of introducing a new referral pathway with non-medical and outreach nurse-led facilitated referrals compared to usual practice of medical led referral. Findings showed increased referrals and increased numbers completing hepatitis C treatment.

Ho et al's (2015) integration of care, placed a mental health practitioner at clinics providing hepatitis C treatment, resulting in higher rates of hepatitis C treatment uptake and SVR rates than in those who did not have contact with the mental health practitioners.

Another study by Hagedorn et al (2007) introduced a hepatitis service into a substance abuse clinic for veterans in USA. The intervention was hepatitis screening, group education and individual nursing appointment where screening results were given with referral onto hepatitis clinics, as required. Findings showed all patients with chronic hepatitis C were referred to hepatitis C clinics, compared to only 50% referral for those not taking part in the intervention.

Wade et al, (2015) evaluated the introduction of community based hepatitis nurses into clinics for PWID in Australia. The nurses' role was to provide hepatitis C assessment and treatment (interferon based) to PWID, in the community. Findings showed SVR rates comparable to rates of those treated in hospital settings, showing potential benefits of community based models of hepatitis C care.

Unusually, Ahmed et al's (2013) study was based in an hospital hepatology service, at a local district general hospital UK. Thus rather than an intervention for linkage to specialist care, this study's focus was on maintaining patients that had already been linked in with the service. The study's intervention was for patients attending the hepatitis C clinic to receive input from a multi-disciplinary team (hepatologist, a specialist

nurse, psychological support worker and community support team) whilst they received their hepatitis C treatment (n=26 patients). The control group received the routine care, which did not include support from community or psychological teams (n=56 patients). Whilst only having a small sample size, the study did find 95% compliance with hepatitis C treatment in the intervention group compared to 46% in the routine care group, and SVR at 69% in the intervention group compared to 20% in the routine care group.

This section has shown there are many different interventions to increase linkage to hepatitis C care and treatment for PWID. As recommended by NICE guidelines:

Ensure people diagnosed with hepatitis B and C are referred for specialist care; for hepatitis C this may involve offering hepatitis C treatment in the community for people who are unwilling or unlikely to attend hospital appointments, and whose hepatitis C treatment could be integrated with ongoing drug treatment (such as opiate substitution treatment)

(NICE, 2012c)

This is also noted by Bruggmann and Litwin (2013), who commented that 'one size does not fit all' and many models of care incorporating hepatitis C treatment into a variety of settings is required. Moreover it is important to provide hepatitis C care at services where PWID are already attending (Bruggmann and Litwin, 2013).

2.3 Peer-based support

Another initiative to increase engagement and reduce barriers to hepatitis C care for PWID is peer based support (Crawford and Bath, 2013). Peer workers can work in a variety of roles and provide a range of support (Keats et al, 2015). Peer-based support has been successful in assisting the management of other diseases such as HIV, cancer, heart disease, diabetes (Crawford and Bath, 2013) and mental health (MacLellan et al 2015). However Harris, Rhodes, and Martin (2013), suggest that peer workers may

be particularly important in drug and alcohol services where service users may mistrust staff, largely due to the strict procedures around providing OST (Rance et al, 2012).

As hepatitis C services are sometimes integrated within drug and alcohol services, peer workers need to be considered in this context. Studies have shown that for hepatitis C, peer workers can provide education about hepatitis, its testing and treatment, accompany service users to hospital appointments, act as advocates and mediators for service users, facilitate referrals to hepatitis C specialists and provide staff with a peer perspective (Norman et al, 2008; Charlebois et al, 2012; Alavi et al, 2013; Treloar et al, 2015; Batchelder et al, 2017). Indeed Bonnington and Harris (2017) note that peer support can potentially be helpful at any point along the cascade of hepatitis C care. For service users, peer support could be realised in terms of increased knowledge on hepatitis C, improved confidence in accessing and negotiating healthcare services and pathways, reducing perceived stigma, reducing isolation, as well as accessing testing and treatment (Galindo et al, 2007; Crawford and Bath, 2013; Treloar et al, 2015; Batchelder et al, 2017).

There are different models of peer support, which generally comprise one on one support, or support provided in group settings (Crawford and Bath, 2013). Crawford and Bath (2013) categorise peer support into 'community controlled' and 'service generated'. The 'community controlled' peer support model historically was implemented as grass root community responses, controlled by drug user (peer) led organisations, and largely provided one on one support for people having hepatitis C treatment. 'Service generated' refers to a model of peer support that is conceived and led by services, supported by peers and usually takes the form of group based sessions, often based around self-help group structures. The OASIS (Organization to Achieve Solutions in Substance Abuse) model was an early example of a service generated peer model (doctor and peer led support groups), often referenced in the literature as successful in engaging and educating PWID about hepatitis C, as well as facilitating hepatitis C

treatment (Galindo et al, 2007; Sylvestre and Zweben, 2007; Grebely et al, 2010). A review of the literature has found a small number of articles on other (non-OASIS model) support groups for PWID with a focus on hepatitis C, which are also led by service providers (Charlebois et al, 2012; Stein et al, 2012). These studies also concluded that the groups were important in facilitating access and continued engagement in treatment. However these articles (except the case study by Galindo et al, 2007) do not provide data on the perceptions of those involved in the peer models. Indeed generally evaluations of experiences of hepatitis C peer support are limited. A systematic review conducted by McLellan et al (2015) on peer support across all diseases, found 1 study (Norman et al, 2008) regarding hepatitis C in Australia. Further perspectives on peer support in Australia, UK and USA have since been provided in work by Treloar et al (2015) Bonnington and Harris (2017) and Batchelder et al (2017) respectively. Models of peer support vary throughout the studies, making comparison difficult, but there were some commonalities in findings.

Norman et al's (2008) study used a paid peer worker as part of a larger multidisciplinary team implementing hepatitis C care and treatment into a community drug and alcohol service. Interviews were conducted with service users and the peer worker. The peer worker explained her role as giving advice and information to service users on clinical and logistical aspects of hepatitis C treatment, as well as providing practical support like acting as an advocate and providing transport. She felt the role was integral in helping people through hepatitis C treatment '*because the drugs [hepatitis C treatment] are savage*' and '*it's a terrifying process*' without support. This was echoed by the service users "...I think she [peer worker] has made the difference between sticking to this [hepatitis C treatment] or not..."; a finding also found by in other studies (Batchelder et al, 2017). Service users felt the peer worker gave good advice, listened, empathised, was non-judgemental, was easier to talk to than doctors and helped communication with doctors.

The peer worker felt that one of the most important parts of the role was that service users were able to openly discuss their drug use:

"Strengths of peer-based services is that there is no us and them, that I identify with the clients which is essentially different to even a very supportive non-peer worker.... A client who makes a bid to stop using and lapses, feels like a failure, they worry that they've let [medical staff] down. All of that makes it very difficult for them to be honest... Whether the judging is real or perceived, it's still very real to clients and it's a huge divide to engage across. Having a peer worker in the role means that I know this territory because it's my reality too. A lot of what I talk to clients about is drug use. I'm very pragmatic, shit happens, people lapse. Lots of clients on treatment have profound fears that drug use will impact on treatment and they can't talk to clinicians about this, I clarify that this isn't going to undermine the treatment, it's about being stable."

(Norman et al, 2008, p. 4)

The peer worker having similar experiences (drug use and hepatitis C) was also seen as important by some service users. One service user explained how, in comparison to medical staff, there was no need to hide things from a peer.

There were however some concerns raised about the peer worker model during the interviews. Some of the service users raised concerns over the level of professionalism for a peer worker. One client suggested peer workers would not have the same professional consequences as other medical/ health staff with one service user expressing the need for peer workers to be both a peer and professional.

The peer workers also raise a couple of concerns, firstly the level of distrust that peer workers faced from other medical/health professionals was noted, stating that *"they [medical professionals] don't welcome peers as professionals"*. Secondly, issues around the need for supervision, ongoing training and a professional framework for the peer role was expressed, with the peer worker admitting: *"Sometimes I feel like I'm making it up as I go*

along and the stakes are high, sometimes I feel out of my depth" (Norman et al, 2008).

In Treloar et al's (2015) study, peer workers were introduced into two community OST clinics. The aim of the study was to engage service users, build trusting relationships and support people through hepatitis C treatment. Interviews were conducted with staff, peers and service users. Like Norman et al's (2008) study, this study found that the peer's own life experience was valued by service users, and the success of the scheme was put down to the non-judgemental attitude of the peer workers and the trust built between peers and service users. Findings from the study met the original aims, with one clear benefit noted by staff being the change in how service users presented for their hepatitis C assessment and care. Other unintentional positive results included peer workers being mediators between service users and staff, enabling service users to access other clinical and support services (such as a dentist) and changing the atmosphere of the services to a more service user friendly space. Benefits were also noted by the peer workers personally, as the work was '*rewarding*' and they were able to '*give back*', a sentiment found in other studies (Galindo et al, 2007; Whiteley et al, 2016; Batchelder et al, 2017), with Batchelder et al (2017) also finding that this improved self-confidence of the peer workers. This finding was not found by Bonnington and Harris (2017) as discussed below.

As well as building good relationships with service users, it was found that positive working relationships were made with staff. However peer workers were not necessarily viewed as equal, with one service disallowing peers into 'staff only areas', and the second service allowing peer workers into staff areas but implementing tightened security measure, such as placing a camera in the room where the safe was located. Services justified this behaviour, saying it was to protect the peer workers as '*if anything went down or if any, any drugs went missing, it would be someone like [the peer*

worker], you know, where the finger would be pointed' (Treloar et al. 2015, p. 995).

Other study findings were that not all service users were aware of the peer workers, staff had initial (unfounded) concerns over confidentiality and boundaries between peer workers and service users and some service users were concerned information discussed with peer workers would be relayed to staff. Treloar notes this concern has been found before (Treloar et al, 2011 cited in Treloar et al, 2015) therefore peer worker's first task should be to establish their autonomy and credibility amongst service users.

In this study it was noted that, unlike in Norman et al's (2008) study, the peer workers received training and regular supervision to ensure their hepatitis C knowledge was up-to-date and to help the peer workers manage any difficult issues.

In comparison to these studies, Bonnington and Harris's (2017) study was conducted in the UK, with the implementation of unpaid peer workers in the form of peer educators and 'buddies' into community drug and alcohol services. Peer workers were defined as those who had personal experience of hepatitis C and buddies did not have experience of hepatitis C but were able to empathise with the service user and share experiences. The peer educator's role was to provide training to service users and other stakeholders (such as homeless hostel staff) about their experience of drug use and hepatitis C, including testing and treatment. They were given training by the Hepatitis C Trust and were instructed to give key messages when they gave their training. The buddy's role was more informal in nature, meeting service users for 'a coffee and a chat' either at the drug service or outside, as well as accompanying service users to hepatitis C testing and treatment if the service user desired. Regular training was provided to all peer workers. Interviews and focus groups were held with service users, drug workers and prospective peer educators and buddies.

As in other studies (Norman et al, 2008 and Treloar et al, 2015) qualities needed for peer worker were to be trustworthy, honest, accepting empathetic, informative, but also motivated, proactive, reliable. Service users wanted peers and buddies to share their own experiences (hepatitis C and/or drug use), to have good knowledge of hepatitis C and, as shown in Norman et al (2008), to generally 'just be there'. People wanted to take on the role of buddies and peers so that others would not have the same negative experiences that they themselves had, such as being marginalised by family and friends following disclosure of a hepatitis C positive status, hoping that the peer role would support and therefore lessen isolation for service users.

Having access to reliable information after diagnosis also prompted people to become peers. *"If it helps one person to get to the hospital . . . I always used to be terrified. I went on my own, which was daunting, to say the least, and I didn't know anything. I just knew nothing. Everything just went straight over my head. And if I'd have had a buddy then, I'd have learnt a bit more"* (p.224). Both peers and service users commented upon previous hospital appointments where *"although the doctor goes through things, at the time your head's not straight because you're still taking drugs or whatever... there was loads of stuff he said to me, absolutely loads. It just flew past my head"* (p.224).

However despite these good intentions pre intervention, post intervention interviews showed a number of difficulties with the implementation of peers and buddies into the service. Firstly there was conflict and a hierarchy amongst the peer roles within the service. Services favoured 'recovery champions' (those who were not on any OST) to be peers, due to the UK focus on 'recovery' in drug treatment (Bonnngton and Harris, 2017). Furthermore peers were not integrated and poorly supported within the service, which consequently affected their ability to work with service users, limiting their impact on facilitating hepatitis C testing and treatment. The study concludes by noting that peer involvement can be

affected by organisational boundaries and structures, especially regarding who is considered a 'peer'. Thus integrating peer workers into an organisations and the wider recovery movement takes time and needs careful consideration.

This section has shown that whilst peer involvement is generally accepted as important in facilitating hepatitis C services into drug and alcohol services with an aim to increase knowledge, testing and treatment, in practice there are many different models and a number of pitfalls that need to be considered.

2.4 Stigma and hepatitis C

During previous sections of this literature review, fear of discrimination and stigma has been recognised as a barrier for PWID to access hepatitis C testing and treatment. Furthermore stigma can affect the everyday lives of those who live with hepatitis C (Zickmund et al, 2003). The peer support section of this literature review gave an example of how hepatitis C discrimination can affect people with hepatitis C in everyday life. Peer workers in one study (Bonnington and Harris, 2017) explained their own experiences of being isolated when marginalised by family and friends following the disclosure of their hepatitis C diagnosis, drawing on this as a motivation for volunteering to provide support to others in a similar situation. Stigmatising attitudes are encountered from family, friends, colleagues and within healthcare settings (Butt et al, 2008; Hill et al, 2014), and researchers have identified the experience of stigmatisation as one of the most significant issues facing people who have hepatitis C (Hopwood and Southgate, 2003; Zacks et al, 2006). It is clear from this that stigma warrants further consideration in this literature review.

Stigma is defined as '*a mark of disgrace associated with a particular circumstance, quality, or person*' (Oxford Dictionary, 2018) and '*the situation of the individual who is disqualified from full social acceptance*'

(Goffman, 1990, p.9). The later gives context to how stigma affects individuals, as the peer example above demonstrates. Goffman (1990) explains that stigma is a relationship between attribute and stereotype and those who have the particular attribute are '*discredited*' by the '*normals*' (those who do not have the attributes). Furthermore;

'the standards he [person with the stigmatised attribute] has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility....'

(Goffman, 1990, p. 18)

Where an individual's stigmatised attribute is known, Goffman describes the person as '*discredited*', and where the attribute is not known, as '*discreditable*'. He notes the '*discreditable*' try to avoid revealing their attribute that may be subject to stigmatisation, to pass as '*normal*'. Indeed research has shown that decisions to not disclose hepatitis C positive status is often borne from fear of stigmatisation (Faye and Irurita, 2003; Butt et al, 2008; Hill et al, 2014), and non-disclosure limits opportunity for support (Faye and Irurita, 2003; Hill et al, 2014). Goffman also explains how support can come from others who share the stigmatised position, which for hepatitis C could perhaps be related to peer support.

This brief explanation of Goffman's work on stigma provides theoretical understanding that can be related to issues already touched on in this literature review, such as people with hepatitis C having difficulties around disclosure of their positive status, interactions with health professionals ('*normals*') being more difficult than with peers, and stigma posing barriers to accessing services and the daily lives of people with hepatitis C. Furthermore research has shown that people with hepatitis C can also demonstrate internalised stigma by expressing widely held societal beliefs, such as feeling 'like a leper', dirty or contaminated (Zickmund et al, 2003; Hill et al, 2014) which is demonstrated by Goffman's quote above.

Stigma has historically been associated with infectious diseases, such as leprosy, tuberculosis and more recently HIV (Butt, 2008). Stigma increases if the disease is seen to pose a threat of being transmitted to other people but also if the disease is viewed to be acquired by the bearer's own inappropriate or irresponsible behaviour (Butt, 2008; Joffe, 2011). Thus for hepatitis C, stigma could be due to the virus being infectious, but also that the main route of transmission is sharing injecting drug equipment. However in considering Goffman's work on 'attributes', if hepatitis C is the 'attribute' leading to stigmatisation of those with the disease, it stands to reason that people who have hepatitis C transmitted from routes other than sharing injecting equipment, such as blood transfusions, or needlestick injuries in healthcare staff, would also experience the related discrimination. Whilst research has shown that people with hepatitis C acquired from routes other than sharing injecting equipment do also experience stigma, this stigma was due to the association between hepatitis C and injecting drug use, '*they automatically think you're an addict-an addict who shares needles*' (Butt et al, 2008, p.213).

The UK Drug Policy Commission (UKDPC) conducted research on stigma towards problem drug users (defined as injecting drug use or long-duration/regular use of opioids, cocaine and/or amphetamines) without consideration of hepatitis C status. (UK Drug Policy Commission, 2010). UKDPC note that problem drug users are perceived by the general public to be deceitful, dangerous, unpredictable, unreliable, hard to talk with and to blame for their predicament. Additionally, health professionals can be judgmental and mistrust problem drug users. Consequently, drug users report the stigmatising views of others to affect their lives, resulting in feelings of low self-worth and avoiding contact with people who do not use drugs. In addition, stigma may be a barrier to people accessing support for their drug use (UK Drug Policy Commission, 2010).

It was also noted that problem drug users reported suffering multiple stigmas such as being female, being black, having a mental health problem, HIV or hepatitis C, but the drug user status was found to be the most stigmatising of all (UK Drug Policy Commission, 2010). Stigma is a complex issue, and for PWID with hepatitis C, stigma maybe multifaceted (Paterson et al, 2007).

Whilst stigma can be encountered by PWID with hepatitis C, from friends, family and colleagues (Butt et al, 2008), there is a wealth of research illustrating stigma as a barrier to accessing healthcare. (Paterson et al, 2007; Swan et al, 2010; Harris, Rhodes and Martin, 2013; Hill et al, 2014; Brener et al, 2015). In the literature, stigma is reported to come from individual healthcare staff (Swan et al, 2010) as well as healthcare systems and its structures (Paterson et al, 2007; Harris, Rhodes and Martin, 2013).

Throughout the literature, services users reported experiences of stigma from healthcare staff where they felt judged based on the fact that they had hepatitis C (Butt et al, 2008; Swan et al, 2010). They felt that usually the response towards them was due to ignorance or misconceptions about hepatitis C or because the person associated hepatitis C with injecting drug use (Butt, 2008; Swan et al, 2010). A study by Butt et al (2008) asked PWID if the stigma of hepatitis C was the same or different from that of drug use. The PWID emphasized that the stigma of those with hepatitis C is different *'because not only are you a druggie and all that this implies, but [it is assumed because you have hepatitis C] you don't care about other people because you shared needles'* (p.211). One participant stated that he *"wasn't well liked"* by healthcare practitioners when they thought he was *"just a user,"* but when he became hepatitis C positive, they treated him *"like I was a lower lowlife than before."* (p.211).

Whilst people who have acquired hepatitis C from routes other than injecting feel they are treated with the same stigma as PWID (discussed above)(Butt et al, 2008; Hill et al, 2014), PWID do not feel that they are

treated the same as those who have got hepatitis C from other means (Butt et al 2008; Swan et al, 2010).

People who got it through blood transfusions, people have sympathy for them but because when you're using drugs it's self-inflicted, people aren't going to have sympathy for ya and they basically don't care

(Swan et al, 2010, p. 756)

The results of stigma/perceived stigma throughout the literature was that the care provided to PWID with hepatitis C was affected (Treloar et al, 2002; Butt, 2008; Swan et al, 2010). This resulted in care being inequitable to that received by people who do not inject drugs (Treloar et al, 2002; Butt, 2008; Swan et al, 2010) and even withdrawal of care, support or services (Butt, 2008). Reports of staff leaving the room or refusing to care for people with hepatitis C were found in Butt et al's (2008) study. One participant reported that following disclosure of injecting drugs and having hepatitis C, the doctor made judgemental comments and then asked him not to return, and another participant recounted a situation where they had attended for a blood test and the nurse recoiled, '*took a step back*' (p.211) when she was informed of the positive hepatitis C status. In terms of inequitable care, one participant noted that when he broke his leg, he received less analgesia, support and attention than others in the emergency department did. He concluded this was due to having hepatitis C and injecting drugs. '*You're not important. You're just, you know, in the back of the bus*' (p.212).

Past experiences of stigma can lead to mistrust of healthcare staff and expectations of future stigma when having contact with services, discouraging some from accessing services (Swan et al, 2010; Harris, Rhodes and Martin, 2013) '*I was really badly treated and I know loads of people that have been treated abysmally down there, really blatant discrimination. Just looking with disgust, clear disgust in the nurses' faces, 'You're drug addicts, oh, so you got it through injecting, well you should*

know better' (Dillon) (Harris, Rhodes and Martin , 2013, p.21). This experience led *Dillon* to vow that he would never undertake hospital-based HCV treatment (Harris, Rhodes and Martin, 2013).

However, Paterson et al (2007) found that even if healthcare practitioners have positive attitudes towards people with hepatitis C, there are institutional and structural forces within healthcare systems that can result in discriminatory practices. Reidpath et al (2005) note that stigmatisation occurs when people with certain diseases are viewed as being unworthy of social investment, and Paterson et al (2007) suggest there are many forces within healthcare that contribute to practitioners defining PWID with hepatitis C as meriting less investment than others. An example of deservedness of social investment being that a person is willing to engage in reciprocal exchange (Reidpath et al, 2005) viewed as the basis for trust in a patient-doctor (healthcare staff) relationship (Paterson et al, 2007), with patients providing relevant information about their health and cooperating with treatment and management of care (Paterson et al, 2007). Therefore those who do not follow these 'rules' are seen as less deserving of social investment than others that follow these social norms (Paterson et al, 2007).

Furthermore institutional and departmental policies on who is eligible for treatment, who receives treatment and the types of support available can be a source of hepatitis C related stigmatisation (Stephenson, 2001). Astone et al (2004) showed that willingness to fund care and treatment for PWID was a significant determinant in what services healthcare staff were able to provide to this population. Whilst this study was based in USA, the similarities can be drawn with the introduction of DAA treatments in the UK.

Thus whilst it is important to address perceptions which are stigmatising from healthcare professionals, there is also a need to address how governmental and institutional policies and structures impede access and

provision of equitable and non-judgemental care for PWID with hepatitis C (Paterson et al, 2007).

2.5 Alcohol use in the context of hepatitis C

2.5.1 Alcohol risk and advice for those with hepatitis C

Since the introduction of DAAs the number of people accessing hepatitis C treatment is increasing (PHE, 2017d), yet there are still many who do not access it. Therefore there is a need to understand more about the experiences of those living with hepatitis C in order to reduce hepatitis C related morbidity and mortality.

The course of a chronic hepatitis C infection is unpredictable and varies between people, with some people being unwell from the start but others having the virus for years before symptoms occur (Hepatitis C Trust, 2018c). There are however certain risk factors that increase the likelihood of accelerated disease progression to complications such as cirrhosis and hepatocarcinoma. These risk factors are: being male, being over 40 years old at the time of becoming infected, being co-infected with HIV and/or hepatitis B and alcohol consumption (Lim, 2001; Chen and Morgan, 2006; Drumright et al, 2011; McDonald et al, 2011b; Innes et al, 2013). NICE (2016b) state that alcohol is the most important predictor of disease progression in hepatitis C, with some evidence indicating that a history of previous heavy alcohol use (>50 units a week for a sustained period) (i.e. at any point in a person's life) can fuel progression (Innes et al, 2013) to further complications of the liver.

In the UK the Chief Medical Officers' alcohol advice for the general population is to not consume more than 14 units of alcohol a week (Department of Health, 2016). Furthermore it is recommended that the total amount is not consumed in one or two days, but is spread out over three or more days of the week (Department of Health, 2016). However

from the literature it appears that although researchers agree alcohol use speeds up the disease progression of hepatitis C (Hutchinson et al 2005; McDonald et al, 2011a) there is currently no stipulated 'safe limits' of alcohol for people who have the virus (Bhattacharya and Shuhart, 2003, Hutchinson et al 2005). It is thought that even levels below the government recommendations may be harmful for people who have hepatitis C (Pessione et al, 1998; NICE, 2016b; SIGN, 2013) and clinical guidelines in the UK are currently for those with hepatitis C to abstain from alcohol (Royal College of General Practitioners (RCGP), 2007; O'Leary et al, 2012; SIGN, 2013; NICE, 2016b), although NICE acknowledges that people with hepatitis C should stop drinking wherever possible, or reduce alcohol consumption if this is not possible (NICE, 2016b).

2.5.2 Alcohol use in PWID: prevalence

Much of the literature on alcohol use in PWID focuses on those who drink above government recommendations for the general population (Gossop et al, 2000; Hillebrand et al, 2001; Costenbader et al, 2007). Various research studies conducted in the USA suggest a prevalence of heavy alcohol consumption (where 'heavy' is defined as exceeding various thresholds for the number of drinks per week) within the PWID population ranging from 11% to 68% (Arasteh and Des Jarlais, Arasteh et al, Hahn et al, Howe et al, cited in Le Marchand et al, 2013).

Closer to home, the DTORS (The Drug Treatment Outcomes Research Study) study, conducted in England over a three year period, considered the effectiveness of drug treatment. This research did not provide prevalence data on alcohol use in PWID specifically but did find that 76% of opiate users used multiple opiates or opiates in combination with benzodiazepines or alcohol at the baseline point and 43 % and 48% at consequent time points in the research (Jones et al, 2009).

An earlier research study, the National Treatment Outcome Research Study (NTORS), researched people attending drug treatment (of which 87% were using opiates) in England between 1995 to 2000, finding a prevalence of heavy drinking (over recommended limits) in approximately 25% of participants throughout the 5 years of the study (Gossop et al, 2000; Gossop et al 2002; Gossop, 2013). However the NTORS study found ‘a wide variation in drinking patterns among drug misusers’ (Gossop et al, 2002, p. 174), noting an abstinence rate of over a third of the sample, from 3 months prior to the study commencing to study completion 5 years later. Gossop (2013) suggests alcohol abstinence in drug users is a ‘little discussed’ (p. 1194) point, and indeed there is a paucity of research on PWID who may be abstinent or drinking low levels.

This thesis did not set out to specifically target either those drinking above government recommendations, or those that were drinking lower-risk levels/abstinent but aimed to generally explore drinking amongst PWID who had hepatitis C who were attending drug and alcohol services.

2.5.3 Relationship between alcohol, heroin and opioid substitution treatment

Gossop (2013) notes that ‘few drug takers confine themselves to using a single substance’ (Gossop, 2013), but multiple substance use seldom gets the attention it deserves. Furthermore, Staiger et al (2012) suggests that alcohol use has the potential to interfere with recovery from drug dependence, but this has not been addressed comprehensively in the research, suggesting that this could be due to research being framed according to the primary drug rather than interactions between different combinations of drugs and /or drugs and alcohol. Gossop (2013) notes that also in treatment, staff may focus on what is perceived to be the main substance whilst ignoring other substances.

Attention is however, given in the literature to whether people ‘switch one addiction for another’, thus substitute heroin with alcohol, largely in the context of receiving opioid substitution treatment (OST) such as methadone or buprenorphine (Stastny and Potter, 1991; Staiger et al, 2012; Henriquez-Gonzalez and Patton, 2013). A study in Ireland interviewed 25 people at a general practice who had ‘used heroin in the past’. 23 people were currently prescribed methadone. The study found that a common reason given for drinking was to substitute heroin. The financial aspects of not using heroin was also a factor: *“I’m not spending as much [money] on drugs, and I’m not thinking in the morning about how much money I have to score, so I drink more!”* (Cullen, 2005, p. 73).

Another study, conducted in the USA, used a qualitative focus group of 41 clients from a methadone clinic. This study also found that many people wanting to discontinue heroin used alcohol as a substitute. The participants also explained that people on methadone use alcohol (and ‘pills’) to heighten the euphoria of methadone.

‘I found that people that are on methadone are also on alcohol...But it’s not enough of a euphoric for us. So we end up taking ...pills....We combine ‘em, because we wanna intensify the euphoria of taking the methadone and ...so when we’re combining all those drugs together, the hardest one I feel is alcohol to drop, because...you know, it’s cooling...you’re high on it...[it] gives you the highest euphoria...’

(Nyamathi et al, 2008, p. 30)

This shows that some people who have been on heroin are still wanting to ‘get high’ even though they are wishing to stop using heroin. Interestingly the comment says that out of all the substances alcohol is the most difficult to stop using. These two studies show examples of people switching heroin for alcohol whilst on methadone, however the findings in the literature present a mixed picture. Indeed Staiger et al’s (2012) systematic review found inconclusive evidence on alcohol substituting heroin.

The earliest study identified on literature searching this topic, was from 1978, where Green et al (1978) interviewed 96 people, receiving methadone treatment, about their lifetime alcohol use. Results showed that of those who drank 'excessively (in alcoholic, problem, or heavy patterns)' (Green et al, 1978) (presumably dependent or higher-risk higher-risk drinkers) did so during two main periods: before becoming addicted to heroin and during periods of abstinence from heroin. Furthermore, most of the participants who were drinking 'excessively' whilst on methadone, had pre-treatment histories of 'excessive' alcohol use.

For some of Green et al's (1978) participants, the switching of one substance to another was not switching to alcohol once on methadone but a more complex picture, where alcohol was actually prior to heroin, with an ongoing pattern of swapping between the two substances. Stastny and Potter (1991) also found that alcohol problems may predate heroin.

The ROSIE (Research outcome study in Ireland evaluating drug treatment effectiveness) study (Stapleton and Comiskey, 2010), which considers 404 opiate users on methadone treatment over a 3 year period, found that those who abstained from alcohol were more likely to have abstained from heroin than those who had not abstained from alcohol. People were abstinent from alcohol and heroin, or using alcohol and heroin, so were not switching from heroin to alcohol. The study also found those who abstained from alcohol were less likely to be on methadone than those who did not abstain from alcohol (Stapleton and Comiskey, 2010). Thus those on methadone were more likely to be drinking than those not on methadone. Backmund et al (2003) also noted this, finding that people on methadone drink significantly more than heroin users not receiving methadone. This finding on alcohol use whilst on methadone is also inconsistent throughout the literature.

Srivastava et al (2008) conducted a systematic review on whether being on methadone treatment affected alcohol consumption levels. 15 studies were identified, 3 studies found alcohol use increased when on methadone, 3

studies found a decrease in alcohol whilst on methadone and 9 studies found no change in amounts of alcohol drunk prior to and whilst on methadone.

In considering alcohol use on methadone, a study conducted in the rural England (Kent) (Henriquez-Gonzalez and Patton, 2013) provided a questionnaire to 170 people receiving methadone (OST), finding 42% consumed alcohol, however 'hazardous drinking' (defined as AUDIT score of 5 or above) was found in 14.2 % of the study population and alcohol dependence was found in 6.5%. Henriquez-Gonzalez and Patton (2013) compare results to alcohol prevalence within the general population in UK, noting an overall prevalence of alcohol at 85% in the UK (Robinson and Harris, cited in Henriquez-Gonzalez and Patton, 2013), hazardous drinking (AUDIT identified) at 24% and alcohol dependence at 5.9% in England (McManus et al, cited in Henriquez-Gonzalez and Patton, 2013). Therefore in comparison with the general population, participants on methadone in this study generally drank less.

This section has shown that the research presents a very mixed picture on alcohol consumption in PWID. For those who are alcohol dependent or drink at higher-risk levels, research shows there are barriers (and facilitators) to accessing support for alcohol consumption.

Nyamathi et al (2008) conducted focus groups with people on methadone to explore strategies they considered helpful in reducing alcohol use. The study found a combination of healthcare provider and personal factors such as being motivated to change and taking small steps. Attitudes and behaviours of healthcare providers were critical, with the participants noting that providers need to show compassion, respect and not '*look down upon*' (p. 30) service users. The perception of being stigmatised because of drug use was noted as a major deterrent for service users seeking help. The participants also commented on guilt, '*guilt is what keeps us down,....the guilt keeps us on alcohol....on drugs.. to escape.....so we don't need guilt thrown at us.....we wanna know how we can be helped today*' (p.30),

suggesting that providers needed to be positive and help promote self-esteem and self-value, in order to aid service users to make changes. Lastly the participants noted that providers needed to be committed to helping service users progress.

Further research based in primary care in Ireland (Field et al, 2013) considered barriers and facilitators to screening and treatment for 'problem alcohol use among problem drug users'. Like Nyamathi et al (2008), healthcare providers were considered an important factor. The patient-professional relationship was noted as important, and participants who did not have a positive patient-professional relationship mentioned distrust or dishonesty and concealment of problem alcohol use. Again the personal factor of motivation was found, as were social factors such as support from family and friends. Structural issues such as how services were organised and delivered were also a factor. Participants noted services to be inflexible, making it difficult to attend due to other commitments. Participants suggested that alcohol specific services were required and noted a need for outreach services in the community.

2.5.4 Hepatitis C diagnosis and its effect on alcohol use in PWID

As alcohol accelerates the progression of hepatitis C to cirrhosis and hepatocarcinoma (NICE, 2016b) and abstinence is recommended (RCGP, 2007; O'Leary et al, 2012; SIGN, 2013; NICE, 2016b), it is therefore important to understand drinking behaviours in people who have the virus.

To note, many of the research studies identified for this section of the literature review included a mixed population of people with hepatitis C (thus PWID and people who have contracted hepatitis C via other routes) therefore studies that do not specify whether participants have injected, and studies presenting mixed routes of transmission are included.

Some studies in the literature found that having hepatitis C had an association with a reduction in alcohol consumption (McCusker et al 2001; Scognamiglio et al, 2007; Tsui et al 2007; O’Leary et al, 2012).

McCusker’s (2001) study with PWID in London, considered whether a perceived diagnosis of hepatitis C affected their alcohol use. The research found that if people thought they had hepatitis C they were more likely to reduce or abstain from alcohol. This finding was reiterated in Scotland by O’Leary et al (2012), who found those who believed they were hepatitis C positive were more likely to stop drinking, however the study also found that those who drank continue to do so to excess (over government recommendations) (O’Leary et al, 2012).

Research in the USA has also shown that a diagnosis of hepatitis C decreases alcohol consumption. Tsui et al (2007) compared people with HIV with people co-infected with HIV and hepatitis C and found those with hepatitis C were more likely to abstain from alcohol and those who did drink, drank less than those with HIV mono-infection. Further work by Tsui et al (2009) observed a cohort of young PWID (< 30 years old) over a period of time, and found alcohol use (and use of non-injection drugs) decreased immediately after diagnosis (and counselling) but this behaviour was not sustained at 6 months and 12 months after diagnosis. Changes in alcohol consumption over time was also found by Stoller et al (2006). Considering ‘non-problematic’ drinkers (defined as AUDIT score of 10 or less), the study found that few participants ignored advice to stop drinking, with >80% abstinent, changing to around 50% over time. Some participants stopped drinking immediately after diagnosis, but others needed other incentives such as negative reactions to alcohol, perceptions of disease progression, or threats to efficacy or eligibility of hepatitis C treatment. Other participants had periods of adherence, non-adherence and tailoring of drinking behaviours such as cutting back the amount of alcohol consumed, trying counter measures to lower the risks of alcohol or monitoring their bodies for signs of disease progression.

Stephens and Havens (2013) study considered the effects of post-test counselling on alcohol consumption following a positive diagnosis of hepatitis C compared to those testing negative who received no advice on alcohol use. Whilst this study showed that those testing positive (and receiving the counselling) reduced alcohol intake, the reduction in alcohol was also seen in the group testing negative who did not receive counselling.

Other research studies have shown that PWID do not change their drinking after diagnosis of hepatitis C (Ompad et al, 2002; Kwiatkowski et al, 2002; Wang et al, 2014; Elliot et al, 2016). Ompad et al's (2002) study reported alcohol dependence in 48% of people with hepatitis C, and half of these did not change or even increased their alcohol consumption after being diagnosed with hepatitis C, despite counselling. A study based on NDTMS (National Drug Treatment Monitoring System) data collected in England compared drinking in hepatitis C positive and negative patients, finding that patients with hepatitis C were more likely to consume higher amounts of alcohol (defined as harmful alcohol use) than those who did not have hepatitis C (Wang et al, 2014).

Elliot et al's (2016) study found whilst 52.8% of PWID abstained from alcohol, younger (age not specified) PWIDs with hepatitis C (or HIV) were more likely to drink than older (age not specified) PWID with hepatitis C (or HIV), however overall having hepatitis C had no association with drinking. Elliot et al (2016) concluded that people who had hepatitis C but did not inject drugs '*appeared to understand the need to eliminate drinking as they were more likely to abstain than their uninfected peers*' (p. 553), suggesting an association between understanding and behaviour. However, other studies have found that having knowledge on the effects of alcohol on hepatitis C made little difference to alcohol consumption in those with hepatitis C (Kwiatkowski et al, 2002; Campbell et al, 2006; Noonan et al, 2009).

A study by Cullen et al (2005) in Ireland found reasons for reduction in alcohol by people who had hepatitis C were due to concerns about health and as part of overall lifestyle change rather than just knowledge. Other studies have also considered lifestyle changes (as well as alcohol) for PWID with hepatitis C.

Scognamiglio et al (2007) looked at quality of life in people with hepatitis C (12.4% of study population were PWID) and found 74% modified alcohol consumption following diagnosis. However the study also found people were unnecessarily restricting other aspects of their lives, such as diet and exercise, following diagnoses. Unnecessary restrictions on diet and changes to sex life following a hepatitis C diagnosis (26% of study population were PWID), were also found by Castera et al (2006), as well as many participants (71%) discontinuing alcohol. Whilst these studies showed that people with hepatitis C modified alcohol consumption, they also showed that people may be restricting their lives in ways that are unnecessary.

Harris's (2010) work provides a qualitative perspective to alcohol use in those who have hepatitis C (majority of study population were PWID), considering the meanings of alcohol use and dilemmas involved in ceasing or reducing alcohol consumption. The study found that for some participants the stigma associated with hepatitis C meant they were reluctant to disclose they had the virus, causing a dilemma on how to decrease alcohol without raising suspicion amongst other people. Some participants avoided social events as it was easier than disclosing or lying about why they were not drinking. Furthermore participants who continued to drink whilst having hepatitis C experienced negative judgments from within the medical profession and others with hepatitis C who were not drinking, which the author concluded could lead to isolation and negative self-esteem. Thus experiences of abstinence (or reduction) and drinking alcohol for people with hepatitis C could both be excluding in different contexts.

2.5.5 Advice/information on hepatitis C and alcohol

Searching the literature to ascertain where PWID get information about hepatitis C and alcohol was unsuccessful, finding no articles specific to alcohol advice. There were however articles on where PWID get information about hepatitis C, although it is important to note that these studies were based in Australia, Canada, Italy, Ireland and the USA and not in the UK.

It is well documented throughout the literature (Munoz-Plaza et al, 2008; Swan et al, 2010; Treloar et al, 2010; Treloar et al, 2014) that peer to peer communication plays an important role in PWID knowledge on hepatitis C. Other studies have shown the information is also obtained from healthcare staff (Carrier et al, 2005; Cullen et al, 2005) mass media public health messages, written materials and posters at clinics, books, television and the internet (Carrier et al, 2005). A study in Italy of 162 PWID found the source of hepatitis C knowledge was: other patients with hepatitis C (29%), healthcare providers (48%) press (36%), internet (10%), television (41%) and 17% had no knowledge (Zanini et al, 2013). Showing people get their knowledge from a number of resources, with healthcare providers being the most common method, followed by the television (in the Italian cohort). Hepatitis C has not featured regularly on the television in England over the years, so this method is an unlikely source of information in England.

Thus on initial searching there appears to be a paucity of research on where PWID in England get their information on hepatitis C and especially around alcohol consumption.

To note, in an attempt to raise awareness of hepatitis C, increase numbers tested and achieve WHO targets (WHO, 2016) in 2017 PHE and partners produced a range of resources, namely banners for social media, videos on YouTube, online testing quiz and posters to be distributed to GP surgeries (PHE, 2018a). These resources were produced after data collection for this thesis so are not discussed in the interviews, however where participants

found out information was discussed in the observation and interviews with service users and is discussed in Chapters 4 and 5.

As noted previously, current clinical guidelines are for those with hepatitis C to abstain from alcohol (RCGP, 2007; O’Leary et al, 2012; NICE, 2016b). Interestingly studies have explored the alcohol advice healthcare providers give to their patients who have hepatitis C. Studies conducted in the USA (Blixen et al, 2008; Stoller et al, 2009a), found advice given by healthcare providers was inconsistent, with advice such as ‘stop completely’, ‘cut down’ and the ‘occasional drink was OK’ being provided. Sometimes providers gave a mix of messages.

‘I tell them “...become a tee-totaler”, when the patient questions this, I tell them that it’s probably unlikely that it would cause a great deal of harm if they had the occasional drink’

‘alcohol was not routinely discussed unless the ‘patient comes in with symptoms or abnormal labs [blood results] then it comes up as part of the discussion, but on just a routine basis, talking about cutting down on alcohol or even the adverse effects of alcohol, takes a pretty minimal role’

(Blixen, 2008, p. 1293)

To my knowledge this study has not been replicated in the UK, however The Department of Health itself has produced reports with ambiguous messages about alcohol use for people who have hepatitis C (Department of Health, 2002; Department of Health, 2004). The Hepatitis Strategy for England suggested “avoidance of alcohol which *may* increase the risk of chronic liver disease” (Department of Health, 2002, p. 30) and the Hepatitis Action Plan stated; “reducing or stopping alcohol *could help* minimise the liver damage from hepatitis infection” (Department of Health, 2004, p. 6).

Harris’s (2010) work with PWID in Australia and New Zealand also found mixed messages from medical professionals on alcohol use. Some participants were advised that alcohol could speed up the progression of

hepatitis C, however others said they received no advice: *'whenever I mention drinking to doctors, they just kind of looked the other way'* (Rebecca). The article discusses the impact of ambiguous health messages on service users - *Luke* would have preferred unequivocal advice *'and I kept saying, "are you sure it's all right to drink?" and whenever anybody says to me, like the nurse or the specialist "yeah it's okay you can have a glass or two. But just don't binge drink or don't overdo it". That's a green light to me. Its either you can or you can't...'* (Harris, 2010, p. 1265). *Luke* drank throughout hepatitis C treatment, the treatment was unsuccessful and *Luke* wondered if his drinking had played a part in the treatment failure. Harris (2010) suggests the apparent lack of definite advice to limit or cease drinking by some medical professionals might be due to the dearth of clinical evidence that moderate drinking affects hepatitis C progression. Furthermore Stoller et al's (2009a) work with 'non abusing drinkers' found participants wanted stronger directives from healthcare professionals in order to quit drinking.

This section has shown advice is not consistent with the recommendations for people with hepatitis C to be abstinent from alcohol and the dilemmas this poses for service users.

2.6 Conclusion

This review has considered relevant literature on testing, treatment, linkage into specialist hepatitis C support, peer support and alcohol and hepatitis C, highlighting barriers and facilitators to accessing support. These topics are explored further throughout the research findings.

From conducting this literature review it is apparent that there is a paucity of literature on alcohol use in PWID who have hepatitis C in England, with a particular dearth of qualitative research on this topic. Following reading the literature on alcohol and hepatitis C, the study aims and objectives were formed. These are discussed in the methodology chapter, Chapter 3.

Chapter 3 Methodology

3.1 Aims

The aim of this research was to explore alcohol use in the context of hepatitis C and to discover PWID experiences and meanings of alcohol use and drinking behaviours over their lifetime with a view to informing services of PWID needs.

More specifically the objectives of the study were:

1. To identify PWID current and past drinking behaviours
2. To examine the impact of PWID recovery from illicit drug use on their drinking behaviours
3. To explore the impact a positive hepatitis C diagnosis has on PWID alcohol/drug use
4. To understand where PWID obtain information about alcohol use and hepatitis C and what that information is
5. To explore PWID perceived alcohol and hepatitis C service needs
6. To explore PWID wider harm reduction and healthcare needs

As explained in Chapter 2 there is a body of quantitative literature on alcohol use and hepatitis C however there is a paucity of qualitative research on this topic. This thesis intends to bridge that gap, using qualitative inquiry to explore the perspectives of people who have hepatitis C in the Merseyside region of England. The research aimed to understand the experiences, practices and meanings of alcohol for people living with hepatitis C to understand their needs and support requirements. The research design was inductive in nature, allowing topics and methods to emerge as the research progressed.

3.2 Methodology - Consideration of approaches

When designing this research, decisions were made on how to ‘tackle’ the topic. As I wanted to explore in depth the lived experience, by talking to people with experience of the phenomenon of interest, this required a qualitative rather than quantitative approach. Quantitative ‘scientific’ approaches such as surveys, randomised controlled trials or use of secondary data requiring statistical analysis, are hypothesis driven and aim to produce ‘objective’, generalizable results (O’Leary, 2017). These approaches would not be suitable to provide the in-depth inductive exploration of experiences, meanings, interactions and perspectives sought in this research. There are however a variety of qualitative approaches available which were considered for use in this research and are discussed briefly below.

The case study approach uses one (or a few) instances of a particular phenomenon with the aim being “to illuminate the general by looking at the particular” (Denscombe, 2017, p. 56). Thus by in-depth exploration with an individual case insights may be gained that have wider implications. Insights that may not have been found with a larger number of cases and less in-depth exploration. With this in mind cases are not randomly selected but chosen based on known attributes (Denscombe, 2017). For this research a case could be a person or an organisation. However how would the case be chosen? Firstly, I did not know anyone who matched the inclusion criteria (person who injected drugs with hepatitis C). Although it may have been possible to find a case from talking with colleagues within the public health department or contacting drug services, the nominated person would no doubt have been selected based on a criteria important to the department/service, such as someone who has previous helped with research or someone who is in ‘recovery’. Criteria that were not important to this research and participants that may not be ‘representative’ of other PWID with hepatitis C. Secondly the research was exploratory in nature. As there is so little literature on the lived experiences of alcohol use in those

who have hepatitis C, a number of participants were required to understand more about the topic. Also with such few historic studies it is difficult to know who is 'representative' to provide transferable findings (important to the approach), such as should the case be a person who drank 'a lot' or 'a little'. Thirdly I also did not know the drug and alcohol services well enough to be able to say if the service I chose would produce generalizable findings. (After conducting the research I am aware that the services considered in this research did all run differently, as shown by the period of observation, service user interviews, and interviews with professionals). And lastly one of the fundamental beliefs of this research is that PWID are not a homogeneous group and therefore there is a benefit to observing and interviewing a number of people to understand the phenomenon, especially as this research relates to access to services, which need to provide access for the many and not a few.

Another concern was whether a service user or organisation wanted to be researched in-depth. My thoughts from talking to services early in the study design phase of this research was that organisations were extremely busy and unlikely to give me a lot of time to do in-depth research on site. This hunch was indeed correct as when I conducted the interviews at the organisations I was often required to wait for a room, and move in and out of different rooms, working around the staff who were trying to see their service users in the same rooms. So based on these concerns the case study method was not chosen for this research.

Action research was also considered but ruled out quickly as it was evident from the 'four defining characteristics of action research' (Denscombe, 2017 p. 127) that it was not the best approach for this piece of research. The four characteristics are, practical in nature, change, cyclical and participation (Denscombe, 2017). Action research requires a practical issue to be researched often by a person working in the organisation who investigates the issue with a view to making a change. The process is cyclical in nature as the issue is identified and once researched, the findings

lead to a change which is implemented and then evaluated. The research at the very least must involve the practitioners as collaborators rather than subjects of the research but more generally it is the practitioners that are leading the research to explore their own practice. This approach was not suitable for this research as, I am not a practitioner in drug, alcohol or hepatitis C services; I did not have an 'issue' I wanted to/could change, rather the topic was more exploratory with a view to understanding peoples experiences and I questioned whether I would be able to receive this much collaboration from an organisation and its practitioners.

Phenomenology was also considered as a potential approach to this research. At first it appeared suitable as it is concerned with understanding descriptions of the lived experience, however on further reading it became apparent that this approach was not appropriate for this research. There are different version of phenomenology; the two main approaches being descriptive as developed by Husserl, followed by Heidegger's interpretive approach (Reiners, 2012; Tuffour, 2017).

The descriptive phenomenological approach is concerned with obtaining detailed descriptions of everyday experiences. Concerned with presenting the experiences as close as possible to how the participant understands them, this approach requires the researcher to put aside 'bracket off' their preconceived opinions, assumptions and prior knowledge. Heidegger rejected the idea of being able to suspend personal opinions, believing instead in interpretation of the presented experiences, to explore perceptions and meanings (Reiners, 2012; Tuffour, 2017). Although my research philosophy is more in line with Heideggers interpretative approach, as I do not believe it is possible to 'bracket off' my assumptions, there are however other criticisms of phenomenological research that makes it unsuitable for my study. Phenomenology seeks to understand the lived experience but does not seek to explain why they occurred or consider past events, histories or social-cultural dimensions (Tuffour, 2017); aspects

deemed important for understanding the life histories of PWID who have hepatitis C and may or may not be drinking alcohol.

The ethnographic approach was also considered but rejected as a methodology due to the ethical complexities associated with access and researcher safety. This methodology requires the researcher to spend a large amount of time 'in the field' (Denscombe, 2017; O'Leary, 2017). As one of the main aims was to explore experiences of alcohol consumption and drug use, presumably the 'field' may often have been out of public sight, so I did not feel this was an option for me as the researcher. Ethnography also seeks to understand a culture (Denscombe, 2017; O'Leary, 2017), which was not one of the research aims.

3.3 Methodology - A Generic approach

Rather than allegiance to any one qualitative methodology, this research drew on the strengths of a number of different methodologies and used a generic qualitative approach to explore the topic. Being highly inductive and interpretive in approach, this research fulfils the general purpose of qualitative research, yet it 'is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies' (Caelli et al, 2003, p.4). Instead of working within the methodological confines of established methodologies such as phenomenology, ethnography or grounded theory, generic qualitative research has methodological flexibility (Kahlke, 2014). Thus rather than being constricted by theoretical 'rules', or 'claiming a hollow allegiance to the accepted methodological positions' (Thorne et al, 1997, p.172) (Sandelowski, 2010) this approach 'simply seek[s] to discover and understand a phenomenon, a process, or the perspectives and world views of the people involved' (Merriam, 1998 cited in Caelli et al, 2003, p.3).

Indeed for this research, the overarching aim was to explore experiences and meanings of alcohol for PWID who have hepatitis C. Thus with this main

aim established, methods congruent with the research philosophy and deemed most useful to explore the research topic were chosen. For example, observation of service users was selected to learn the context of this topic and to build rapport prior to the interviews, and life history interviews using a calendar method were chosen to understand sequences of events over time. Regarding analysis, an ongoing constant comparison approach (see Figure 2) was used with one stage of the research informing the next. This constant comparison approach to analysis originates from grounded theory, yet intrinsic to this methodology is the generation of a theory (Strauss and Corbin, 1994). Although this research benefitted from using the ongoing constant comparison approach to data collection and analysis, it was not my intention to generalize the results and generate a theory. Likewise whilst using observation, the intention was not to understand a culture as ethnography requires (Cresswell, 2007; Denscombe, 2017). However by selecting these methods/approaches to analysis, and using them outside of their traditional philosophy, interesting and informative research was produced. Research that would not have been possible and questions that would not have been explored, by using the more rigid traditional methodologies alone. Rather than finding a methodology that provides an ‘awkward fit’ to the research questions, ‘questions can and should drive methodology rather than the other way round’ (Kahlke, 2014, p 47). Furthermore Lim (2011) suggests ‘this tendency [to inductive methodological approaches] is natural and even inevitable for those conducting their research on a topic or in an area where few theories or empirical studies have been available’ (p.53). Indeed as noted previously (Section 2.5.4) there has been only one other qualitative research study on experiences of alcohol use by people with hepatitis C, opening the way for new approaches to this topic, enabling exploration and furthering ‘knowledge’ in a field that has a scarcity of such empirical studies.

This pragmatic approach to research (Cooper and Endacott, 2007) is advocated by many (Cooper and Endacott, 2007; Lim, 2011; Kahlke, 2014 and Percy et al, 2015, Bellamy et al, 2016) yet the freedom and flexibility

this approach allows engenders discomfort in those accustomed to working with a prescribed framework. Critique centres around ‘how to do it [this approach] well’ (Caelli et al, 2003) and issues of rigour (Caelli et al, 2003; Cooper and Endacott, 2007; Kahlke, 2014), generating a call for structure and ‘criteria for their [generic qualitative approaches] design and evaluation’ (Caelli et al, 2003, p.2). Caelli et al (2003) describe four key areas which ‘must’ be addressed in generic qualitative research to achieve credibility. The four areas are, the theoretical positioning of the researcher, congruence between methodology and methods, strategies to establish rigour and the researcher’s analytic lens.

Theoretical positioning

“Theoretical positioning refers to the researcher’s motives, presuppositions, and personal history that leads him or her toward, and subsequently shapes a particular inquiry” (Caelli, 2003, p. 5). Thus a researcher’s reasons for researching a certain topic are “never a naïve choice” (p. 5). Caelli et al (2003) recommend that researchers using generic approaches must clarify their theoretical positioning by covering three aspects, namely, identifying their disciplinary affiliation, discussing what brought them to the research questions and any assumptions they make about the topics being researched. Indeed it was not a ‘naïve choice’ that I am researching this topic, in this manner.

I applied for an advertised PhD on topics that I was interested in, namely addictions and infectious diseases. Although I do not work in the field of hepatitis C or addictions, I do work as a nurse, so it is not a coincidence that I am conducting research on a health condition. Furthermore the way in which the research is conducted, qualitative as opposed to quantitative, is also not a coincidence, as my job requires me to work within ‘The Code’ of professional standards for nurses, which stipulates nurses must ‘listen to people and respond to their preferences and concerns’ (Nursing and Midwifery Council, 2015, p.4), an endeavour not too far removed from

conducting inductive qualitative interviews in order to understand people's experiences with view to informing services.

Approaching this topic from a different discipline such as the probation service or employment services, or from the position of a peer, would clearly produce different research questions and findings than research considering health and health services by a healthcare professional.

Also for my PhD I have been based within a university public health institute where the majority of research conducted is applied, and not just an entirely philosophical endeavour. This again will also have influenced my style of researching and my desire to use the pragmatic generic qualitative approach.

As a nurse, the 'lens' in which I view disease is from a medicalised viewpoint. Lupton (2012) notes that in Western society 'medical views of the health, illness, disease and the body dominate public and private discussions' (Lupton, 2012, vii), with little thought to the social and cultural meanings of disease. This research aimed to understand the meanings and experiences of alcohol and hepatitis C, the 'lived experience', for those who have the virus, requiring me to be aware of how my medicalised background leads me to make assumptions about health, disease, health seeking behaviours and so on. Some researchers (see phenomenology above) believe it is possible to put aside (bracket off) their assumptions, however it is my belief that this is not possible. My assumptions based on my experiences of working within health, along with identifying gaps in the literature, informed the research questions, as well as method, methodology and interpretive approach.

Methods, methodology and the analytic lens.

Caelli et al (2003) require researchers conducting generic qualitative research to distinguish methodology from methods and explain the analytic lens with which they engage with their data. "Methodology reflects the beliefs about knowledge and existence that arise from the values on the

philosophical framework that is to be employed” (van Manen, 1998, cited in Caelli et al, 2003, p. 6).

This research uses an interpretive theoretical perspective, which ‘seeks to understand values, beliefs and meanings of social phenomena.’ (Hussain et al, 2013, p. 2375). Inherent to interpretive research is the belief that understanding and interpretation cannot be separated (Bhattacharya, 2008; Hussain et al, 2013). Bhattacharya (2008) argues that, ‘at some level, then, all social research [whether qualitative or quantitative] is interpretive because all such research is guided by the researcher’s desire to understand (and therefore interpret) social reality’ (p. 464). Clarity of the ‘understanding being sought’ (Bhattacharya, 2008, p. 464) is given by considering the interpretive theoretical perspective in light of the ontological and epistemological underpinnings (Crotty, 1998).

Ontology concerns the nature of the social world we aspire to understand and what we believe is reality. ‘What is the form and nature of reality and therefore what is there that can be known about it’ (Guba and Lincoln, 1994, p. 108). Epistemology is the theory of knowledge (Crotty, 1998) or more specifically explaining ‘how we know what we know’ (Crotty, 1998, p.3). The epistemological question is ‘what is the nature of the relationship between knower or would be knower [researcher] and what can be known [or knowable]?’ (Guba and Lincoln, 1994, p.108). Thus the epistemological position cannot be considered without prior thought to the ontological position.

Understanding of the interpretive ontological/epistemological stance, is perhaps explained best, by first considering, ‘what it isn’t’, and discussing the positivist position.

For those working in a positivist paradigm, reality is out there in the world, existing independently of being observed. This reality can be studied objectively without the perceptions of the researcher (Hussain, et al,

2013). Guba and Lincoln, (1994) explain ‘the investigator and the investigated “object” are assumed to be independent entities, and the investigator to be capable of studying the object without influencing it or being influenced by it’ (p.110). Research conducted in this manner, finds the ‘truth’ (Guba and Lincoln, 1994).

From an interpretive perspective, reality is constructed and interpreted. Thus ‘objects depend for their existence on the perception of people, the viewers’ (Hussein et al, 2013 p.2376). As human’s [researcher and the researched] perceptions are dependent on their experiences, cultural position and ideologies, and a phenomenon can have multiple meanings or interpretations (Guba and Lincoln, 1994; Creswell, 2007; Hussein et al, 2013), thus there are multiple realities and multiple truths. Findings are created between the researcher and the researched (Guba and Lincoln, 1994) and rather than being objective, the interactive researcher influences and interprets in light of their own experiences and background (Creswell, 2007; Hussein et al, 2013).

Methods are tools used to collect data. The tools used must be congruent with the epistemological and ontological beliefs (Calelli et al, 2003). In this research observation and interviews were used. Methods were chosen with an understanding of and ongoing analysis of the researchers impact and the type of knowledge sought. Thus the interview methods chosen (especially with the service users) encouraged conversation, on the understanding that data is co-constructed. Also throughout the research especially the observation period, reflexivity (see below) occurred to reflect upon the researchers impact on the knowledge found.

Strategies to establish rigour

There are many strategies used in qualitative research to establish and verify rigour, such as saturation, crystallization, prolonged engagement, persistent observation, broad representation, peer review , triangulation,

full explication of method and member checking (O’Leary, 2017). A number of these strategies are discussed below in relation to this research.

Triangulation involves “using more than one source of data to confirm the authenticity of each source” (O’Leary, 2017, p. 385). In this research, triangulation was achieved in a number of ways. Firstly, a variety of methods were used. For the service user aspect of the research, observation and interviews were conducted, as well as follow up interviews using a different interview technique with some service users. A range of research sites were also used. Service users for the research were from four different organisations. This sought to provide a variety of perspectives and not produce findings particular to one organisation. Having a range of participants along with a constant comparison approach to analysis, also ensured triangulation. Thus findings from the period of observation were checked with participants interviewed. Findings from interviews were checked on an ongoing basis with the next interview participant and so on, and interview findings were checked at follow up interviews. Furthermore, findings from the service user interviews and observations, were also discussed in the interviews with professionals, providing further triangulation (Shenton, 2004). Also as the professional interviewed were front line (service user facing) staff and commissioners which provided further triangulation on findings about the services provided.

Explication of methods requires researchers to provide enough methodological detail so studies are reproducible or auditable (O’Leary, 2017). A thorough explanation of the methods employed in this study (observation, calendar interviewing, interviews with vignettes and semi structured interviews) is provided in sections 3.5, 3.6, 3.7. and displayed in Figure 2 and interview schedules including interview questions are in appendices.

Prolonged engagement is where the researcher spends sufficient time with participants or at an organisation in order to gain an understanding of

context and to establish a rapport in order to build trust (Shenton, 2004; O’Leary, 2017). The service user aspect of this research was designed after significant consideration of this point, as I believed participants would be more willing to share their opinions, perspectives and experiences with me (the researcher) if we had rapport and trust. The research design involved firstly a period of observation of support groups for people with hepatitis C. After a period of time (and hopefully rapport and trust built) the service users could then volunteer to take part in the interviews. One criticism of prolonged engagement is that researchers may become too immersed which could affect their professional judgement (Lincoln and Guba, cited in Shenton, 2004). However working reflexively should bring an awareness of this behaviour.

Reflexivity is a continuous process of reflection by researchers on how their own values, preconceptions, behaviour or presence and those of the respondents, can affect the interpretation of responses. This involves researchers recognising that they are part of the social world under study (Parahoo, 2006). Thus researchers need to reflect on how their position, knowledge and interests affect every stage of the research process. Indeed in this research, reflexivity occurred throughout and is written into this thesis in numerous places, especially the observation method and findings sections (section 3.5 and Chapter 4). Prior to conducting the observations I considered how I may impact the support group, group leader, group members and ultimately the research findings. How should I act? How much should I say? Should I tell them I am a nurse? Where should I sit? This reflexivity continued on an ongoing basis as situations arose throughout the period of observation and throughout the whole research process, scrutinising my impact and ‘how I know’, on ‘what I know’ (Jootun et al, 2009).

Member checking is “checking the interpretation of events, situations and phenomena gels with the interpretation of insiders” (O’Leary, 2017, p. 144). This occurred to a certain extent in this research however it was more

difficult in practice than envisaged. When observing the hepatitis C group, field notes were made. I offered to show these notes to the group I was observing but they declined. I did however have the opportunity each week to ask questions about previous weeks observations to clarify situations and check my interpretations. Also the service user interviews included follow up interviews, where participants could look over their transcribed interviews and timelines (see section 3.6.7). Unfortunately only 4 follow up interviews occurred, however these were helpful to clarify information not just concerning that participants but also in general and to check my interpretation of the interview findings.

Saturation is when the researcher believes data collection can cease as any further data would not yield new findings or provide further understanding. (O’Leary, 2017). Caelli et al (2003) states that saturation in generic qualitative studies frequently lacks clarity and requests that researcher using generic approaches provide a clear explanation of the meaning of saturation within the context of the study. In this research 36 service user interviews were planned but after 21 participants I decided that I had reached saturation. Not regarding the individual intricacies but the broader pictures. For example, I had not reached saturation and (probably never would) on individual drinking practices or the individual stories on the circumstances surrounding their hepatitis C test, but rather saturation of the themes, such as hearing various stories of stigma, various comments about the difficulties with accessing treatment, stories of fear and examples of lack of knowledge and the impact of this. For the observation saturation was reached when there were no new members coming to the group and discussions did not provide any additional information or further depth.

Methodolatrty

People wary of generic qualitative research for its nonalignment with an established methodology, risk being charged with methodolatrty, ‘the privileging of methodological concerns over other considerations in

qualitative health research.’ (Chamberlain, 2000, p. 285). Chamberlain (2000) and Porter (2008) argue that a focus on methods/methodology originates from a positivist approach to research, and stops us looking at the assumptions behind our research (Chamberlain, 2000). Not only this, ‘a preoccupation with selecting and defending methods [is] to the exclusion of the actual substance of the story being told’ (Janesick, 1994, p.215). Thus this research rather than fixating on adherence to orthodox methodologies ‘prefers to capture the lived experience of participants in order to understand their meaning perspectives’ (Janesick, 1994, p.215).

3.4 Introduction to the research methods

A qualitative multi methods approach was used in this research. The first part of the research was with service users (PWID who have/had hepatitis C accessing hepatitis C or drug and alcohol services) and the second part of the research was with professionals (working in or commissioning hepatitis C, drug and alcohol services).

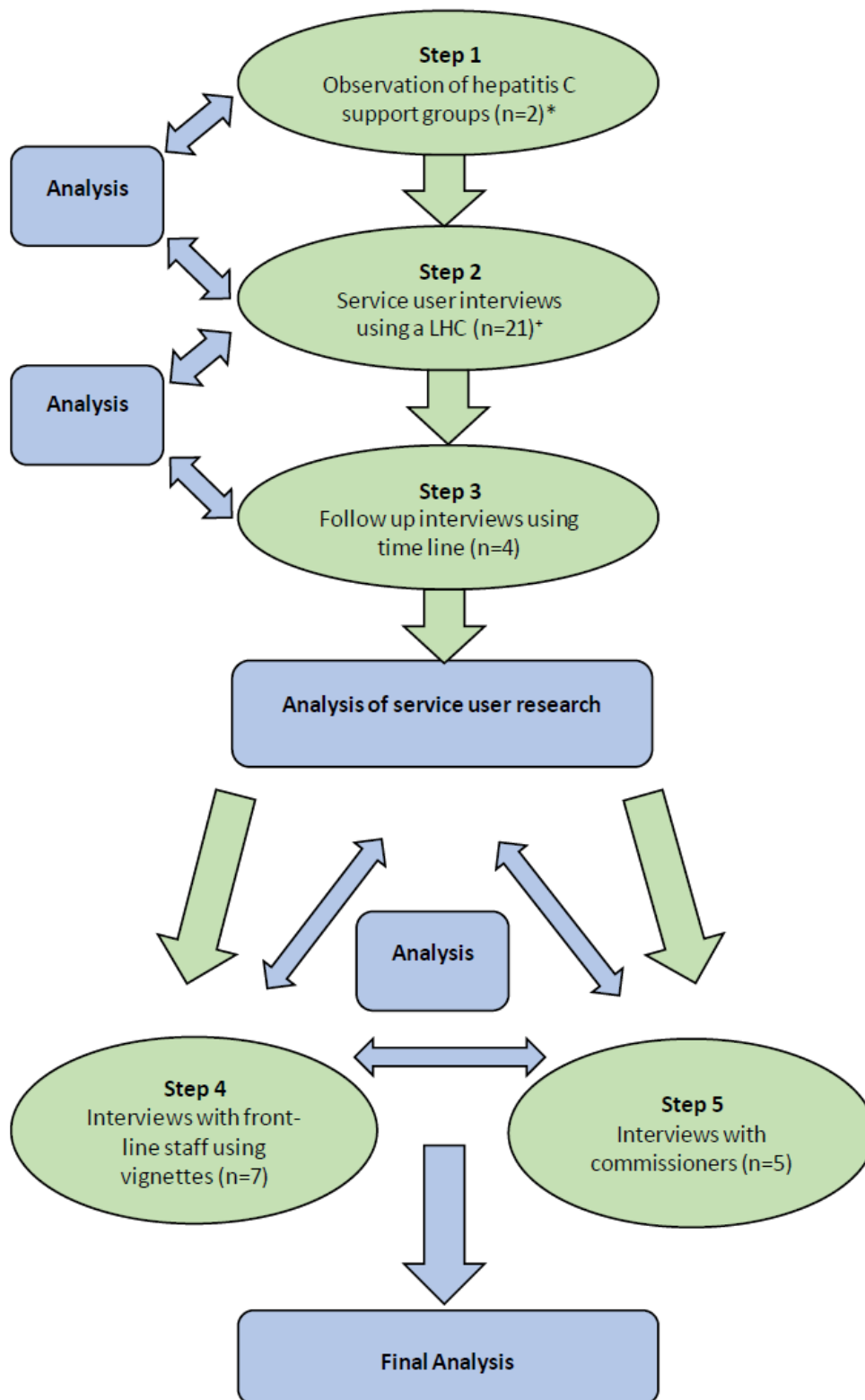
For the service user research, a period of observation at hepatitis C support groups was undertaken followed by life history interviews using a calendar method. Follow up interviews with timelines (a form of calendar) were also conducted with some interview participants.

For the research with the professionals, interviews were conducted. Vignettes of hypothetical service users were used with staff who work face to face with service users and more traditional semi structure interviews were used with commissioners.

Ethical approval was provided by the Liverpool John Moores Research Ethics Committee, reference 14/ENC/050. The documents used to support the ethics application are provided in Appendix 1 and ethical issues are discussed within the methods sections (3.5, 3.6).

The methods employed in this research are discussed in more detail in the next sections of this chapter and depicted (along with the analytic process) in Figure 2. Data in this research were analysed using a combination of approaches. Generally, an ongoing constant comparative approach occurred throughout the various stages of the research and interview transcripts were analysed using thematic analysis as per the method described by Braun and Clarke (2006). For the service user interviews, individual calendars were studied to ascertain the sequence of events in a participant's life.

Figure 2 Methods and analytical process



*Initially 3 groups were to be observed but Group 3 did not form. The majority of observation was conducted at 1 group, namely Group 1.

* LHC (life history calendar) 16 interviews used the LHC, 5 interviews did not use the LHC (see section 3.6.6.2.1. for explanation)

3.5 Observation - method

3.5.1 Introduction

The first stage of this research was a period of observation.

“Observation involves the systematic viewing of people’s actions and the recording, analysis and interpretation of their behaviour.”

(Gray, 2018, p.407)

Whilst providing a basic explanation, this description over simplifies the research method which is not simply a question of looking at something and writing down ‘the facts’ but is a complex combination of the researcher’s senses, perceptions and interpretation of meaning (Gray, 2018). Furthermore observation concerns itself not just as a research technique to gather data, but involves gaining ‘entrance into and social acceptance by a foreign culture or alien group so as better to attain a comprehensive understanding of the internal structure of the society’ (Merriam Webster Dictionary, 2018). The degree to which the researcher seeks entrance into and social acceptability of the group depends on the researcher’s level of participation in observation. Spradley (1980) suggests five different degrees of participation from non-participation, where the researcher has no contact with the group, to complete participation, where researcher is completely integrated into the group or may even have been a member of the group beforehand. For this research, the level of participation changed throughout the period of observation and is discussed further in Section 3.5.4.

3.5.2 Reasons for conducting observation

As explained in Section 1.5, prior to conducting this research my knowledge of hepatitis C was limited. Although I had nursed people with hepatitis C, this had been a medical issue in the background, as my role required

prioritisation of the more acute condition, such as a heroin overdose in the emergency department, or monitoring the patient after a surgical intervention when I worked in theatre recovery. Thus this observation period was to explore and build an understanding of 'context', learning the issues that were important to the service users themselves which could then be discussed further in the next stage of the research, the service user interviews.

The observation period also aimed to facilitate recruitment of participants to the interviews. As the observation was to be for a set period of time, it was hoped that the service users would learn about the research and would subsequently volunteer for the interviews. This also aspired to a shift in the traditional power dynamics between the researcher and participants, where service users could make an informed decision, over a period of time, regarding participation in the interviews and could then approach the researcher, rather than the researcher approaching them.

Finally, I hoped that by spending time with the service users rapport and trust would be established, with a view to facilitating openness in the interviews and thus providing rich, in-depth data on their experiences of alcohol and hepatitis C.

In reality this approach proved to be ineffective in finding participants for the interviews. At the first meeting with the group (Group 1), I explained that I would like to observe the group for several weeks and then I would be conducting interviews that they could take part in if they wanted to. I explained that if group members wanted to take part in the interviews they could let me know and before they took part they would need to read an information sheet and sign a consent form. I also explained that their participation and information they provided would be kept confidential. The group members seemed keen to participate in the interviews and asked a few times in the first couple of weeks if they could participate. Unfortunately at this point I felt I had not observed the group for long

enough to gather enough context and I did not think trust and rapport would be built after just a couple of weeks. However unfortunately during the course of the observation the group members dwindle and some of the people who initially showed interest in participating in the interviews stopped attending the group. In the end only one group member went on to be interviewed. Prior to data collection this strategy had been discussed with the group leader who noted the group was stable and had been well attended for many years, however in hindsight this lengthy recruitment strategy was not productive in finding interviewees from this group.

3.5.3 Gaining access to the field - finding service user groups to be observed

Preliminary discussions with organisations about this research commenced early in the research process. With the intention of conducting research with service user involvement as per patient and public involvement (PPI) policies, I visited a user forum (group for people who use/d heroin who had previously conducted their own research and attended conferences). At this meeting the study design was discussed and their views on the proposed research were obtained. They were keen to be involved with the research, however following ethical approval I contacted the forum and unfortunately the group had disbanded (see Group 3 below). Other than testing the interview method (see pilot interview section 3.6.5.2) there were unfortunately no other opportunities for PPI within this research. Indeed finding organisations where I could conduct this research proved to be challenging and protracted, requiring numerous emails, telephone calls and personal visits, resulting in discussions with seven organisations across Merseyside, of which two organisations had groups I observed.

Group 1 was situated in a homeless charity. It ran one afternoon a week and lasted 1.5 hours. Observation occurred on nine occasions over a four-month period (November 2014 and February 2015).

Group 2 was a hepatitis C group based in a drug and alcohol service. The group took place every other week and ran for 2 hours. Observation occurred on three consecutive occasions in February and March 2015.

Observations of Group 1 and Group 2 are discussed below, but first an explanation of how I located the groups as this challenge was a point of learning, to be considered in any future research with this study population. It is important to note that in the interest of time management, conversations with these organisations were occurring simultaneously in the hope that I would gain access to at least one group, requiring much juggling and tenacity from me as a lone researcher. Also this section warrants explanation, as comments and events that occurred during the process of finding the groups, which seemed unimportant at the time, took on a different meaning and became significant as the research progressed.

3.5.3.1 Access to Group 1

I met with another researcher from my department, who had recently worked with a service user led organisation in Merseyside that provides peer support and drug and alcohol recovery information. This seemed like a suitable organisation for my research, and after discussions with the chief executive of the organisation, I visited the service. At the meeting, an explanation of the research was given and I was told, "*We don't do anything about hepatitis C here*". I wondered if I had met with the right people at the organisation, as their role was to get members involved in volunteering and work opportunities, however the importance of this comment became apparent as my research progressed, with findings showing occasions where hepatitis C was not discussed between healthcare professionals and service users. The organisation did however have an opioid support group and they provided details of the group leader, who I had numerous calls and emails with, however it became evident that the group had unfortunately dissolved. On discussion with the opioid group leader, he mentioned that this was largely due to the local drug and alcohol services, who referred

service users on to this service, going through a tender process. He suggested that service users are affected when services change and there are different staff, paperwork and processes being implemented. The result of this was that no service users were attending this opioid support group so there was no group for me to observe; an unfruitful outcome that had taken 5 months to establish. However, the visit was beneficial as they informed me about a local hepatitis C group in another organisation. I spoke on the telephone to the group leader (*John*), who was happy for me to go and meet the group to discuss the research, consequently this group became the first group I observed 'Group 1'.

I went to meet the group and explained my research; they confirmed they were happy for me to observe, which commenced a month later after obtaining gatekeeper consent (as required by the ethics committee). Gaining gatekeeper consent was not without its own complexities, it required much diplomacy to finally obtain. Although *John* (group leader) was happy to sign the form, and I felt an urgency to start data collection, I was unsure of his standing within the larger organisation, concerned that managers/directors at the organisation may not be aware that I planned to conduct research there. After further conversation with *John* it became apparent he was a peer educator (a person with personal experience of hepatitis C) and a volunteer at the organisation. I felt conflicted as I did not want to undermine *John*. I also strongly believe in the ethos of peer educators as a method which in the main, empowers those involved (Norman et al, 2008; Batchelder et al, 2017) and as explained previously, PWID are viewed as the experts in this research, but I also felt I needed to gain organisational approval for my research to go ahead. I surmise this caution's origins lie in my background of working in clinical research where a strict approval process is followed prior to conducting research in any research site. After careful discussion with *John* he suggested that the manager should sign the form. Mindful of not getting *John* 'in trouble' for agreeing to participate in the research, in combination with a not-so-altruistic need to find somewhere to conduct the research, I broached this

cautiously with the managers, who readily signed the gatekeeper consent. Once the form was signed I returned to the group the following week and the same people were present as at the initial introductory meeting. I explained the study again, provided the written information sheet about the research and they gave verbal consent for me to observe, so the observation started that day.

It is worth acknowledging that the research focus changed at this point, as it is likely that observation of a general support group for PWID (such as the opioid support group or a user forum) would have provided different research findings than observation at a specific hepatitis C support group.

3.5.3.2 Access to Group 2

Communication with this organisation commenced in May 2014 and the first observation was in February 2015, thus taking a period of 9 months to gain access to the field. I had previously conducted clinical research at this organisation, in my role as a research nurse, and it is my belief that this previous collaboration, along with my status of being 'a nurse' helped me to get access for this PhD research. I met with a senior staff member who I had met during my previous research and explained the PhD research. She suggested that I observe their hepatitis C group rather than any other group at the organisation. This seemed appropriate, as I had already been observing another hepatitis C support group (Group 1). Following a formal approval process and receiving a letter of approval to conduct the research from the organisation, I arranged to attend their hepatitis C support group (Group 2). When I attended, I met with the two group leaders (*Greg* and *Brian*) but unfortunately there were no group members there. *Greg* and *Brian* demonstrated the hepatitis C test they used. *Greg* signed the gatekeeper consent and I arranged to attend the next support group in a fortnight. There were no ethical issues with the gatekeeper consent at this organisation, as the research had already been formally approved by the organisation and *Greg* was happy to sign the form.

3.5.3.3 Access to Group 3 (when established)

As explained previously, the user forum I had met with at the beginning of the research had ended. This was due to changes in commissioning of services in that local area. The facilitator of the forum suggested another local service that I could contact. This service agreed for me to conduct the research there, however they did not have any groups I could observe, but mentioned they were in the process of setting up a hepatitis C support group which I could attend when it was established. On discussion about this the staff commented how difficult it was to set up a group, due to the stigma of having hepatitis C, saying they were not sure where to hold the group, as if people knew you were going to the group then they'd know that you had hepatitis C. This is an interesting point that is discussed further in Section 4.2.1. With no groups for me to observe I did eventually go on to conduct interviews at this organisation. Contact with this organisation continued until December 2015, and up until this date the hepatitis C support group was to my knowledge not set up.

3.5.4 Method

Two different hepatitis C support groups (Group 1 and Group 2), in two different areas of Merseyside, were observed.

After each session, field notes were made in a note book, as soon as possible after leaving the group. These notes were factual in nature, regarding events that happened and topics that people spoke about. Rarely were direct quotes remembered and written down (depicted by quotation marks (“) in the field notes included in Chapter 4). After factual observations (things seen and heard) were documented, an early interpretation was made. The field notes were typed up at a later date. When returning to the notes I found that I thought differently about the documented events and gave further interpretation.

It is important to note that during the observation everything that was discussed was not recalled and that names and other identifiable information was not recorded. All entries in the field notes were depicted with an initial of a pseudonym only. The group participants were aware notes were being made and had verbally consented to this. I offered to share these notes with the participants, but they declined to see them.

Service users and staff were able to opt-out of this process at any time by informing the gatekeeper or the researcher. No one opted-out during the course of the observation but if they had, their decision would have been accepted without question. The option to opt-out was explained at the initial meeting and on an ongoing basis when meeting new people (staff and service users).

Although observation at Group 1 commenced prior to Group 2, Group 2 is discussed first, due to minimal observation and therefore findings.

3.5.4.1 Observation of Group 2

I attended Group 2 on the first week and met the two group leaders (*Brian* and *Greg*). There were no group members there. They also explained their roles, which comprised of conducting groups for *Greg* and running the needle exchange for *Brian*. They explained there was previously two hepatitis C groups in the organisation, one on the outskirts of town, and this one in the town centre. Due to lack of people attending, they decided to reduce to one group and kept the town centre group running as it was easier for people to get to if using public transport. The next time I observed the group (2 weeks later) *Brian* and *Greg* were the only people at the group again. They had arranged for a service user to attend to meet me and take part in the interviews for this research. The interview took approximately 1.5 hours and during this time no other person attended the hepatitis C support group. The third time I went to the group, once again,

no one attended. I decided not to go to the group again as there was not a 'group'.

A few months later, when I was at the service conducting an interview, I saw *Brian*. He offered to arrange for me to meet with a person he had recently conducted a hepatitis C test on at the group, which had shown a positive result. I declined, feeling that it may not be in person's best interests to be interviewed for research so soon after being diagnosed. However the discussion with *Brian*, hinted at the function of the group again, as an opportunity for testing and not accessing group/peer support.

From this observation, it was apparent there was no 'group' despite two staff being on hand to take the group. There were also numerous posters and fliers advertising the group in waiting rooms and communal areas around the organisation. The reasons for nonattendance at the group were unclear at this point in the research, but were illuminated later in the observation of Group 1 and the service user interviews (see Sections 4.2 and Chapter 5).

3.5.4.2 Observation of Group 1

3.5.4.2.1 Researcher's role

As observation requires the researcher to be the 'primary tool' for data collection (Schensul et al, 1999) it was important for me to consider my role.

Considerations before entering the field

Prior to the first time I met a group, I considered how I might come across to the group. I considered how I was going to introduce myself, how I was going to explain my research and what I should wear. I felt there was a lot riding on people's impressions of me, and did not want to deter people from

helping me. According to Walsh (1998), "once access to a setting has been achieved, the success of observational work depends on the quality of the relations with the people under study. Firstly, the researcher needs to consider the initial responses of people in the field and how to gain their trust." (p. 225). This 'impression management' was to facilitate observation and avoid generating obstacles (Walsh, 1998). In terms of dress, I opted for jeans and trainers, as felt the group would probably be wearing casual clothes and I wanted to fit in, although this was not a vast difference from my usual attire on the days I was 'a student', this was definitely different to the attire I wear on the days I am 'a nurse'. However there were certain personal characteristics that were non-negotiable, such as my age, gender, ethnicity, physique and voice, giving an expectation of how I act and interact in society and understanding that a person with different personal characteristics would build different relationships and therefore produce different research results (Denzin and Lincoln, 1994).

At the introductory meeting, everyone sat around a table and talked. The room was not much bigger than the table itself. I presumed that every week they would sit around the table and talk, so between the introductory meeting and the first observation, I considered how I would conduct myself within the group and where I would sit. I decided I would sit beside them at the table as I thought sitting away from the group, which would effectively in this small room be sitting right behind them, would make people feel uncomfortable and emphasise their position as research 'subjects' being 'watched'. Deciding I would need to sit with them at the table and converse with them, the decision on how much to talk was, however, more difficult. As a naturally sociable individual, whose career as a nurse requires regular communication with people, trying to get the right balance between joining in with the conversation and observing others was something I needed to consider prior to the observation. I was aware of a conflict between ensuring data was obtained and a need to maintain ordinary social behaviours in order to fit in, create rapport and ensure continued acceptance to remain in the group.

Self-disclosure

As one of the main aims of the observation was to build rapport with the group members in an attempt to build trust in the interviews, I felt I needed to 'be myself' to forge these trusting relationships, yet this brought up an ethical dilemma for me - should I disclose I am a nurse? My concerns were that I may sway the discussion towards more medical themes or they may start asking me questions about their own health, for example, or that the opposite may happen and that people would not talk about certain things as there was a nurse present, such as illegal activities (injecting or crime) or they may decide not to discuss staff in case I know them. I was also aware of the power dynamics of a nurse/patient relationship, which went against my research ethos of the participants being the experts in this topic. Although feeling duplicitous, I decided I would not tell them I was a nurse unless I was asked directly. However I was confronted with this dilemma the first time I went to meet Group 1.

A lady asked me directly a few times, in a few ways, my background. I skirted around nursing a bit, but in the end felt like I was coming across a bit vague and probably like I was hiding something. I ended up saying I'd done a degree in health studies and a nursing degree. She just replied 'you'll have loads of degrees', no one else appeared to pick up on my nursing.

[Field notes: Introductory meeting]

It is impossible to know if the group discovering my vocation impacted on the group's discussions. However when my nursing job came up in conversation I was keen to explain I worked in a completely different speciality and not the hepatitis C or drug/alcohol services, but I was interested in hepatitis C and wanted to learn from them.

Conflict of roles

One person said “you get hep C from drinking”, I corrected him, should I have?

[Field notes: Introductory meeting]

This situation occurred during the first time I met the group. My response had been immediate, as if on autopilot, without thought to the consequences of my actions. After, I questioned my response, concerned I had acted as a nurse rather than a researcher and wondering how this might affect my research. The aim of the observation was to learn from the group, not impart knowledge. I speculated, after this ‘correcting’, that group members may view me as someone with knowledge, which may encourage them to ask me questions about hepatitis C (rather than telling me their experiences of it) or perhaps cause hesitancy to speak, in fear of getting facts wrong. My concern was of introducing bias by altering how group members acted/spoke (Ashton, 2014). This situation prompted me to revisit my reflexivity, to acknowledge my influence on the research (Colbourne and Squire, 2004).

Although the impact of this situation on the ongoing observation is unknown, in its immediacy however, I had potentially curbed a conversation about alcohol and hepatitis C, the exact topic I was researching.

Also as it was *John’s* (group leader) role (and not mine) to educate the group, I was retrospectively aware of the potential effects my comment may have on my relationship with *John*; not wanting to ‘step on his toes’ by taking over his role, or ‘showing off’ making him feel inadequate, if he did not know the information I was giving. Although not meaning to offend *John*, I realised if I had caused offense I could be disallowed to continue observing; a catastrophic result for my research, but should I have let the comment go, without correcting it?

As hepatitis C is predominately transmitted by contact with blood that contains the virus and not through drinking alcohol, this comment gave an

interesting but worrying insight into their level of knowledge on the transmission of hepatitis C. Not knowing how the virus is transmitted increases the risk of transmitting hepatitis C to others but also puts the person with hepatitis C at risk of contracting a second hepatitis C virus with a different genotype.

Thus I had acted as a nurse would, educating those with an illness about the disease to reduce harm. Although in this environment I was a researcher and these people were not patients I was looking after, I still felt a duty of care towards them. I felt conflicted by my actions but also contemplating which of my roles should take precedence in such situations.

This conflict of roles between researcher and nurse is documented by many nurse researchers (Beale and Wilkes, 2001; Colbourne and Sque, 2004; Wilkes and Beale, 2005; McGarry, 2007; McConnell-Henry et al, 2009-10; Ashton, 2014). The majority of literature is based on those who are conducting research in a clinical environment (Gerrish, 1997; Beale and Wilkes, 2001; Wilkes and Beale, 2005) or where a life threatening situation occurs. In my opinion, this is a less ambiguous situation, as nurses in the UK follow a code of conduct that requires us to 'always offer help if an emergency arises in your practice setting or anywhere else' (Nursing and Midwifery Council, 2015). Thus we are required at all times to offer help in an emergency, which would include whilst conducting research. However the roles are more blurred when there is not an emergency situation, but one where nursing skills or knowledge could be provided, such as talking to bereaved relatives (Ashton, 2014) or as in my situation, offering education to reduce harm. The literature reaches no overall conclusions on when nurse researchers should act as nurses or researchers (Beale and Wilkes, 2001; Wilkes and Beale, 2005). During the ongoing observation, I considered dilemmas on a case by case basis, striking a balance of acting 'within the boundaries of [my nursing] knowledge base' (Eide and Khan, 2008, p. 205) and signposting to other sources, such as their own care team. The latter of these was the approach used in the majority of cases.

Ethical dilemma: “Do you want a lift”

Usually when the group finishes, Kath [group member] gives John [group leader] and Seb [group member] a lift home in her car. However, tonight Kath didn't attend the group. When the group had finished, we all left the building at the same time and my car was parked right outside the door. Should I ask if they want a lift home? A spur of the moment decision was required. I offered, they accepted.

[Fieldwork Notes Week 4]

This dilemma was a situation I had not considered prior to commencing the observation. According to Schensul et al (1999),

“In ethnographic research, researchers lack the kind of control over the conditions of research that characterizes clinical, experimental, or even cross-sectional survey or epidemiological research. Ethnographers must always be open to surprises...”.

(Schensul et al, 1999, p. 274)

My usual behaviour after attending a group in my own social life, such as my yoga group for example, would be to offer a lift. I did not really see this as anything different, as I had spent time with these people talking over tea and cake and now I was driving in the direction of their home. It was a cold, dark, winter's night, so it seemed like the decent and habitual thing to do, but what would the ethics committee say if they knew? On the ethics application I stated the risk to the researcher was 'low', as I would be meeting with service users in an organisation, yet I had a service user in my car. Although I felt safe, I had invited two men into my car, one of which was potentially using illegal substances; I am not sure the ethics committee would agree with this action.

When reading on ethnography, at a later date, I found the following point:

“Reciprocity also is important. Often, research participants will ask researchers for personal favours. Failing to respond not only harms relationships but may even jeopardize the project. Thus, ethnographers should be individuals who enjoy helping people out in difficult situations, rather than viewing such requests as an instrumental obligation encountered primarily as a means to facilitate getting data.”

(LeCompte and Schensul, 1999, p. 162)

Whilst wanting to help, my reasons for offering a lift were however not out of kindness alone but also a conscious decision, due to a continuing awareness of how my actions would appear to the group and feeling that my continued acceptance within the group may depend on this decision. Initially when observing I was continuously working at building relationships and trying to gain rapport, in order to maintain permission to observe and in anticipation for the future interviews.

The researcher's changing role

My position as an observer was difficult to define, lying somewhere between participant as observer and observer as participant, fluctuating between the two and changing throughout the period of observation. For participant as observer:

“the observer and the people being studied are aware that theirs is a field relationship which minimizes the problems of pretence. It involves an emphasis on participation and social interaction over observing in order to produce a relationship of rapport and trust”.

(Walsh, 1998, p. 222)

This description fits with my overt method of observation, where the ‘field relationship’ was established when I met the group to explain about the research and my role in it. This description also corresponds with my endeavour of building rapport and trust with people during the period of observation, to increase trust and depth of information provided in the interviews. I was also able to achieve a level of ‘social interaction’; we

were a small group, in a small room, sitting, talking and drinking tea. However, I question how much I was able to 'participate'. Although I was able to sit at the table and have conversations, as the group members were, each group member discussed their hepatitis C, which, I was unable to talk about as I do not have hepatitis C, therefore my complete participation in this activity was not possible. I also consciously did not want to participate (talk) too much, as I wanted to observe what the group were saying, to learn from them, rather than talking myself. The placing of observation above participant is key in observation where the researcher's role is observer as participant. Although it is suggested that this

“restricts understanding because limited participation in social activities heightens the possibilities of superficiality, so that important lines of inquiry may be missed or not pursued. Things go unobserved and the activities of participants are not properly understood”

(Walsh, 1998, p. 222)

This point seems somewhat irrelevant here as I largely participated in the social activities, which were sitting around a table, drinking tea and talking (which was not always about a personal experience of hepatitis C). However, I did miss one social activity which was going outside for a cigarette break. As a non smoker, it did not occur to me to go outside with the smokers. This may have produced interesting information and therefore be an omission in this research. However overall my role was as a participant observer rather than observer participant, participating progressively as time went on.

Early in the period of observation, I noted the following:

One man said 'fuck', looked at me and then apologised - was he and perhaps they, altering their behaviour/ vocabulary for me?

[Field notes: Introductory meeting]

As someone that ‘required’ an apology for a word being used, there was some judgement being made on me; I was definitely an outsider, a visitor to their group. As the weeks went by I fell into a balanced role of ‘chatting’ with the group when they spoke about non hepatitis C related topics and listening when they spoke of hepatitis C. My relationship with *John* was different from the rest of the group, as I assisted him in his role of making tea at the start of the session or washing the cups at the end. Although not a deliberate strategy, but rather trying to make myself useful, I believe this ‘helpful assistant’ position helped me to be accepted within the group, and like Purdy (Purdy and Jones, 2013) in her research, “I was certainly aware that I wanted to and was moving in from the periphery of the research context in the search for more personal access” (Purdy and Jones, 2013, p. 300).

Over time, my role within the group evolved further, as my relationship with *Kath* was changing and we were becoming ‘friends’.

Week 7 of the group only Kath, John and I were there. Kath had already offered to take part in the interviews and John suggested, I should interview Kath in the group time as there were no other group members there. I interviewed Kath and when we were leaving to go home:

Kath hugged me when I left tonight- she hasn’t done this before

[Field notes: Week 7]

At the time I wondered if she felt closer to me after the interview, as she had shared aspects of her personal life with me, not only about her hepatitis C and drug use, but other information about her life such as broken relationships and family deaths (see Section 3.6 for explanation of the life history calendar method). However I observed the group for a further 2 weeks and she continued to hug me when saying “bye” at the end.

I had hoped to build rapport during the observation period and interviews, and now I had built this relationship with *Kath*, I felt uncomfortable. *Kath* was not imagining this ‘friendship’ as we did really ‘get on’ and I could see myself being friends with *Kath* if we’d met under different circumstances, however, we had met when I was a researcher, who had to a certain extent portrayed a version of myself, reacting to some conversations as my role as a researcher and not providing my own opinion.

Discussions in the literature have focused on the blurring of boundaries between researcher and participant, and rapport and friendship (Eide and Khan, 2008; McConnell-Henry et al, 2010; Miller, 2016). With Duncombe and Jessop (2012) suggesting ‘doing rapport’ and ‘fake friendships’ encourages participants to disclose information they would not otherwise have done. I definitely did not want this for *Kath*, and I prefer to take my lead from Oakley (2016) who suggests distinctions between friendship and rapport in research are unhelpfully blurred (Glesne, cited Oakley 2016), concluding that friendships are not uniform and in any context can take many forms. Indeed Coffey (1999) suggests such ‘ethnographic friendships’ are actually important as they remind researchers that they are part of what they study. I certainly was not having a ‘fake friendship’ with *Kath* yet I continued to grapple to maintain a degree of the methodologically required ‘marginality’, “a poise between strangeness which avoids over-rapport and a familiarity which grasps the perspectives of people in the situation” (Walsh, 1998, p. 227). A position that causes the researcher ‘considerable strain’ and will affect the researcher “physically and emotionally” (Walsh, 1998, p. 227). Indeed our ‘friendship’ was to cause me emotional upset as I navigated leaving the field.

As the weeks went by, the group became less well attended, with *Kath* being the only person to attend for the last 3 weeks I observed (weeks 7, 8, 9). During week 8, my observation was:

*John watching TV, kept saying he felt tired
Kath sitting quietly*

*They chat every now and again
John didn't even ask Kath how she was this week
Group finished early - 5pm
Kath had only got there 4.30*

[Field notes: Week 8]

Although I initially could not understand why *John* had not led the group in the usual way and had not even asked *Kath* how she was, it became clear that they had met earlier in the week when *John* accompanied *Kath* to a hospital appointment, so this prior meeting may have explained the lack of conversation between them. Therefore they were in touch and *Kath* was getting support, outside of the group time, which led me to question why *Kath* was still attending the group when there was in effect no 'group'. I decided that the following week would be my last week of observation, as there was no 'group' for me to observe and I had reached saturation in my observation.

I felt uncomfortable on the last week of observation, realising that my role within the group had changed again and I was at risk of over-empathising as I had in effect become a group member. I was 'propping up' the group, keeping the group running, suspecting that as I was leaving the group, it would cease to exist. This caused a feeling of guilt which magnified when I said bye, and *Kath* said:

"it's been nice having some female company" - hugged me

[Field notes: Week 9]

Confirmation that although not my intention, I had played an important role in 'the group' and a realisation of what *Kath* was perhaps receiving from the group - company.

Walsh (1998) notes, 'Leaving the field will have to be negotiated, as it entails closing relations with participants that may have been firmly

established and which they may not wish to relinquish' (p. 227). However as well as the group's feelings around this, I also found disengaging with the group (especially *Kath*) difficult emotionally, knowing that I may not see them again and feeling extremely grateful for their contribution to my research and PhD. A realisation that leaving the field had been more difficult for me than entering and recognising that I had given minimal advanced consideration to disengagement, a situation noted to be common amongst qualitative researchers (Allum, cited in Labaree, 2002).

3.6 Service user interviews - method

3.6.1 Introduction

Interviews using a life history calendar (LHC) were conducted with PWID who have hepatitis C, to explore their experiences of substance use, alcohol use and hepatitis C. Follow up interviews were then conducted using a timeline (a form of calendar). As the method employed for these interviews is innovative in nature, the initial section of this chapter is dedicated to discussing the method and its application. More specifically, this chapter commences with an explanation of what calendar interviewing is, with examples of how others have used calendars in their research. My motivations for using calendar interviewing are then explained, followed by my experience of conducting interviews using a calendar, starting from designing the calendar to the practicalities of using it and the experiential learning that took place. The methodological findings are then discussed, explaining the benefits and limitations I found when using calendar interviewing.

3.6.2 Background to calendar interviewing

Calendar interviewing is "a data collection method for obtaining retrospective data about life events and activities" (Caspi et al, 1996, p. 101). A chart is used to plot the participant's life events enabling the

“construction of a visual temporal framework” (Wilson et al, 2007 p. 136), which allows the timing, sequence and interrelation of events to be seen (Axinn et al, 1999).

Calendar based interviewing was developed and first used in 1969 by Balán and colleagues, who sought a technique that could gather rich retrospective life histories from a large sample size. Prior to this innovation, detailed life histories were collected from small numbers of people or quantitative approaches were used to gather specific and partial life course data from large numbers. Balán et al’s (1969) calendar approach combined these aspects, enabling multiple events and their sequences to be explored on a large scale. Balán et al (1969) interviewed 1640 Mexican men and gathered histories on their education, work, partners, children and health.

Since Balán et al’s (1969) innovation, the method has been developed and adapted and numerous studies using calendars of varying names and designs have been used in a variety of ways, to gather data on a wide variety of subjects, with differing study population sizes. Calendars have been adapted for use in many specialities including criminology, psychology, nursing, economics, education, marketing, social work, psychiatry, and sociology (Belli et al, 2009). A few examples of using calendar interviewing in research include: using a ‘self-discovery tapestry’ (Meltzer, 2001), an ‘occupational events calendar’ or an ‘occupational history calendar’ (Hoppin et al, 1998, Engel et al 2001, Zahm et al 2001, Porcellato et al, 2010; Lilley et al 2011) to explore people’s occupations over their lifetime; using a ‘life events calendar’ to understand women’s roles in violent crimes (Kruttschnitt and Carbone-Lopez, 2006), socioeconomic behaviours over a 2 year period (Belli et al, 2001) and drinking, smoking or marijuana use by men and women during pregnancy (Bailey et al, 2008); ‘life grids’ to investigate health inequalities over a lifetime (Holland et al, 1999), ‘life history calendars’ to understand the impact a physical disability (Scott Ricks et al, 2011) or domestic violence (Yoshihama et al, 2002) has over a lifetime

and 'life chart interview' to track the course of psychopathology over time (Lyketsos et al, 1994).

From the literature, there does not appear to be an explanation for the variation in terminology (Glasner and van der Vaart, 2009). Belli and Callegaro (2009) have circumnavigated this issue by coining the term 'calendar interviewing' to be inclusive of all methods using a time based chart to gather retrospective data.

In the research conducted for this thesis, the calendar was initially called the life 'events' calendar, however during the process of conducting the research this was changed to a life 'history' calendar; although the calendar itself did not alter and the change was in name alone, the change was made to reflect the research philosophy; aiming for in-depth descriptions of participants lives. Martyn and Belli (2002) stated "Life history calendar (LHC) may be used interchangeably with event history calendar (EHC) however the LHC label is used when long-term life course data is collected and EHC is used when specific event data is collected over shorter periods of time" (Martyn and Belli, 2002, p. 270). During the course of conducting the interviews it became apparent that for the participants, drug use, alcohol use and hepatitis C were not 'specific events over short periods of time' but were intertwined situations with a history, a future and a present, infiltrating many aspects of everyday life, lingering, sometimes in the background sometimes in the fore, but whose impact was long term; thus a 'LHC' was used to gather rich life histories from the participants.

Since Balán et al (1969) pioneered the technique, calendar interviewing has gained momentum, predominantly due to its accuracy on recalling self-reported data (Sayles et al, 2010; Sutton, 2010). By visualising events on the calendar, participants can cross reference these events and consider the sequence of events, which can trigger further memories (Freedman et al, 1988; Axinn et al, 1999). Many studies have since tested the calendar method to assess its reliability for recalling retrospective data (Freedman

et al, 1988). For example, Belli et al (2001) compared the quality of data obtained from a 'question list' interview and a calendar interview when recalling retrospective reports from 1 to 2 years before. The study found "higher quality retrospective reports" (Belli et al, 2001, p. 63) with the calendar method. Considering a longer recall period, Berney and Blane (1997) conducted calendar interviews with people aged 64-83 years to ask them about their social circumstances during their childhood and youth. This data was then compared to archived material from the same people that was recorded 50 years earlier. The study found a "useful degree of accuracy" (Berney and Blane, 1997, p. 1519) when comparing the two data. More specifically, Caspi et al (1996), found a 90% agreement between retrospective data collected on a LHC compared to reports from 3 years before.

Concern regarding the reliability and validity of retrospective data, is largely a quantitative endeavour, thus historically calendars have predominantly been used quantitatively. More recently, a few researchers have used versions of the calendar as part of mixed methods research (Scott Ricks and Harrison, 2011; Porcellato et al, 2016) or for qualitative studies (Parry et al, 1999; Martyn and Belli, 2002; Martyn and Martin, 2003; Harris and Parisi, 2007; Nelson (2010); Porcellato et al, 2016). To my knowledge, the first example of calendars being used qualitatively was in 1999 in Parry et al's research exploring long term patterns of smoking behaviour amongst adults with a smoking related illness. Martyn furthered the qualitative use of calendars in her work researching adolescents' patterns of sexual activity within the broader context of their lives (Martyn and Martin, 2003, Martyn, 2009). Other examples of research using calendars qualitatively include: Harris and Parisi's (2007) work exploring welfare transitions in females; Wilson et al's (2007) study with young people (aged between 16 and 23 years) to explore their experiences of parental substance use (illicit drugs, alcohol or poly drug use) and resilience in this context; Feldman and Howie's (2009) research to understand life after work and the effects of health on leisure time activities with older people and Nelson (2010) who

explored educational trajectories with Latino young adults. These studies vary in design but their commonality lies in their main focus, which was not quality of recall, but, as with the philosophy of qualitative studies in general, was to explore individual's stories and to hear their views and experiences.

In regards to the topics (hepatitis C, alcohol and substance use) and study population (PWID with hepatitis C currently or in the past, who may or may not be on opioid substitution therapy) of this thesis, there have been a number of studies across the quantitative (majority of studies) and qualitative paradigms that have used calendar interviewing.

In terms of substance use, pioneering examples are: the study of drug use careers (trajectories of drug use over time) by Adams and Henley (1977) and a calendar technique named the 'natural history interview/instrument' in 1975 by Nurco et al, (cited by Hser et al, 1992) and adapted in 1977 by McGlothlin et al (cited by Hser et al, 1992) and more recently advocated by Hser, Anglin, Chou and colleagues to study drug careers and drug treatment careers (trajectories of drug treatment over time) (Hser et al, 1992; Anglin et al 1993). An eminent example in alcohol use research and clinical practice is the 'Timeline Follow-Back' technique developed by Sobell and Sobell (Sobell et al, 1988), which asks people to recall their daily drinking over short periods of time (up to 12 months).

More recent examples of calendar research on substance/alcohol use are: Skinner et al (2011), Copeland et al (2012) and Fikowski et al (2014). Skinner et al (2011) used a calendar quantitatively as part of a larger study design following the lives of opiate addicted parents. The parents were originally recruited in 1991 and then followed up 2005/2006. In the 2005/2006 interviews a LHC was used to gather information on drug use, health service utilisation, drug treatment, marital status, employment and incarceration over the 10 years between 1995 and 2005. At the time of the interview using the LHC, approximately half of participants were using illegal drugs

(opiates, marijuana, cocaine, crack cocaine, amphetamines or benzodiazepines) and others were on opioid substitution therapy (OST), so although this study did not consider hepatitis C it showed that a LHC could be used with a similar population to this PhD. Fikowski et al (2014) used a LHC to explore patterns of drug use and access to drug treatment in chronic opioid users in reference to a life time period. Although this research was published after I had commenced my interviews so had no bearing on my decision to use calendar interviewing with this population, it is another example of calendars being used successfully with the study population. It also demonstrates that calendars can be used to gather data on a long-term 'life time' basis. Copeland et al (2012) used a life grid to collect life histories and explore premature deaths amongst PWID in Scotland.

In relation to hepatitis C, a life grid (McGowan et al, 2013) and timeline have been used qualitatively to understand protective practices employed to avoid transmission of hepatitis C (Harris and Rhodes, 2011; Harris et al, 2012) and hepatitis C/HIV (Friedman et al, 2008) in PWID. Harris and Rhodes (2013b) have also used a timeline to explore injecting practices within sexual partnerships. Although these articles focused on injecting and prevention of hepatitis C (and HIV in one article), as opposed to drinking in people with hepatitis C, they demonstrate that calendar methods can be used qualitatively with PWID to discuss hepatitis C. The timeline method used by Friedman et al (2008) and Harris and colleagues (2011, 2012 and 2013b) was employed in the follow up interviews in this thesis.

Russel et al (2012, 2014) have published two papers that used a 'lifetime event calendar' to discuss hepatitis C, alcohol and drug use. One paper assessed the impact of drug use on outcomes of hepatitis C treatment (Russell et al, 2014) and the other explored if alcohol use impacts on the outcome of hepatitis C treatment (Russell et al, 2012). Although this study considers alcohol and hepatitis C it is different to this thesis in two ways. Firstly, it specifically considers the outcome of treatment when drinking with hepatitis C, which this thesis does not set out to explore. Secondly, it

is with a different study population to those interviewed for this thesis, as it focuses on privately insured members of an integrated healthcare plan in the USA, where there were high rates of employment. According to the authors, the majority of the participants had a history of injecting drug use, but ‘they differ from patients recruited from drug treatment programs in that few, if any, were withdrawing from recent heavy drug use’ (Russell et al, 2014, p. 226).

Calendar interviewing has been used with PWID (who may or may not be on OST); to consider alcohol use; to consider substance use; to explore different aspects of hepatitis C; and has been used qualitatively, but to my knowledge the research explained in this thesis is novel as it combines all of these aspects.

3.6.3 Reasons for using LHC

There are three main reasons why the LHC was the chosen method for the service user interviews, namely, it enables sequences, triggers and patterns of behaviours to be seen over the long term; it places events at a time point, giving context to the event; and it is a method that challenges the traditional power dynamics of interviews. These points are explained in more detail below.

3.6.3.1 Sequences, patterns, triggers and interrelationships of behaviours and events.

“...human lives are uniquely shaped by the timing and sequence of life events and experiences across rather lengthy periods of time. It is now a commonplace assumption that events occurring in the past can have powerful influences on present and future well-being”

(Belli et al, 2009, p. 2)

In keeping with this assumption and in line with the aims and objectives of this research (see Section 3.1), I wanted a method that would allow participants to describe their past as well as present situations; to explore patterns, sequences and connections of events and behaviours, along with the ‘triggers’ for behaviours. Calendar interviewing is a method that has been shown to enable this (Freedman et al, 1988; Sutton, 2010) by allowing sequences of events to be plotted on the calendar and more than one topic to be considered. By plotting all domains on the calendar, observation of how they relate is possible. As explained by Freedman et al (1988, p. 38) “the life course is not a unidimensional series of events unfolding and evolving over time but a simultaneous unfolding of many dimensions all interwoven temporally and causally in complex ways.” In this research, I hoped the method would allow the connections and interrelations of hepatitis C, alcohol and drug use over the participants lifetime to be seen, illuminating experiences such as: how stopping heroin affected alcohol consumption; how a hepatitis C diagnosis affected drinking or heroin use not just immediately after diagnosis but over the lifetime; if life events affected substance use/alcohol use/the person’s hepatitis C journey; if there were any patterns, behaviours or events that affected drinking and drug use; if contact with services had any effect on alcohol use, substance use or hepatitis C.

3.6.3.2 Situated in time

In addition to the sequence and interrelation of past events being important for this work, being able to situate events in time is also crucial to understand the context of the event. I believe that illnesses and the threat they pose differ depending on when an illness is diagnosed. Consider being diagnosed with an illness prior to effective treatment, compared to being diagnosed at a time when effective treatments are available. Hepatitis C was untreatable when it was first discovered in 1989, since then there has been considerable scientific, medical and public health advances, improving knowledge, prevention, testing and treatment. Although there

are still barriers to diagnosis and treatment, I believe that experiences now compared to 1989 may be different. Thus I felt it was important to hear peoples' stories and understand them within a context, with a belief that peoples' experiences of hepatitis C would be different depending on when they were diagnosed and what treatments were available at that time.

According to Sandelowski (1999) time should always be considered by qualitative researchers, as “.....the people and events they [qualitative researchers] study are always situated in time” (Sandelowski, 1999, p. 79) and she urges qualitative researchers to consider “the overall temporal structure of their study design” (Sandelowski, 1999, p.80) differentiating between synchronic (cross sectional) and diachronic (longitudinal) work. Because of this, the service user interviews in this research were longitudinal in nature as they sought to capture participants' lifetime histories of hepatitis C, alcohol and drug use and included a follow up interview a few months after the first interview.

3.6.3.3 Power dynamics

In keeping with my beliefs that those with hepatitis C were the experts in this research, I wanted the interview to be non-intimidating, aiming for as much rapport as possible and a relationship in which the usual interviewer and participant power balance was challenged. The method needed to reflect this philosophy, working inductively and enabling participants to discuss issues that were pertinent to themselves. The calendar method has previously been shown to enable this.

Many authors have discussed how calendar interviewing provides more social interaction, trust and rapport between interviewers and respondents compared to 'traditional' interviews (Parry et al, 1999; Nelson, 2010; Sutton, 2010; Harris et al, 2012). Calendar interviewing uses a flexible conversational approach (Belli and Callegaro, 2009), where participants and researchers work in collaboration to co-construct the calendar (Freedman

et al, 1988; Parry et al 1999). Many researchers feel it is this conversational approach that encourages the rapport (Belli and Callegaro, 2009; Nelson, 2010). Furthermore, Harris et al (2012) found “within this format there was space for new topics to emerge and for participants to take the lead, bringing up issues of importance to him or her” (Harris et al, 2012, p. 34). This was also found by Parry et al (1999) who felt respondents were able to take control of the direction of the interview and the construction of their biographies. She suggested that this method required researchers to “relinquishing some control over data collection” (Parry et al, 1999, p. 11) and “one of the main attractions for qualitative researchers is its potential to alter traditional interview dynamics” (Parry et al, 1999, p. 11). Thus the main purpose of using the calendar for this research was not to collect ‘accurate’ data on recall, but was used primarily as a visual aid to engage with the participants, encouraging them to tell their stories and to hear their ‘voice’.

3.6.3.4 Consideration of other methods

There are many other methods that can be employed to explore participants’ lived experiences. These alternative methods were excluded when considering their ‘fit’ to the research topic, research aims and objectives and their suitability for use with the research participants. Two of the considered methods are discussed here; the biographical narrative interpretive method (BNIM) and Murray’s narrative framework. Like the LHC, these methods are used to encourage participants to tell their stories, are interpretative in nature and have previously been used in health research. Murray’s framework has been used to explore the lived experience of conditions such as fibromyalgia (McMahon et al, 2012) and HIV (Proudfoot, 2014) and the BNIM has previously been used in studies considering end of life care decisions (O’Neill, 2011) and men’s experiences of domestic violence (Corbally, 2011).

The BNIM interview requires an uninterrupted story from participants, and commences with the researcher asking an initial unstructured single question, a 'SQUIN' (single question aimed at inducing narrative) such as: "I would like you to tell me your life story, all the events and experiences which were important to you. Start wherever you like. Please take the time you need. I'll listen first, I won't interrupt" (Wengraf, 2001 p. 119). This initial interview can then be followed by 2 or 3 further interviews 'sub sessions' where the researcher asks questions about the information provided by the participant in response to the SQUIN (Corbally and O'Neill, 2014).

As a novice researcher I was unsure if I would be able to use this technique to ascertain information on the topics of this research. Although I understood that "in qualitative interviewing, 'rambling' or going off at tangents is often encouraged [as] it gives insight into what the interviewee sees as relevant and unimportant" (Bryman, 2012, p. 470), I was also aware that I had aims and objectives about particular topics to explore. As hepatitis C is a stigmatised health condition, I thought there was a possibility that participants may completely avoid talking about their experiences of hepatitis C in the first interview. However the LHC method used in this research encouraged participants to talk freely but the researcher could also ask questions as the interview progressed, using the conversational style typical of the method.

Although in the BNIM, hepatitis C could be broached at the sub sessions, I was aware, from my experience of working as a clinical research nurse, of the difficulties involved in getting people to participate in follow up interviews. I was concerned that some participants might not talk about hepatitis C in the first interview and then not attend the sub sessions. Although follow up interviews were planned for the service user interviews in this thesis, they were not expected to occur with every participant and were not vital.

As well as the BNIM being unsuitable as a method for this research, the analytical process was also inappropriate. The BNIM has a structured ten stage analysis strategy, with four of the stages concerned with analysing how the participant tells their story, focusing on the textual structure, changes in speaker, tone and topic (Casey et al, 2016). The “lived life” and “told story” are analysed separately and then merged into a case account which are compared with other cases. Panel analysis also occurs. Panels are presented with ‘chunks’ of the participant’s story to interpret. Challenges of this method are noted to be; excessive or overly complex data and needing skilled and trained researchers (Casey et al, 2016).

Although understanding the value of analysing how stories are constructed and language is used, this level of discourse analysis was not required in this research as the content of the story, not how it was told, was the main focus. During the LHC interviews, participants’ tone was noticed during the interviews and whilst transcribing, giving ‘a feel’ for the sentiment behind comments, but the main focus was not to use a structured approach to formally interpret how people used language. Considering people’s narratives in ‘chunks’ rather considering the person’s story as a whole also did not seem to be appropriate. The ethos of this research was to build relationships with the service users who participated to gain their trust, and also to value service users as the experts and as individuals who had stories and lives other than drink, drugs and hepatitis C. The possibility of breaking their stories down into chunks to discuss with a panel, felt impersonal with perhaps the risk of focusing on the lifestyle behaviours out of context of the person. As topics of discussion were likely to be about sensitive, highly stigmatised topics, I was also unsure as to how participants would respond to this method of analysis, knowing that their stories (although anonymous) were being discussed by a panel of people they did not know. I wondered if this could ‘stunt’ the information they provided. As I have never used the BNIM my thoughts are not based on experience of using the method but rather an educated ‘hunch’, and perhaps with the

appropriate training (as recommended by Casey et al, 2016) this method could have been suitable for PWID with hepatitis C.

Like the BNIM, Murray's narrative framework is also a narrative approach and is therefore concerned with how a participant describes their experiences. However Murray's framework is classed as an experience centred narrative approach where the main concern is the content and meanings of the presented lived experience, thus understanding the 'what' (Casey et al, 2016). This involves semi structured interviews and a hermeneutic approach to analysis, where the researcher goes back and forth between stories rather than a structured linear analytic process. The framework does however require participants stories to be explored through four lenses, namely personal, interpersonal, positional and ideological (Murray, 2000). Like the BNIM the personal lens considers how the story is constructed. The interpersonal lens examines how the accounts are co-constructed between the participant and researcher, such as examining the flow of the conversation. The positional lens is concerned with the relationship between the participant and researcher, considering where the power lies and the impact this may have on the story told. The ideological lens considers the persons story in relation to sociocultural norms, such as stigma and hepatitis C. As this approach requires consideration of all four lenses, it was not a suitable 'fit' for the research conducted in this thesis. As explained previously in the analysis of BNIM, how the participant's story is constructed is not a main concern for this research, nor is an analysis of how the conversation between researcher and participant is formed or an analysis of the power between researcher and participant. As previously explained the methods employed in the service user aspect of this research (observation and LHC interviews) were chosen after consideration of power dynamics and data collection occurred with this in mind, however analysis of how the power dynamics affected the stories told was not a focus of this research. Rather than analysing the data by looking for the topics stipulated by these four lenses, analysis

focusing on finding themes within the data was chosen as the main analytic technique.

After consideration of other research methods available, the LHC was chosen as the best 'fit' for the study population and topics researched. The next consideration was the design of the calendar.

3.6.4 Development of the LHC

As discussed before, calendars can be used qualitatively or quantitatively, which dictates the design of the calendar, however there are many other aspects of calendar design that need to be considered, such as the information required and how they are to be applied.

Calendar interviewing is, in the main, conducted face to face where the calendar is completed as part of the interview. However, some researchers have completed calendars over the telephone (Freedman et al, 1988), asked participants to complete the calendar on a computer (Kruttschnitt and Carbone-Lopez, 2006), or the calendar is self-administered by participants prior to the interview (Martyn and Martin, 2003; Martyn, 2009). Many studies have used calendars in conjunction with other research methods or activities, such as Wang et al (2014) who used calendars as part of a clinical examination or Skinner et al (2011) who used a LHC for interviews conducted 12 years after the initial interviews as part of a longitudinal study.

To reflect the level of detail required, some calendars are highly structured in their design with a prescribed list of questions and set format of completion (Meltzer, 2001; Martyn and Martin, 2003; Harris and Parisi, 2007). However, Feldman and Howie (2009) used a structured life history tool with older people and found that the tool constrained engagement and in a pilot test of a structured format Nelson (2010) found participants did

not give detailed answers as were restricted by the structure. Instead Nelson (2010) opted for blank pieces of paper where histories were drawn as the interview progressed.

For the purpose of this research, face to face administration of a paper based calendar was chosen as computer access was not guaranteed at the research sites and the level of computer literacy amongst the study population was unknown. A blank page method (Nelson, 2010, Harris et al 2012 and 2015) was also eliminated, due to its complete lack of structure (Nelson, 2010), which I feared would be difficult to administer as a novice researcher. Therefore, a pre-printed semi structured chart was used and completed during the interview. The decision to complete the calendar with participants rather than over the telephone or self-administered prior to the interview was to assist participants with the calendar, enabling them to ask any questions they may have about the calendar, to make the calendar as non-intimidating as possible for participants and to enable the rapport building co-constructed calendar approach as discussed previously. I decided to use a calendar based on Porcellato et al's (2016) occupational calendar for its simple, clear design and also because it could be used qualitatively. According to Nelson (2010, p. 416), "like any methodology, the LHC demands thoughtful implementation and often modification". There were five further things I took into consideration before finalising the calendar design, namely: domains, time units, historical events, personal events and recording techniques.

3.6.4.1 Domains

Domains are events or situations of special interest, selected to reflect the research aims of the study (Caspi et al, 1996; Freedman et al, 1988). For example in Freedman et al's (1988) research with mothers and children, there were eight domains (geographical residence, cohabitation and marital statuses and transitions, living arrangements, fertility, employment, school enrolment, military service and monetary exchanges

between respondents and their parents), however in Porcellato et al's (2016) research considering occupations over time, unusually only one domain (occupation) was discussed. For my research the chosen domains were hepatitis C, alcohol and drug use. I decided not to use any other domains, such as service provision despite this also meeting the objectives, as I felt that more domains would mean more direction from me as the researcher rather than participants being able to talk freely about these three domains.

Many of the studies in the literature write the domains on the calendar (Caspi et al, 1996; Axinn et al, 1999; Martyn and Martin, 2003), listing them down the left hand side and giving them a row each for data recording linked to that domain. However, I decided this made the calendar cluttered and more complicated to look at, and again this would also be prescriptive in terms of the discussion. Instead I chose to explain to the participant that I would like to hear about their alcohol use, drug use and hepatitis C over their lifetime. Thus these domains were the broad themes of discussion allowing for participants to bring up topics that were important to themselves.

3.6.4.2 Time units

The time units (day, week, month, year etc.) used on the calendar again depend on the data required for the research (Freedman, 1988), along with the time period the calendar is to cover (Axinn et al, 1999). For example, if the calendar was to cover a two-week period, days would be appropriate. However, in this research lifetime information was required and as PWID are noted to be an aging population (Beynon et al, 2009), the calendar needed to cover decades, therefore recalling events on a daily or even weekly basis was unrealistic. It is also important to consider the amount of space required on a calendar for the time units involved (Freedman et al, 1988) and the size of calendar this would produce. I opted for quarterly (January to March, April to June, July to September, October to December)

time units, as I did not need to know exact dates of when substances were commenced, stopped or switched, or the exact date a hepatitis C test was performed for example, it was the general patterns that were of interest, not the exact day that something happened. For this research, getting people engaged and talking and to see the general pattern of events was the purpose of the calendar. Each column represented a three-month period and each row represented a year. Each sheet of paper covered a decade (see Figure 6 in Appendix 5 for a part-completed LHC), so for each participant many sheets were used, five sheets if they were aged 50 years for example.

3.6.4.3 Historical events

Whilst conducting interviews with older adults, Hoppin et al (1998) noticed respondents used world (historical) events and personal events to aid recall. “The practice of including landmark [historical] events has since become commonplace in LHC research” (Nelson, 2010, p. 416). The purpose of the historical events, along with personal events (as will be explained in Section 3.6.4.4) is to trigger memories and enable an event to be placed at a time point. Although my main focus is not on gaining ‘accurate’ data, I felt using a tool to aid participants was a worthwhile endeavour. Basing the calendar for this research on Porcellato et al’s (2016) I decided to change the historical events from their calendar to events that I felt may be more meaningful to my participants, such as more local Merseyside events. Unintentionally many of my events were those that were more traditionally gendered towards males, (such as football specific events).

3.6.4.4 Personal events

Similar to Hoppin et al (1998) and Porcellato et al (2016), computer generated stickers of personal events, such as weddings, births, hospitalisation, education and incarceration were made, to place on the calendar at the corresponding time points during the interviews. I decided

to use stickers as felt they would be quick and easy to use and therefore would not interrupt the flow of conversation as could just be stuck on quickly as the person was talking. I also thought it would reduce the amount of writing on the calendar, enabling an event to be noted at a glance rather than reading it every time.

3.6.4.5 Recording techniques

There are various techniques to record information on a LHC, but generally these strategies feature a combination of symbols with lines connecting the symbols, to depict when a situation occurred, how long that situation continued, and when that situation ended (Freedman et al, 1988). For example, Freedman et al (1988) used an 'X' to depict the start and end of a situation and a horizontal line between the two X's to show how long that situation occurred (Freedman, 1988). Axinn et al (1999) used letters at the start and end of the situation with a horizontal line between, for example an 'M' indicating marriage at the start of the horizontal line with an 'S' indicating separated at the end of the line. In Porcellato et al's (2016) occupational history calendar a vertical line was used at the start and end of the situation, with a horizontal line between. They also used different coloured pens to indicated different employment status such as pink for part time and black for unemployed. As the calendar used in this research was based on Porcellato et al's (2016), their recording technique was also used, but in this research each colour was used to depict a different substance, such as heroin, alcohol, marijuana, or for an event related to hepatitis C, such as length of time on hepatitis C treatment. A broken line indicated non-continuous use of a substance during that time, such as going out for a drink every few months.

How to proceed through the calendar is generally omitted in the literature. Bradburn et al,(1987) (cited in Porcellato et al, 2016) suggest recall is improved when moving from the present to the past however Nelson (2010) encouraged her participants to begin with any topic or time period. She

believed by “allowing the respondents to dictate its [the LHC] own progression, respondents became engaged and assumed ownership of their own narratives” (Nelson, 2010, p. 418). As the focus of this research was to engage with participants and encourage them to discuss issues pertinent to themselves, rather than on accurate recall of data, Nelson’s (2010) approach was followed.

3.6.5 Application of the LHC

This section explains the interview process, which took much thought and careful planning and deliberation on whether this method would produce the envisaged conversation and rich data that others have claimed (Parry et al, 1999; Belli et al, 2001; Harris and Parisi, 2007; Wilson et al, 2007; Bell and Callegaro, 2009; Nelson, 2010). The section starts with an explanation of the interview method, continues with the thoughts and findings from the pilot interview and concludes with sampling, recruitment and inclusion/exclusion criteria for the study interviews.

3.6.5.1 The interview process

Stage 1: The interview - participants’ history

The LHC was introduced at the beginning of the interview. The calendar was placed between the participant and myself (the researcher) and a verbal explanation of the calendar and how it was to be used in the interview was given. The calendar was used as a tool to assist the participant to consider their alcohol, substance use and hepatitis C history. Completion of the calendar was a collaborative effort between the participant and researcher, and the method was conversational in approach.

The first step was to record participants' demographics on the calendar. As the calendar is to remain anonymous, names were not included, but instead the calendar was labelled with the participant's code. (A separate record of which code matches which participant was stored in a locked filing cabinet and viewed by the researcher only). Gender and age were also recorded. Age was recorded for each year on the calendar, so therefore their current age was by default also recorded. Ethnicity was not included on the calendar due to the small numbers of ethnic minorities assessing drug services in Merseyside (Whitfield et al, 2017) and the risk of a person becoming identifiable.

Participants were asked to plot important personal 'life events', such as births, jobs, relationships, periods of illnesses and so on, on the calendar. The pre-prepared stickers of these events were used sticking them on the calendar in the relevant quarter (January-March, April-June, July-September, October-December) of the relevant year (see Figure 6 in Appendix 5).

Participants were then asked to explain their alcohol and substance use over their lifetime. As explained previously, each substance (including alcohol) was allocated a different coloured pen and a horizontal line was drawn on the calendar marking the time they used that particular substance. A short vertical line was drawn at the start and end of using a substance (see Figure 7 in Appendix 5). Participants were free to decide the order of how they discuss their substance use history /move through the calendar.

Once the participant felt they had completed their substance/alcohol history, if they had not already mentioned when they had their hepatitis C test/s, this was asked by the researcher and then plotted on the calendar. It is important to note that participants were aware events around their hepatitis C diagnosis would be discussed, as this was explained during the informed consent process prior to commencing the interview.

Following this, I then asked questions and cross referenced information given by the participant facilitating further discussion and understanding of certain events; for example on Figure 7 (Appendix 5), “Can you tell me a bit more about this time in 1984 when you started on alcohol as well as the heroin?”. These questions/conversations were different for each participant, as they were dependent on the issues raised in their individual histories.

It is important to note that the main focus of the interview was on the participant’s history not the calendar itself. The calendar was used to ‘trigger’ memories, but if the participant was talking freely they were not interrupted to complete the calendar.

Stage 2: The interview - semi structured questions

Once the participant’s history had been discussed, follow on questions were asked. Questions around services and where information about health is obtained (as per objectives) were prepared prior to the interviews. Again, the questions asked were different for each participant as depended on what had already been discussed in stage 1 of the interview.

All interviews were audio recorded and transcribed. Participants were aware of this as it was written on the study participant information sheet and was discussed during the informed consent process prior to the interview.

3.6.5.2 The pilot study - testing the LHC

Although I understood the purpose and benefits of using a LHC as documented in the literature, I was concerned regarding the practicalities of using it, as I had not used a LHC before and to my knowledge a LHC had not been used qualitatively with this target population to discuss their

experiences of hepatitis C, alcohol and substance use. Therefore, a pilot interview was conducted with a member of a local service users' forum who I had previously made links with. The purpose of the pilot was to trial the chosen method to see how it fared when applied.

The interview was conducted in a secluded corner of a public library. The purpose of the study and the pilot interview were explained to the pilot interview participant (*Frank*) and written informed consent was obtained. I then ran through the interview as if it was a real interview, to see if the method worked when applied, to practice using the method, to see how long the interview took and to receive *Frank's* feedback on the method.

Prior to the interview I felt apprehensive about using the calendar. My concerns were twofold; could I as researcher use this method and will the participants like and be able to use the method. There seemed to be aspects that could 'go wrong' such as getting confused with the numerous sheets, pens and stickers, or not being able to 'think on my feet' and employ the flexible, conversational approach required in this method. However, these concerns were largely unfounded and from the researcher's point of view, the method was reasonably easy to apply and the interview flowed. Although consideration would need to be given to interviewer training if there were multiple interviewers working on a study (Glasner and van der Vaart, 2009; Porcellato et al, 2016), for this research I was the lone researcher therefore consistency in technique was maintained.

Another concern was whether the method could have a negative effect on the participants. As a researcher I am aware of my ethical responsibilities to avoid harm to my participants and although I believed that drug users who attend services are frequently required to talk about their substance use and medical history, I was mindful that going back over history could potentially raise difficult events and therefore emotions in some people. The information sheet explained that participants did not need to talk about any topic they did not want to talk about, and this was also explained verbally at the start of the interview. *Frank* seemingly happily chatted

about his history, however at the end of the interview he looked at the pages (decades) of coloured lines indicating the substances he had used and said:

“Shit look at all those years I’ve wasted where I didn’t do anything coz I was on drugs”

(Frank)

Obviously he knew he had taken drugs for that period of time but I believe this comment was due to seeing his life drawn out in front of him. We are often reminded of the power of images in the media, where a picture of an event causes a stronger reaction than the written or verbal account of the event and I believe the visual aspect of this method has a similar effect.

Frank’s comment then led to two points of learning. Firstly, we discussed my initial concern of whether this method would be too upsetting for participants; *Frank* thought it would be fine as people would be used to doing similar with the drug services and secondly, after *Frank* made this comment I said “but you’re doing well now”. On reflection after, I realised I had been acting not as a researcher but as I would in my role as a nurse.

In practice the calendar technique had worked well, but the completed calendar was much more complex and disorderly than envisaged, requiring notes to be made on the calendar during the course of the interview. *Frank* gave positive feedback on the method but suggested changing the size of the calendar from A4 to A3 enabling it to be seen more easily. This change was implemented to the calendar for the study interviews.

Another learning point was the location of the interview. Although I was advised that I could conduct the interviews in a public place, such as a cafe, in practice, I felt uncomfortable with this, realising that this advice is content specific. I felt it was inappropriate to be talking about people’s lived experiences of sensitive topics (illegal drug use and communicable

diseases) in a public place, and felt this may potentially affect the depth of information participants were willing to divulge.

Conducting this pilot was a worthwhile exercise, because not only did it enable learning from trialling the method, it also raised some ethical dilemmas which required thought prior to conducting the study interviews. Following the success of the calendar method in the pilot, this method was then used for the study interviews.

3.6.5.3 The interviews

3.6.5.3.1 Participant selection

As this research set out to explore the views and experiences of PWID who have hepatitis C, it was therefore important to interview people who met this criteria. Purposive sampling was undertaken at drug and alcohol services and hepatitis C support groups in Merseyside to locate people who met the inclusion /exclusion criteria (See section 3.6.5.3.2 and section 3.6.5.3.3). Once a service user expressed an interest to be in the study (either by speaking to their key worker/group leader or speaking directly to the researcher) the inclusion/exclusion criteria was discussed with the potential participant. Participants were recruited based on a self-report of meeting the inclusion criteria (including criteria related to hepatitis C), as the researcher did not have access to participants' records within the centres.

Purposive sampling is a form of non-random sampling. Although random sampling is considered superior to non-random sampling by quantitative researchers there is a “growing recognition that there is no longer a need to ‘apologize’ for these types of samples” (O’Leary, 2017, p 208). Indeed in qualitative research non random sampling is useful to understand extreme, unique, deviant, misunderstood, misrepresented, marginalised, or unheard aspects of a population (O’Leary, 2017), situations that may be

missed with random sampling. Furthermore O’Leary (2017) suggests that “when working with populations that are hard to define and/or access non-random strategies may be the best option” (p. 210). As PWID are generally seen to be marginalised and a hard to reach population and hepatitis C is a stigmatised disease that is often not spoken about, a non-random sampling strategy was chosen. It is however important to note the limitations the sampling technique brought to this research. As the research was conducted at drug and alcohol services and hepatitis C support groups, this means that all the participants were attending these services. So this research does not capture the wider range of experiences of people who do not attend services perhaps because of ongoing drug use or unknown hepatitis C status, or people who do not inject now and do not require OST and feel they do not need support from a group for their hepatitis C.

This research has also only captured the experiences of those who wanted to talk about their hepatitis C. Due to the stigmatised nature of hepatitis C it can be difficult for people to talk about their experiences of having the virus so there may be other people at the services who met the inclusion criteria but did not want to be interviewed.

3.6.5.3.2 Inclusion criteria

- Current or previous injecting drug use
- Current or previous diagnosis of hepatitis C (‘previous’ such as those who have cleared the virus naturally or have been cured by treatment)
- Ever drank alcohol
- 18 years of age or above
- Able to give informed consent
- Willing to take part and be contacted for follow up interviews
- Attending a drug and alcohol service and/or hepatitis C support group in Merseyside

3.6.5.3.3 Exclusion criteria

- Never injected drugs
- Injectors of performance enhancement drugs
- Never been diagnosed with hepatitis C
- Never drank any alcohol
- Under 18 years of age
- Unable to give informed consent
- Not attending a drug and alcohol service and/or hepatitis C support group in Merseyside

3.6.5.3.4 Participant recruitment

If a service user felt they were suitable for the research, the researcher discussed the study with the potential participant and provided a participant information leaflet advising them to take the leaflet away, read the leaflet (or have the leaflet read to them) and discuss with friends, family or their support worker if they would like to. However, all participants preferred to be interviewed at the time of the discussion. Informed written consent was obtained, with 1 copy of the consent form being kept by the researcher and 1 copy by the participant. Interviews were conducted in a private room within the drug service/ hepatitis C support group building.

3.6.5.3.5 Sample size

The study originally set out to conduct interviews with 36 participants. This number was decided by considering Kuzel's (1999) work, which advises that 5-8 participants are usually sufficient for a homogeneous sample and 12-20 for a heterogeneous sample, where it is important to maximise variation across the sample. It was proposed at the start of the study, that participants would be recruited from services in three different areas of

Merseyside, therefore 12 participants from each centre were to be sought. However, saturation was reached earlier and 21 participants were interviewed (16 using the LHC and 5 without the LHC, as explained below and in Section 3.6.6.2.1). These points are explained further below.

In reality finding service users to be interviewed for this research was difficult resulting in one further site (four in total) being used for recruitment. This benefitted the research by providing further variation amongst the sample. Not only was there variation in sites as the research was conducted at different areas of Merseyside and at organisations providing different types of support (hepatitis C support group, drug and alcohol service, service focusing on long term recovery) but this also provided heterogeneity of the sample of participants. For example some participants were still injecting whilst others had stopped injecting but were smoking heroin, others had stopped using all drugs and were taking OST, some were not drinking alcohol, others were dependent on alcohol, some had failed hepatitis C treatment and were waiting for the DAA treatment, others had never received treatment and then at the fourth site most of the participants were no longer taking drugs, alcohol or on OST and were free of hepatitis C.

Even though the sample was not homogeneous, saturation was reached. I felt saturation was reached when the same topics were emerging in various peoples stories. As explained previously there were of course differences in people's individual life histories but broader topics such as situations demonstrating discrimination and stigma, accounts of fear around hepatitis C, difficulties accessing services and so on were evident in many participants account. I was satisfied I had reached saturation when I went to the fourth research site where the majority of people were further down the 'road to recovery' as were not taking drugs, not on OST and were cured of hepatitis C, yet their stories revealed the same broad topics of stigma, fear etc., as the participants who currently had hepatitis C and were in the midst of active drug use.

Rather than using a large sample size to create generalizable results as required in quantitative data, qualitative research seeks in depth information from small sample sizes. However the broader applicability of the findings can still be considered, by asking how transferrable the findings are to other instances (Denscombe, 2017; O’Leary, 2017). This is known as ‘transferability’, “whether findings and/or conclusions from a sample, setting or group lead to lessons learned that may be germane to a larger population, a different setting or another group.” (O’Leary, 2017, p. 68). The heterogeneity of the sample (sites and population) in this research increases the transferability, the ‘lessons learned’ (O’Leary, 2017), that may be applicable to other services and inform practice and policy. Denscombe (2017) and O’Leary (2017) both explain the key to transferability of findings, is providing enough information on the research, methods, participants, organisations and processes and so on for the reader to decide how applicable, ‘transferable’ findings are.

As mentioned above 21 initial interviews were conducted, 16 with a LHC and 5 (carried out within the service focusing on long term recovery) without. Table 1 shows the distribution of interviews, including the 4 follow up interviews using a timeline.

Table 1 Site of interviews

Organisation	Interviews Conducted	Follow-up interviews conducted
Hepatitis C support group	1 LHC	0
Drug and alcohol service	6 LHC	0
Drug and alcohol service	9 LHC	4
Service focusing on long term recovery	5 without LHC	0
Total	21	4

To maintain anonymity participants and sites were given codes. Each site was given a different letter and each person in that site was given a

different number. Samples were analysed on an ongoing basis using the constant comparison method, comparing participant to participant regardless of site but also noting nuances amongst sites, thus an ongoing inter and intra site analysis occurred. The codes assisted me as the researcher to understand which interview transcript was from which site, and therefore the context when reading back through, analysing and interpreting the transcripts. So for example, if a participant said they did not know about the hepatitis C support group at their organisation, I could look at the code and know which organisation it was and then relate that information to that organisation, such as whether that organisation had a hepatitis C support group and how that group was advertised within the organisation. However at the end of data collection samples were analysed as a whole and not split into sites as the broad themes that emerged from the data were relevant to all sites.

3.6.6 Methodological findings - benefits and limitations of the LHC

3.6.6.1 Benefits of the LHC

This research is, to my knowledge, the first use of the LHC for PWID to explore their experiences of alcohol use and hepatitis C. Furthermore, the LHC was found to be an effective method when used qualitatively to explore these topics with PWID. Used inductively the LHC produced a large volume of data on the views, beliefs, meanings and experiences about hepatitis C, substance/alcohol use and health services along with a rich contextual understanding of how these and other issues affect the lives of the participants.

In Section 3.6.3 I explained reasons why I chose to use the LHC, based on the methodological findings of other researchers who had used this method. These reasons were: the LHC enables sequences, triggers and patterns of behaviours to be seen over the long term; the LHC places events at a time point, giving context to the event and the LHC is a method that challenges

the traditional power dynamics of interviews. These points are now discussed in relation to this research, together with other benefits I found from using the LHC method.

3.6.6.1.1 Sequences, patterns, triggers and interrelationships of behaviours and events.

One of the main benefits of using the LHC is that it has enabled the collection of sequential data, providing a ‘fuller picture’ of alcohol consumption following a positive hepatitis C result, as it provides an insight over a longer period of time rather than a snapshot of a certain time point. This is different from other studies on alcohol use after hepatitis C diagnosis, which focus on short periods of time after the hepatitis C test result, such as 6 months post diagnosis (Ompad et al, 2002) or 6 and 12 months post diagnosis (Tsui et al, 2009). Other studies have considered a one off cross sectional approach of current alcohol use regardless of time since the hepatitis C diagnosis (McCusker et al, 2001; O’Leary et al, 2012). My study considers the time from diagnosis to the current day, which is a varied time period for each participant.

The method has also enabled observation of how a personal event triggered/changed use of a substance/alcohol. This is demonstrated below by *Ed* who plotted family deaths and a leg abscess (caused by injecting heroin into his groin) on the calendar as important personal events.

So he [Dr] said “that’s it or lose your leg”, you know what I mean

(Ed)

And did that change your injecting?

(Researcher)

Oh yeah that was it, kicked that to [makes a noise], never again

(Ed)

Straight away?

(Researcher)

Yeah straight away yeah you know coz you get a fright, you know, like I had the doctors and the surgeons telling ya you know, you gonna have to start making preparations here, you know you start saying ta ra to your family [voice wavers] and things like that you know, yeah but er gives you a kick up the wall then, never again and I never will

(Ed)

And when you came out of hospital did you start smoking it again then

(Researcher)

Oh god it was about nearly a year, yeah I done well

(Ed)

And what, why did you start again what happened?

(Researcher)

Well me mum died and then, no sorry me niece died first

(Ed)

Ed explains how the leg abscess stopped him injecting heroin, but the deaths of family members led to him commencing heroin use again, albeit smoking rather than injecting. This demonstrates the effect these personal life events had on his substance use. From this it can be seen that this tool could potentially be used therapeutically, to help identify triggers to

behaviours and enable service users and staff to see areas where service users may require help; in Ed's case it may be that he needs some support around death to help him cope differently if and when the next family death occurs.

Another benefit of the calendar is that it allows visualisation of patterns of behaviours and events, which enables some questions to be answered without having to ask the direct question. For example, information such as how long they had been living with hepatitis C or how much they drank following a diagnosis of hepatitis C could just be seen on the calendar after the personal and hepatitis C related events and lines indicating substance/alcohol use were plotted on. It is my belief that this method provides more information than if a direct question was asked, such as, for the latter example above, 'what did you drink after your hepatitis C result?'. This question may have produced a shorter response, with the participant not explaining differences over time. Also as people who have hepatitis C are generally discouraged from drinking (RCGP, 2007; SIGN, 2013), this question has the potential to sound like a judgment, with the possibility of participants editing their responses to provide answers they think the researcher wants to hear.

Regarding how participants moved through the calendar, the majority of participants commenced with the first substance they used and moved forward to the present day, although this was not always the case and substance use was not always explained sequentially but given in combination with stories about other issues. In reality drug users' lives do not always move forward in straight lines. The road to coming off substances is often a process as explained by *Phil*,

..and then you'd get off it and then you get back on, you know what I mean, you know, you get that battle then of going back and forth from methadone then back on it and then erm, you know I got off it for a few years and then went back on it again.

(Phil)

For those with hepatitis C, the pathway to clearing the virus is also not a straight path, with people falling off (and sometimes re-joining) the pathway at various points, such as the testing or treatment phase. This method has allowed data capture of these nonlinear processes and also allows for an understanding of the numerous events that can be co-occurring for a person at any given time.

3.6.6.1.2 Situated in time

Prior to commencing the interviews, I believed that peoples' experiences of hepatitis C would be different depending on when they were diagnosed and what treatments were available at that time. This was shown to be the case as demonstrated by extracts from *Jack* and *Steve's* interviews. *Jack* was diagnosed prior to treatments being developed and *Steve* was diagnosed within the last few years and had interferon therapy.

...they found out I had hepatitis C but they didn't even understand it then, you know what I mean, they just said you've got liver damage right, but then, treatment wasn't out like the way you get now interferon an stuff like that you know, there was no treatment for it, it was just basically, me I was shittin meself cause I thought it's a death sentence me, so I sort of did it on myself and thought look just go and get fucking bladdered every day

(Jack)

Doing what every day?

(Researcher)

Just go and get bladdered every day, just get wasted and whatever

(Jack)

Drunk?

(Researcher)

Yeah and I felt well ur I thought it was I mean, I'd done something there and for a bit [inaudible] about it. I didn't see anything changing I just thought there's nothing I can do

(Jack)

That's it?

(Researcher)

Yeah, you know that's how I see things coz there was no help, there was no treatment there was nothing so, you had it that's the way it was

(Jack)

I was gutted at first when I got the result yeah um because I mean I had, planned, I was going to, I wanted to go to university you know and I thought if I'm on interferon I don't know how it'll affect me. Um also I was seeing a girl at the time and I'd waited for my results before you know, before doing anything and I hadn't told her why we hadn't done anything, oh fuckin hell you know I actually have got it. So yeah put things back and I felt like if I started interferon then it was gonna run into any course that I was doing so I'll have to wait til the next year to do even an access course, you know felt like I'd put my life off by a year or two just, and that's you know if the treatment does end up working I thought, get to feel rough for 6 months a year, just a lot of er yeah it was a bit of a, bit of a setback you know I was quite gutted at the time

(Steve)

And what happened then and what did the GP do after they told you the results?

(Researcher)

Yeah they referred me straight to the um, it was quite good actually, they referred me straight to the specialist clinic in XXX [hepatitis C clinic] and I had an appointment there within, I can't remember, I think it was within like 6 weeks but, yeah I ended up starting treatment.

(Steve)

This shows *Jack* felt his life was over whereas *Steve* saw his hepatitis C diagnosis as more of a 'setback'. Although this is a simplistic analysis of the two data, and there will of course be other factors at play, it does show that time provides a context that needs to be considered when analysing the data.

3.6.6.1.3 Power dynamics

Many of the participants expressed that they had enjoyed the interviews, however it is my belief that it was the conversational aspect of the method and not necessarily the calendar itself that people had enjoyed.

No, no I've just been enjoying talking to ya, really nice, nice speaking to someone.

(Neil)

Mm have you got any questions for me, I think I've kind of finished really

(Researcher)

Ur no just I think it's good like, I'm made up I've got a little bit off me chest

(Pete)

The conversational approach enabled participants to direct the conversation, which I believe encouraged rapport between the participant and researcher. The technique allowed new topics to emerge, as participants talked about issues that were important to themselves. This provided information on many aspects that were not included in my initial objectives and thus provided the data that is of real importance to PWID. This method allowed participants to bring up issues at their own pace and at times these were issues of a sensitive nature, (also found by Parry et al, 1999 and Wilson et al, 2007) such as rape and mental illness. With participants talking freely, as opposed to a set of structured questions, I felt I gained a holistic view of their lives, with a greater understanding of the complexities and the role that drugs, alcohol and hepatitis C have. The collaborative working, which allowed me to clarify points that were unclear, also allowed participants to ask questions, which provided an unexpected insight into their understanding and opinions of hepatitis C, alcohol and services, as demonstrated below.

And do they know that you injected and it might be linked to that or?

(Researcher)

Urm I didn't really know that it was linked to that

(Brenda)

OK, OK

(Researcher)

Is that how I would have got it yeah?

(Brenda)

Although in this example I had made an error in assuming that the participant would know routes of transmission for hepatitis C, this error provided an insight into *Brenda's* level of understanding about hepatitis C despite being diagnosed for approximately 10 years. Interestingly, this is harm reduction information that should be given on receiving a positive hepatitis C test result, to reduce sharing of injecting paraphernalia and the risk of further transmission to others, as well as continued education throughout contact with drug services/other health services. Below, *Pete* demonstrates his understanding of the disease and testing process.

As I was waiting yesterday, a lad come in Jane [researcher], he had took it [injected heroin] up his groin and he went "yeah I've come in to find out me results on me hep". He went "I have got it" and he come back out plus he went "me bodies cleared it up itself". Can that happen?

(Pete)

Showing that *Pete* did not know that some people can spontaneously clear hepatitis C. This is information that should be given with the antibody test results prior to going for the next stage of testing (PCR test) which looks to see if the virus is still present in the body or if it has spontaneously cleared.

Both of these examples show a lack of knowledge on some of the basic facts about hepatitis C, which should be frequently discussed by drug and other health services and is information that is readily available in hepatitis C leaflets. Although the reasons behind the participants not knowing this information is not addressed here, the point I am making is that the conversational style of the method enabled participants to feel comfortable enough to ask questions to me as the researcher, which in-turn gave an insight into their level of understanding, which I believe I would not have found from 'traditional' interviews.

3.6.6.1.4 Other benefits

The main advantage of the calendar method is the combination of seeing the data on the calendar and hearing the verbal account from the participant about these events. Pragmatically this dual approach enabled the story to develop throughout the interview and provided benefits for both the participant and researcher.

During the interviews participants would sometimes realise the relationship between different events, leading to a discussion of these connections as they emerged. Parry et al (1999, no pagination) also found this and noted, "This is quite different from the 'traditional' interviews where the majority of associations are discovered subsequently during analysis".

Finally, an unexpected methodological finding from this study is how beneficial I found the calendar method in helping me as the researcher. I found the calendar helped me to clarify and contextualise what the participants were saying. It helped me to place what they were saying at a point in time but also to think about further questions, as shown in this extract from *Sadie's* interview.

So when you were pregnant with your, just thinking right

(Researcher)

Yeah

(Sadie)

So when you were pregnant with your son

(Researcher)

Yeah

(Sadie)

You'd already been injecting?

(Researcher)

Yeah but I wasn't [stopped speaking]

(Sadie)

Did they do a hep C test then, when you were pregnant?

(Researcher)

3.6.6.2 Limitations of the LHC

When conducting research with a LHC there are logistical concerns that need to be considered.

3.6.6.2.1. Interview length

Interviews using the LHC varied in length depending on how much participants talked. The majority of interviews lasted between an hour and 1.5 hours, which is, in general, longer than 'traditional' interviews. When conducting this research, the time requirement caused a practical and ethical dilemma, as explained further below.

As finding participants to take part in the interviews was proving to be quite difficult, I approached another service to inquire if I could recruit some participants from there. After hearing about the study and my requirements to conduct the research, they were extremely enthusiastic and organised a date for me to re-attend to carry out the interviews. I went, expecting it to be the same as the other services, with 1 or 2 people to interview after they had seen their key worker at the service, but they had booked in 7 people, 5 of whom attended. I was delighted that I had participants, however, they had been given appointments to attend the service just to

see me, and had been booked in, in 30 minute slots. This therefore caused a dilemma, as I knew the 30 minute slots were inappropriate for the method but the potential participants were already arriving with the sole purpose to be interviewed for this research. From my previous research experience, I was aware how difficult it is to organise people to attend for an interview and here there were 5 people waiting to be interviewed. In the ethics application I had written;

“However it is important to note that the main focus of the interview is on the participants’ history not the calendar itself. The calendar will be used to ‘trigger’ memories, but if the participant is talking freely they will not be interrupted to complete the calendar”.

(Research protocol V2, 23rd July 2014)

I decided to continue with the interviews; I went through the same process but without the calendar, asking them to describe their substance and alcohol use over their lifetime, then asked about their experience of hepatitis C and finally the questions about services. I feel this showed initiative and flexibility whilst working within the ethical approval, however it is also an interesting insight and valuable learning point into the practicalities of conducting research ‘on the ground’. This demonstrated how as a researcher you are at the mercy of the organisation to which you are visiting and how sometimes other people/services misunderstand what is required for the research. I also felt a greater responsibility here, not just for my own research, but for other researchers, or health professionals/services in general, who work with this population who are ‘hard to reach’ (Zanini et al, 2013) yet here they were attending an ‘appointment’, I could not turn them away. Interestingly I felt these interviews were more difficult to conduct than those I had done previously with the LHC, compounding my thoughts that the calendar itself was helpful to me as a researcher in understanding the information the participants were giving (see Section 3.6.3). Interestingly, I also felt like the information given did not have the same depth of that provided with the participants

who used the LHC. I felt like I knew the participants who did not use the LHC less well, whether this was due to the method or the fact that I spent less time with these participants is unclear, however it is my belief that the visual aspect of the LHC, where participants' lives are drawn out in front of them, encourages the rich conversations that occurred during the LHC interviews.

3.6.6.2.2 Size, space and facilities

Due to its size (A3 sheets), the number of sheets (each sheet represents a decade of the participant's life), the pens and stickers, the LHC is slightly cumbersome to administer. Also as the method requires people to be able to see the calendar and to apply stickers and draw on it, a table is required to lay the total calendar on. Thus the LHC method requires a bigger space than 'traditional' interviews.

Many in the literature who have used calendars talk of sitting side by side (Freedman et al, 1988; Caspi et al, 1996; Martyn and Martin, 2003 and Wilson, et al 2007), to assist with the collaborative approach to calendar completion, however in this research this was not always possible, due to the layout of the room or facilities available. The services where recruitment took place were extremely busy and I was required to fit in with the service, using whichever room was free. Sometimes the layout of the small rooms were unchangeable, and we sat as close as possible but not always side by side. Sometimes we were on high chairs with a low coffee table, making it difficult to view and work on the calendar. I also had not taken into consideration the physical ability of my participants prior to the interviews. Many had medical problems with their legs and one person her back, resulting in sitting in a certain position or needing a certain height chair, meaning it was not possible to sit next to each other and sometimes made seeing the calendar quite difficult.

3.6.6.2.3 The LHC

Although most participants expressed that they had enjoyed the interview, two participants mentioned they were dyslexic, and others said they had a bad memory, expressing that they were not going to 'do it right'. After further explanation they understood that their story was the important part and not the calendar itself but it is important to consider peoples' feelings towards the calendar in future research.

Also, I was expecting an interactive collaborative approach with both myself and the participant adding information to the calendar. This in reality did not happen, with the person telling the story and looking at the calendar with myself adding the lines and stickers.

Only one person used the historical events down the side of the calendar to reference in time the information they were saying. Although I don't know the reason for this, it is possible that the events were not the correct events for my participants, as I chose these events myself (see Section 3.6.4.3). In research by Hoppin et al (1998) focus groups and informal interviews were used to ascertain historical events that were of importance to the study population (farmers). This approach may have been helpful with my specific population group. However conversely all participants used the personal events as 'anchors' for telling stories around.

Yeah I went to school but I finished early and went the market at 15. That was when the trouble started to be honest because I had money kind of thing, got in with the wrong crowd, and the next thing is drug use...

(Phil)

My feeling after this experience is that for future research using a calendar method, I would pilot a calendar with the historical events removed and just have a calendar where personal events could be plotted.

3.6.6.2.4 Analysis

The method produced a large quantity of data as it included data gathered on the calendar and transcriptions from the audio recordings of the interviews. Whilst it is obviously a benefit that the method has produced large quantities of rich data, the quantity does however pose a challenge in terms of analysis. Also, unlike a 'traditional' interview, questions were not asked in any specific order, with the conversational style of interviewing meaning that searching for themes and coding (thematic analysis) was a lengthy process. Other researchers using various analysis techniques have also noted difficulties with the data. Sutton (2010) suggested steps in the research process including computer programming, data cleaning and data analysis are cumbersome and difficult. Martyn and Belli (2002) found data entry to take longer than traditional interviews (Martyn and Belli, 2002) and Freedman et al (1988) felt coding was more difficult and expensive than a conventional questionnaire. Nelson (2010) used a LHC qualitatively with 10 participants and like my study, she predominantly analysed the interview transcripts. Nelson (2010, p. 426) concluded that this method is "not well suited to large samples because of the potential complexity of data entry and coding", concurring with my findings on data analysis for this method.

3.6.7 Follow up interviews using a timeline

After the initial interview was transcribed, the verbal information, along with information collected on the calendar, was entered into a timeline software (Timeline Maker Professional, 2015) to produce a computer generated timeline (Friedman et al, 2008 and Harris et al, 2012), (See Figure 8 in Appendix 5). This timeline is another form of calendar (Belli and Callegaro, 2009), but differs from the LHC in that it is contained on one page. The purpose of the timeline was to represent the jotted data collected on a participant's LHC, so it was easier to see for the second interview with that participant. It is important to note that the data was

not changed during this process, but presented in a different format. The timeline was then taken to the follow up interview.

It was never my intention to conduct a follow up interview with every participant, but to conduct ongoing analysis (see Figure 2) of the initial interviews, see the emerging topics or if more information was required, I would contact certain participants for a follow up interview. Participants were aware of this as it was written on the participant information sheet and a verbal explanation given. However, contacting people for a second interview was very difficult and the success here was mixed, largely due to how the drug service was set up. At service 1, I was unable to conduct any follow up visits; 1 person said his “life had taken a turn for the worse” since we last spoke and he couldn’t meet me, 1 said she’d meet me but did not attend and 4 people I was unable to contact on the telephone and were not returning to the drug service on set days, but were able to ‘drop in’ to the service when they wanted to. At service 2, people attended on a set day to collect their methadone prescriptions so I was able to meet people on the day they were attending and this was the service where all (n=4) of the follow up interviews were conducted. From this service, reasons for no second interview were: 1 person said he did not want to see me again; 1 person I decided not to follow up as they had spontaneously cleared the hepatitis C many years ago and I felt I had enough information from the first interview; 2 other people had come off methadone and had left the service. A total of 4 follow up interviews were conducted.

As I was transcribing an interview, questions would arise. I then read through the interview transcript of each person and wrote down questions that I had. I also wrote down questions from the emerging data from other participants’ interviews that I wanted to ask to this person in the follow up interview.

We started the interview with the time line laid out on the table for the participant to comment on, and then I asked my pre-prepared list of

questions and any other questions that arose during the interview from the conversational approach.

Again I was concerned about how seeing aspects of their lives mapped out would affect the participants. As the technique has the whole lifetimes worth of alcohol and substance use on one chart, as opposed to on a few pages with the LHC, the number of years on and off substances were even more visible. When Harris et al (2012) used this technique with PWID to discuss hepatitis C avoidance they found “reflection of the timeline often caused participants to see aspects of their lives in a new light, with some expressing surprise at how long they had been on methadone, for example. The viewing of a life mapped out in this way could also be challenging for some participants, provoking feelings of loss and regret” (Harris et al, 2012, p 34). The interviews were commenced very gently and I asked if they were okay looking at their chart. I was also working within a service where there was support for the participants if they needed it. However I did not find the same as Harris et al (2012) and all 4 participants in my study who had a follow up interview with the timeline, said they felt comfortable with it, (as did all 16 participants in the LHC interviews) but this is a point of consideration for future research using calendar methods.

The follow up interviews provided a further richness to an individual’s data, whilst also enabling topics raised by other participants to be discussed. The follow up interviews were therefore valuable to this study, however, disappointingly only 4 follow up interviews were conducted. From the follow up interviews I have learnt the importance of understanding the service where participants are to be recruited from for the research. In this study, service 1 was a drop in service, where service users did not have to attend the service on a set date, which affected my ability to see participants for a second interview. Also the time gap between interview 1 and 2 meant that people’s circumstances had changed over that period, making it more difficult to contact them for the follow up interviews. However, this did also allow me to see if there had been any changes in

their substance use or hepatitis C care/knowledge during this time, which proved to be extremely insightful. This is demonstrated by this extract from a conversation with *Beth* at her follow up interview, which was 6 months after the first interview.

So I was going to ask you, since I saw you last, which was June, what's happened about your hep C?

(Researcher)

Nothing

(Beth)

Have you made any enquiries or anything

(Researcher)

No

(Beth)

Nothing else, nothing new

(Researcher)

No

(Beth)

Have you spoken to the people here [the drug service]?

(Researcher)

No

(Beth)

Have they spoken to you about it?

(Researcher)

No, no. When XX [keyworker] was here before XX [keyworker] she was talking about there's somewhere in town where doin something over the hep C and I went 'oh yeah I'm up for that' but nothing

(Beth)

I remember you telling me that story [at previous interview], there was a mix up with phone numbers and stuff wasn't there

(Researcher)

Yeah so I don't know but I see all these posters on the walls er hep C, get tested but I know I've got it because it wouldn't be on me medical history otherwise

(Beth)

So last time you said you might go for another test, have you thought about that again?

(Researcher)

I don't know where to go. I got told there was a nurse in here but I don't know

(Beth)

And have you found out any more information since I spoke to you last

(Researcher)

No, no

(Beth)

Beth's comments indicate there has been no change to her hepatitis C care or knowledge in the 6 month period, which is an interesting research finding enabled by conducting a follow up interview.

3.7 Interviews with professionals - method

3.7.1 Introduction

Following the research with services users, the second part of this research was interviews with professionals working in services that the service users discussed, thus drug, alcohol and hepatitis C services. The purpose of these interviews was to explore professionals' experiences of drug, alcohol and hepatitis C services in order to enable a comparison between the 'lived experience' and the 'professional experience'.

3.7.2 Participant characteristics

Twelve professionals were interviewed. Seven were service user facing staff working in drug, alcohol and hepatitis C services across hospital and community settings and five were public health commissioners of drug and alcohol services. All professionals worked in the Merseyside area (See Appendix 7, Table 3)

3.7.3 Recruitment

Ethical approval for interviews with professionals was obtained from Liverpool John Moores University ethics committee, as an amendment to the original service user study (observation and interviews). Approval was also sought from research departments and service managers at the drug,

alcohol and hepatitis C services and public health departments of local councils. Following approval, professionals were informed of the study and were then free to volunteer to take part. When a professional expressed an interest in participation, a participant information sheet was provided, along with a verbal explanation of the study. Interviews were arranged at a time that was convenient to the participant, to fit in with their other work commitments. Interviews commenced with a further explanation of the study and written informed consent was obtained. All information collected during the research has been treated confidentially and anonymised. Direct quotes have been used in the findings section (Section 6.2), participants names and workplaces have not been included but are replaced with 'P1' to 'P12' to depict the 12 professionals who were interviewed.

3.7.4 Method

To gain an overall understanding of current and historical drug, alcohol and hepatitis C services, semi structured interviews were conducted with public health commissioners. Interviews with service user facing staff used written vignettes of hypothetical service users (see Boxes 1 to 4 for the vignettes). The content of the vignettes was based on information gained from the previously discussed service user observations and interviews.

Vignettes were chosen as they aim to mirror a 'real life' situation (although it is important to note that in general, research tools can only ever cover aspects and can never completely mirror real life) (Hughes and Huby, 2002). As a method vignettes have been used widely in health and social science research. A few related examples include: presenting vignettes about sharing needles to people who inject drugs to gain a better understanding of injecting practices (McKeganey et al, 1995; Carruthers, 2005); providing scenarios of patients with urinary problems to healthcare staff to understand the factors affecting decision making and management of this condition (Farrington et al, 2015) and using a vignette of a female with

breast cancer with staff and cancer survivors to see gaps in breast cancer services (Lea et al, 2013). For this research vignettes were used to gain an understanding of the services provided to people living with hepatitis C.

Vignettes were also chosen to elicit information about the service rather than the participant's personal viewpoint on the topic. Participants were asked to discuss a number of points in relation to the vignette, such as: what the service would do for the hypothetical service users; what advice/information the service user would be given; how the service user would be referred to their service and what service they would refer on to.

Participants were asked to discuss 1 or 2 vignettes (depending on time and the relevance of the vignette to the service). Interviews lasted between 20 to 30 minutes. All interviews (vignette and semi structured) took place between December 2015 and March 2016.

As with the service user interviews, all interviews with professionals were audio recorded, transcribed verbatim and imported into Nvivo. A constant comparison approach was used for interviews that discussed the same vignette, thereby enabling analysis of how each service would respond to that specific hypothetical service user. Thematic analysis was also used to identify themes across all the professionals' interviews. These findings were compared and contrasted to the findings from the service user interviews and observations, which is presented in the discussion chapter (Chapter 7).

Box 1: Rob (Vignette 1)

Rob is a 45 year old man with a medical history of COPD and hepatitis C (diagnosed in 2000). He previously injected heroin and crack cocaine but stopped injecting 10 years ago. He has been on a methadone script for 15 years and is currently on 40mls of methadone a day. He currently smokes heroin around twice a month and drinks 5 cans of 9% Skol super strength

lager a day. He lives with his partner in stable accommodation (a secured tenancy with a registered social landlord). His partner does not know that he has hepatitis C. She would like to start trying for a baby.

Box 2: Kate (Vignette 2)

Kate is a 35 year old female with a 3 year history of injecting drug use. She currently injects and/or smokes heroin daily. She is on a methadone script although she only attends the drug service sporadically. Kate has had periods of homelessness but is currently living in a hostel. She says she finds it hard to get to the drug service as it is not near the hostel. She currently does not drink alcohol.

[After initial discussion]

Kate had a hepatitis C test 2 years ago at her previous GP practice. The blood was sent to the laboratories at the hospital. The test showed that she has hepatitis C. Kate does not know this as she didn't go back for the results.

Box 3: Ben (Vignette 3)

Ben is a 42 year old man who is currently drinking approximately half (35cl) a bottle of vodka a day. He previously injected heroin but is now maintained on a methadone script. He started drinking 2 or 3 cans of Fosters/Carlsberg (3.8-4%) lager a day when he was stopping heroin 2 years ago, but since then has changed from lager to vodka. He lives alone.

Box 4: Sarah (Vignette 4)

Sarah is a 52 year old woman with a medical history of depression and hepatitis C genotype 1a with no cirrhosis. She thinks she got hepatitis C by injecting heroin a 'few times' in her twenties. She has never been addicted to heroin, so has never been on methadone or attended drug services. She drinks alcohol socially. Sarah goes out with her friends about once a month and has 3 or 4 gins. She has previously received treatment for hepatitis C which was unsuccessful. She works full time and is a single mum to 2 teenage children

3.7.5 Methodological findings - vignettes

Whilst the vignettes aimed to engage staff in discussions linked to the original topics of this research (alcohol, hepatitis C and hepatitis C support) the research showed that for service users such as 'Kate' and 'Ben', and the staff trying to support them, there are many conflicting priorities other than hepatitis C. Thus the vignettes had posed a rather simplistic picture and had not encompassed the complexities of life for service users such as 'Kate' and 'Ben'. Also staff sometimes appeared to find it difficult to discuss the vignette, asking for more details , such as 'what level of fibrosis has he got?'

3.8 Analysis

There is no singularly appropriate way to conduct qualitative data analysis, although there is general agreement that analysis is an ongoing, iterative process that begins in the early stages of data collection and continues throughout the study.

(Bradley et al, 2007, p. 1760).

Due to the different research methods employed in this thesis different analytic processes were required for each method, with analysis occurring throughout.

For the observation, field notes were made after each observation and then I (the researcher) would read these through and write tentative interpretations, questions and thoughts to be considered and asked about at the following periods of observations, gaining over the weeks an understanding of concepts and emerging themes. At the end of the observation period data was not coded, opting instead to read the data in its entirety to help the identification of emerging themes without losing the connection between concepts and their context (Bradley et al, 2007). The themes and sub themes identified through this process are displayed in a thematic map in Section 4.1. With a perception of context and tentative emerging themes, interviews were then conducted to further understanding of the experiences of service users.

The service user interviews produced two forms of data per participant; the transcribed interview/s and the calendar/s (plural if participated in a follow up interview). These documents required different approaches to analysis. Firstly individual calendars were studied to ascertain the sequence of events in a participant's life, to understand points such as drinking practices after the hepatitis C result or the time from hepatitis C test result to hepatitis C treatment. Then each calendar and the corresponding participant's interview transcript were considered together to give context to the data on the calendar and provide clarity and further understanding to the experiences relayed by the participant. The calendar and transcript were considered in their entirety (as field notes were in the period of observation) to identify emerging patterns and themes whilst maintaining

the connection between concepts and context. Then using an ongoing constant comparison approach emerging topics, patterns and themes from one interview were discussed at the next interview and the follow up interviews to get further clarity and more in-depth data.

When data collection was complete the interview transcripts were then coded. Coding provides ‘a formal system to organize the data, uncovering and documenting additional links within and between concepts and experiences described in the data.’ (Bradley et al, 2007, p. 1761). The coding process was iterative and lengthy as suggested by Bradley et al (2007).

The code structure was mainly inductive in nature, thus rather than approaching the data with preconceived codes (deductive coding), codes were assigned from the data. Firstly data was considered line by line and as a concept arose it was given a code. As further data were considered and more concepts emerged further codes were given. I continued this process until all lines, paragraphs, segments had been highlighted and coded. By comparing and contrasting each section, codes were changed and reassigned until segments that reflected the same concepts had the same codes. Codes were then collated into themes, themes were then checked against the coded segments to ensure the theme related to the data in the segment, then themes were named and a map was generated (Braun and Clarke, 2006; Bradley et al, 2007). Deductive coding is where researchers have a ‘start list’ of codes, that they then apply to the data. One such code that was used in this research was participant characteristics; age and gender of the participants.

There is debate amongst researchers as to whether coding should be completed by a single researcher or by a team of researchers. The discussions revolve around philosophical approaches, research traditions, paradigms and researcher biases (Bradley et al, 2007). I was the only person coding the data in this research. This was justified in this research as I was

embedded in the research with ongoing relationships with participants and my biases and assumptions were not bracketed but acknowledged.

Coding was difficult. As explained previously, the LHC method produced vast quantities of data, with most interviews being over 20 pages long, furthermore due to the inductive nature and conversational approach, questions (and therefore answers) were not in an order like other types of interviews with a predetermined list of questions. However coding was completed and the themes and sub themes from the service user interviews are displayed in a thematic map in Section 5.1.

The interviews with professionals consisted of semi structured interviews with public health commissioners and interviews using vignettes with service user facing staff.

A vignette was considered by 1 participant, the interview was recorded and then transcribed. I then read this transcript and noted points, questions, emerging themes which were then raised with the next participant who considered the same vignette. This interview was then transcribed. Transcripts were then compared and contrasted to understand the service that would be provided (or not provided) for the hypothetical service user. This process was completed for all four vignettes. Then I compared and contrasted all the vignette transcripts looking for commonalities and differences. Initially this was by reading the transcripts through in their entirety.

The commissioner interviews were transcribed and then read through. Then all transcripts (commissioner and vignette) were coded as per the inductive technique explained in the service user section above. Deductive interviewing of considering participants characteristics was not used.

This process allowed 'intra' and 'inter' transcript analysis to identify themes. For example, the gaps in services were visible from analysing the

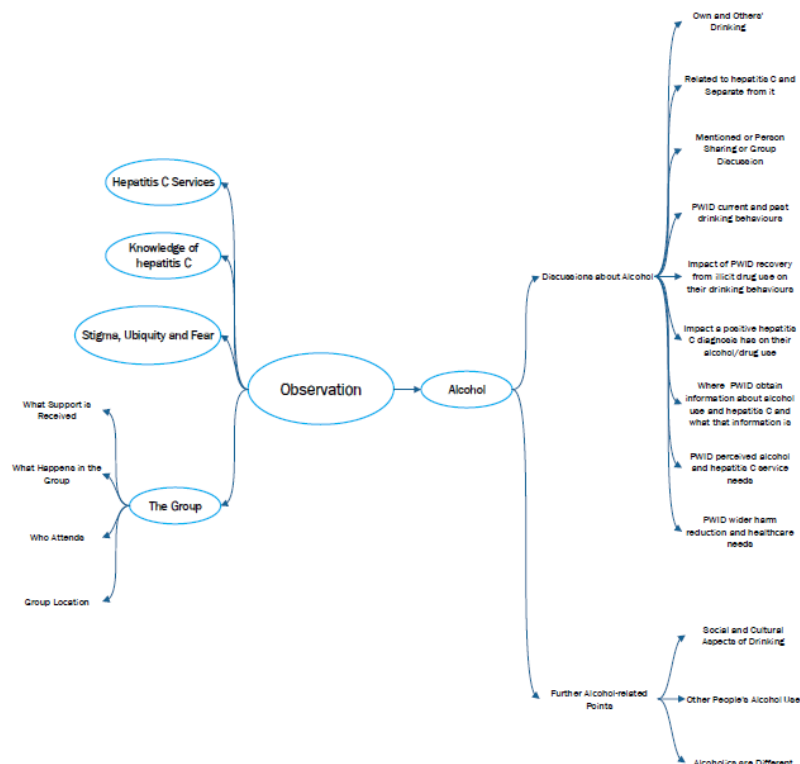
narratives of the participants who considered the same vignette, as they explained which services they would provide to that individual hypothetical service user and this theme also emerged from the commissioner interviews. The themes and sub themes from the interviews with professionals are displayed in a thematic map in Section 6.1. These findings were compared and contrasted to the findings from the service user interviews and observations, which is presented in the discussion chapter (Chapter 7).

Chapter 4 Observation findings

4.1 Introduction

This chapter presents the findings of the period of observation. As explained in Chapter 3, two hepatitis C groups were observed, however ‘Group 2’ was not attended by any service users, so there were limited findings from that group. Therefore this chapter discusses findings from observation at ‘Group 1’ only. Group 1 ran one afternoon a week and lasted 1.5 hours. Observation occurred on nine occasions over a four-month period between November 2014 and February 2015. Themes and sub themes identified from the period of observation are displayed in a thematic map (Figure 3).

Figure 3 Thematic map for the observations



4.2 Findings

4.2.1 Group location

The group was located in a meeting room at the offices of a homeless charity. Finding the group on the first day was a challenge, driving around what appeared to be an industrial area outside of town. I did not feel particularly safe, despite it being mid-afternoon; it was getting dark, the area was poorly lit and there appeared to be no one around. Later, I talked to *John* the group leader about the location of the group:

The group used to be behind the hostel [which is nearer to the town centre]

(John)

Was that convenient for people?

(Researcher)

People [not living in the hostel] didn't like going as might be seen. Also people in the hostel didn't like going as others in the hostel might see them going there.

(John)

Stigma?

(Researcher)

John agrees and said that where we were now was “out the way and no one will see us”.

[Field notes: Week 1]

People with hepatitis C having to be “out the way” where “no one will see us”, resonated with the comments made by staff at Group 3 (see Sections 3.5.3.3 and 4.2.1), who were deliberating on the location of their proposed

hepatitis C group, aware that if ‘others saw group members attending, they would discover those people had hepatitis C’. A stance different from that of Group 2 who were not ‘out the way’ but had moved their hepatitis C support group to the drug service in the town centre, so it was convenient for people to get to. A stark difference in approach between the services, which caused me to question what evidence these decisions were based on. Presumably services wanted people to attend, yet I wondered if the intended people were consulted when deciding the location of their support groups (Stigma is discussed in Section 4.2.6).

4.2.2 Who attends the group

I was informed that there were eight core group members, however during the time period I observed, the group consisted of three people (*Kath*, *Simon*, *Seb*) who had been coming to the group for about two years, *Andy* who attended once and the group leader/peer educator (*John*). All group members had hepatitis C (*John* previously) and all group members (including *John*) had injected drugs (although *Kath* had never been dependent and had not received treatment for her drug use). Although the hepatitis C group was linked to the hostel, attendance was not limited to people who lived in the hostel. *Andy* and *Seb* were currently residing in the hostel, *Simon* had previously stayed there but *Kath* had not lived there. *Kath* had found out about the hepatitis C support group from someone she knew who previously ran their own peer led hepatitis C support group. *Kath* was employed full time, *John* did voluntary work (including running the hepatitis C group) and *Seb*, *Andy* and *Simon* were unemployed however *Simon* also worked ‘cash in hand’.

Although all group members had injected drugs, it was evident that every group member’s circumstances were different, thus PWID are not an homogeneous group.

4.2.3 What happens in the group - what 'support' is received?

2 turn up for the group (Seb and Kath). All sit around a table and talk. Everyone sat down, there's tea/coffee and a plate of donuts. John (group leader) starts off with "How's your week been?" The atmosphere is calm he talks quietly, people are quiet and appear to be listening. People talk one at a time, but are free to chip in. He also later asked "what's your plans for this week?" the group get things 'off their chests'. Seb talked about hepatitis C but talked more about the other aspects of his life. He is in a hostel trying to get a house. His ex-girlfriend has turned up. He doesn't want to see her as she may jeopardise his chances of getting a house, as she has kicked doors etc. in past. He says she's an alcoholic and he'll "end up supporting her" "I haven't even got a house" He says he doesn't sleep well and is "anxious" he says he "does worry about her but can't go back." John advises him to think about now and not the future and to talk to his key worker and ask them why they think he's not ready for a house. Kath is offering advice too (about the ex-girlfriend). John tells Seb to think about himself, healthy eating, wellbeing, all part of starting to look after yourself. I ask does that start when you get your hep C result. John explains "no it's a journey and getting tested is part of the same journey of starting to want to look after yourself"

[Field notes: Week 1]

This extract demonstrates that conversations were not just about hepatitis C but also other aspects of their lives. However in the second week of observation, hepatitis C was the main topic of discussion. This was largely due to a new group member (Andy) attending.

Seb, Kath, Simon and a new person, Andy were at the group today. Andy says he's anxious about the group, hep C, symptoms and side effects to treatment. He talks of the big sheet of side effects in with the interferon [hepatitis C treatment]. He has many questions about hep C and treatment. "Can I get it from sex, cigarettes?" "I've been washing cups in boiling water". He was diagnosed 2 and a half years ago, and started treatment recently, although stopped after 4 weeks and has started again. He thinks he probably got it [hepatitis C] from injecting as a teen [Andy looks around mid 40's] says he didn't share needles. The group tell him hep C is also in filters and spoons. The group answer all his questions. The group are laughing. (I enjoyed being there, the group are fun, perhaps Andy will come back)

Despite *Andy* being diagnosed with hepatitis C over 2 years previously and attending the hepatitis C service to commence treatment, he appeared to lack basic knowledge on transmission of hepatitis C, questioning if sharing cigarettes or cups could transmit the virus and not knowing the risk associated with sharing any injecting equipment and not just needles. The group answered his questions, seemingly knowledgeable about the routes of transmission, and gave him good advice about the treatment and other aspects of his life; a good example of peer support in practice. *Andy* did not come to the group again.

The regular group members had been coming to the group for around two years and had all been through hepatitis C treatment. This longevity meant the support they required from the group differed from that required by *Andy*. Over the following weeks, conversations around hepatitis C were mainly about treatment and forthcoming hospital appointments. Sometimes aspects of their lives, such as drinking, were talked about in relation to hepatitis C and sometimes other aspects of their lives were discussed without reference to hepatitis C, such as: accommodation, other illnesses, money, family and friends. The group members appeared to be in a position of 'waiting'. *Seb* had recently finished hepatitis C treatment and was waiting for blood tests to see if the virus had cleared and *Simon* and *Kath* had previously received hepatitis C treatment which failed to cure the hepatitis C, so were waiting for further treatment. Thus on a backdrop of hepatitis C, the group provided support for other aspects of their lives, perhaps keeping people on the 'journey' 'to looking after themselves' that *John* spoke about in week 1. For *Kath* the group provided company, for *Seb* it showed engagement with services as a step towards recovery from addiction and a move towards leaving the hostel, for *Simon* a chance to discuss his alcohol consumption and, perhaps not to be ignored was the fact that the group was enjoyable.

Other support group members received was ‘buddying’, where *John* would accompany the group members to their hepatitis C hospital appointments. Group members appeared to value this support, informing *John* when their next appointments were and checking if he was free to go with them. *John* would also speak to people over the phone outside of the group time. *John*’s support was sincere, steady and encouraging, without force or nosiness and was without doubt appreciated by the group.

On the fourth week of observation *John* gave out information about hepatitis C medications that he had found on the internet and written out himself. There were no other written resources such as leaflets about hepatitis C available for the group to read/take home. In week one *John* talked about how previously a doctor at the hospital had suggested he speak to the finance department to see if the support group could receive funding. *John* had declined this as felt “*they would try and have a say in your service - take over*” [Week 1]. There appeared to be no funds provided for the group. The group seemingly ran on good will, with *John* volunteering, and the refreshments and space provided by the hostel organisation.

The support group used a poster to advertise itself. The poster mentioned that guest speakers came to the group, however during the time I observed there were no guest speakers. *John said they used to have guest speakers but they hadn’t for a while*. Therefore talking and buddying were the main support observed.

4.2.4 Discussions about alcohol

I observed alcohol to be mentioned in the group on five out of the nine weeks of observation. This was sometimes in relation to their own consumption and sometimes about other people’s drinking. The context was both in relation to hepatitis C and separate from it, at times discussing

alcohol as its own entity, but often flitting between the two. The reference to alcohol took many forms, from a passing comment, to a person sharing about their own consumption and on one occasion a group discussion. The discussion, although shedding light on some of the original research objectives, also raised further interesting points for consideration. Firstly findings connected to the original research objectives are considered, progressing onto a discussion of the other topics that emerged during the period of observation.

Conversation about drinking on treatment.

You can't drink on treatment as it makes you feel bad

(Seb)

Simon stopped drinking for treatment. He said others don't but he will stop again when he gets treatment again.

[Field notes: Week 2]

"the only reason I want treatment is so that I can drink later in life"

(Simon)

"have you told your hepatitis nurse that?!"

(Researcher)

[laughing] "of course not. Just to drink I won't be addicted or nothing like before"

(Simon)

I can't imagine New Year's Eve without a drink

(Andy)

You just have to not have a drink

(John)

I've been drinking a lot lately as the football's on - "can't go to the pub and watch football without drinking. Everyone's drinking"

(Simon)

Seb can go to pub and drink coffee. Starts talking about healthy living and jokes about will be going to gym and running soon!

[Field notes: Week 2]

Once you start drinking it's not like taking drugs

"after a few days you start to look different"

(Andy)

Andy said his brother died of alcohol and his mum had problems with drink

Seb said his brother also died of alcohol

[Field notes: Week 2]

Conversations indicated that there was variation in the amount of alcohol currently consumed amongst the group. Although the discussion about alcohol does not give definitive information about *Seb's* drinking, it hints that his consumption levels were low. No further information was gained during the following weeks of observation as *Seb* did not speak about his own alcohol consumption again, although he spoke openly about other difficulties in his life including his drug use and other people's alcohol use

(especially his ex-partner), suggesting alcohol was not a main concern for him at that time. In contrast *Simon* talked about his alcohol consumption every time he attended the group. In the conversation he talked openly about being addicted to alcohol previously and his current drinking levels. On week 4 *Simon* spoke more about his alcohol consumption.

Simon has not been drinking but on Fridays someone phones and asks him out to pub. "I can't say no" goes to pub but "is just drinking beer" Thinking of stopping Sky [television] as people come around to watch football and bring beer.

Had 4 pints in pub and 16 cans at home recently but this is less than he used to "no spirits"

Feeling anxious and stressed as wants to reduce so that blood results are okay when he has next meeting with XXX (hepatitis C nurse) about treatment. Has had 4 pack in fridge untouched but when someone calls he's eager to get to the pub.

Previously drank litres of cider and bottles of vodka, so moving to beer is much better

[Field notes: Week 4]

Although unable to quantify *Simon's* current level of drinking, as the time period in which he had 4 pints and 16 cans was not provided, the general tone of his narrative suggests a struggle with alcohol, as he demonstrates practicing a harm reduction strategy of reducing the strength of alcohol drunk (moving from spirits to beer). He also mentions previously being "addicted" to alcohol.

John also talked about his own alcohol consumption.

John talked about not having a hangover now and he thought it was as his liver was better [after receiving treatment and curing hepatitis C]. He talked about how in the past he wasn't bothered about drink- said he'd buy a 4 pack, drink 1 or 2 and give the others away. He said he use to drink vodka in the morning when he wasn't on drugs, to help him cope with his partner at the time.

[Field notes: Week 6]

Interestingly *John* told me on two separate occasions that he “was never a drinker” although drinking in the morning is considered in both the CAGE (Ewing, 1984) and AUDIT (Babor et al, 2001) alcohol screening tools which are used to identify those drinking hazardous or harmful amounts. One of the research objectives was to examine the impact of recovery from drug use on drinking behaviours. As the group talked generally about their alcohol and drug use, it was difficult to chronologically order their use to be able to explore this objective. *Simon* for example, talked of previously injecting drugs and previously being “addicted” to alcohol, but the relationship between the two was unclear from the discussions. *John* however did talk about alcohol use after heroin, but in a different context to the original objective, explaining how he had used alcohol in the acute phase of stopping heroin use, rather than a long term use of alcohol.

Went cold turkey [sudden withdrawal off heroin] and drank Korn [spirit] to cope with the cold turkey symptoms

[Field notes: Week 9]

Guidelines advise people with hepatitis C to stop drinking (RCGP, 2007; SIGN, 2013; NICE, 2016b) yet the research on alcohol consumption following a diagnosis of hepatitis C reports a varied picture in consumption levels, with some people reducing or stopping alcohol and others not decreasing consumption (see Section 2.5.1).

All group members (excluding *John*) had hepatitis C at the time of the observation. Therefore if they were drinking at the time of the observation, they were drinking whilst having hepatitis C. However as already discussed, understanding the group members’ current drinking behaviours was difficult. Although *Andy* did say he had been drinking since being diagnosed with hepatitis C, *Simon* was the only person to talk explicitly about his

drinking. From *Simon's* conversation it was apparent that he previously drank more than he did at the time of the observation but the reasons for this reduction were unclear, i.e. whether he reduced his drinking due to his diagnosis of having hepatitis C or whether he was reducing his alcohol consumption for other reasons. However, inadvertently hepatitis C did impact on alcohol consumption, as both *Seb* and *Simon* talked about not drinking whilst on treatment for hepatitis C.

Although *Simon* had reduced his drinking, his comment, "*the only reason I want treatment is so that I can drink later in life*", implies a short term behaviour change only. The comment shows he was aware of the risks of the combination of hepatitis C and drinking and therefore knew he had to treat the hepatitis C, but rather than wanting to cure his hepatitis C out of concern for his health, it was out of concern for his ability to drink in the future. This provides insight into the meaning of alcohol in *Simon's* life, and as noted by Harris, (2010) the benefits people received from drinking are often missed from the discourse on alcohol and hepatitis C.

Throughout the observation period, no reference was made to where information about alcohol was obtained. Regarding what information was known about alcohol, discussions demonstrated a mix of recommended harm reduction strategies (reduce spirits to beer), misconceptions (*you can get hepatitis C from alcohol*) and knowledge gained from personal experiences (*John says the ones he knows that have died have died of drinking - those with hepatitis C and without, drinking has killed them* [Week 9]).

Simon says he is *feeling anxious and stressed as wants to reduce* [his drinking]. His discourse implies he is reducing his alcohol himself. He does not mention any services that are supporting him with this. Over the weeks the group talk about alcohol but never discuss alcohol services.

4.2.4.1 Further alcohol related points of interest

As well as discussing issues that covered the original alcohol related objectives, the group conversations raised other points about alcohol that were interesting for this research, and are therefore included below.

4.2.4.1.1 Social and cultural aspects of drinking

Andy: I can't imagine New Year's Eve without a drink

Simon: I've been drinking a lot lately as the football's on "can't go to the pub and watch football without drinking. Everyone's drinking"

[Field notes: Week 2]

Simon: Has not been drinking but on Fridays someone phones and asks him out to pub. "I can't say no" goes to pub but "is just drinking beer". Thinking of stopping Sky [television] as people come around to watch football and bring beer. Has had 4 pack in fridge untouched but when someone calls he's eager to get to the pub.

[Field notes: Week 4]

Watching football and drinking, drinking on New Year's eve, "everyone drinking" at the pub are all comments that demonstrate the normalisation and ubiquity of alcohol within Western society. Indeed drinking alcohol is embedded deeply within Western culture, evidently causing conflict for those who are advised to reduce or stop drinking. Clearly *Simon* enjoys going to the pub and drinking ("*the only reason I want treatment [for hepatitis C] is so that I can drink later in life*"). Pleasure is frequently omitted from the literature and health promotion discourse regarding alcohol use for those with hepatitis C (Harris, 2010). The meaning of alcohol use for people with hepatitis C is explored further in the interviews.

4.2.4.1.2 Other people's alcohol use

The group were cognizant of the dangers of alcohol and frequently talked about other people's alcohol use. *John*, *Seb* and *Andy* all spoke about people they knew who had died from drinking alcohol. For *Seb* and *Andy*, alcohol use had affected members of their own families, with both having brothers who had died from drinking and *Andy's* mum having '*problems with drink*'. It was unclear if/how this family history of harmful drinking had affected *Seb* and *Andy's* alcohol consumption.

Seb spoke openly about his ex-partner's drinking, saying she was "an alcoholic". Towards the end of the observation period *Seb* stopped coming to the group. The group said he had started using drugs again and was also back with his ex-partner. Although the run of events were not known, the group felt getting back with his girlfriend who was drinking and starting to take drugs again were connected.

[Field notes: Week 6].

4.2.4.1.3 'Alcoholics' are 'different'

During the first week, *Seb* was discussing his ex-partner, explaining "*she's an alcoholic*". *John* replied "*alcoholics think differently*". There was no further explanation as to how 'alcoholics think differently', however in week 2 *Andy* commented that "*once you start drinking it's not like taking drugs - after a few days you start to look different*", again pointing out a difference between drug users and alcohol users. I wondered how these comments related to people who used drugs and alcohol simultaneously or for those people who had changed from drugs to drink, and if these people had hepatitis C, what support they might receive from the group.

These comments are also interesting as there is actually a group member, *Simon*, who admits to be struggling with his drinking and being an 'alcoholic' previously. I wondered if they thought *Simon* looked and thought differently to themselves or if he was not included in those that are 'different'. I also

wondered what level of drinking they were talking about as *John* certainly did not class himself as ever being a ‘drinker’ yet had previously drunk vodka in the mornings to cope.

At this point in the research the importance of people who drink alcohol being ‘different’ was unknown, however, reflecting back to the start of the research, when meeting with the users forum, they explained how the “drinkers” sat separately to the people who inject/ed drugs. This point is discussed further in the service user interviews

4.2.5 Knowledge of hepatitis C

As shown previously *Andy*’s level of knowledge on hepatitis C was low, despite being diagnosed for two years and having contact with hepatitis C services (as had commenced treatment). The group’s support towards new member *Andy* showed the group had a good basic knowledge of transmission of hepatitis C and an experiential understanding of hepatitis C treatment. However over the weeks it became clear that their knowledge, including *John* the group leaders, was limited.

Conversations often turned to hepatitis C treatment, although those involved in the conversation seemed to understand what was being said, as an onlooker, these conversations seemed vague and confusing. Over the weeks I questioned the group, to understand the conversations and realised my confusion was a result of having different knowledge of the treatments than the group themselves did. For example, they referred to a treatment as ‘*the new one*’ however they were not actually talking about the (then) current new to market drug (sofosbuvir) but were actually talking about telepravir and bocepravir that were the ‘new drugs’ in 2012. Thus, their knowledge was not up to date in a field of medicine that was advancing at a fast pace at that current time.

When talking personally about their own hepatitis C, they were unsure of the genotype, using phrases such as '*the easy one to treat*' or '*the one to treat that only takes 6 months*'. Different treatment is given for the different genotypes of hepatitis C, so it is therefore important to know the genotype. A basic understanding of this would help the group know their treatment options.

On week 2, the group discussed where they could get more information about hepatitis C.

We had a discussion about where they could access information. I suggested the Hepatitis C Trust website. The group (excluding John) said they didn't know about hepatitis C websites. Seb said he is doing computer training at the hostel. He is learning how to search on the internet. Andy wants to look into doing this training too.

[Field notes: Week 2]

The group did not use computers to find out information and as discussed previously there were no leaflets or guest speakers at the group during the time period observed. *John* did his best to educate the group, such as looking on the internet to gather information to give to the group. However *John's* knowledge was incomplete, which he then passed onto the group. An example of this was when he informed them of the new drug sofosbuvir, not realising that (at the time) sofosbuvir was not being used in clinical practice as it had not been approved for use by NICE.

I asked *John* about his training. He had been trained on a peer to peer scheme, which he thought was in 2010 and had not received any refresher training since.

4.2.6 Stigma, ubiquity and fear

In week 1, John showed me pictures drawn by someone living in

the hostel. One picture was a needle and syringe with a hook on the end and a dead person hanging off the hook- the hook was through the persons chest. John was considering using it for a poster for the hepatitis C group. I commented that hepatitis C doesn't necessarily kill you, John said people who inject will get it - "hooks you in, tears you apart"

[Field notes: Week 1]

A poster of injecting drug use to be used for a hepatitis C group advertises this group to be for people who have contracted hepatitis C from injecting and not by other routes of transmission. The poster demonstrates an inextricable link between injecting and hepatitis C, yet hepatitis C groups need to be 'hidden away' from other's who attend a drug service or the hostel. This inevitability of injecting leading to hepatitis C was demonstrated further in week 2.

Simon talks about a neighbour who says he's got hep C. Simon says he went for a test but never went back for the results. Simon's neighbour says all his friends have it, so he's got it Seb - "everyone's got it"

[Field notes: Week 2]

Presuming this 'all' and 'everyone' is PWID, this conversation suggests a ubiquitous nature of hepatitis C amongst this population, causing me to question further why if all PWIDs have 'got it', hepatitis C groups are hidden away. Seeking clarification on this, I asked *John*.

Researcher asked about, 'everyone's got hep C' but there's stigma of having it, can it be both? John said stigma is only outside of drug circles for example in the hostel those who don't inject, knowing that you had hep C

[Field notes: Week 9]

An explanation suggesting that amongst PWID hepatitis C is not stigmatised, yet this explanation does not explain the consideration for confidentiality

when planning the location of the hepatitis C support group 'Group 3' which was based within a drug service. At this point in the research this finding was unclear, however this is clarified in the interviews.

Considering ubiquity of hepatitis C further, below is the second part to the conversation with *Simon* about his neighbour who went for a hepatitis C test and did not go back for the results.

Why doesn't he (the neighbour) want treatment?

(Researcher)

It's not causing him any trouble, no symptoms, bury head in sand

(Group)

Like why men won't go for a prostate check

(Kath)

[Field notes: Week 2]

Demonstrating that despite suspecting hepatitis C as "everyone's got it", people avoid confirming their hepatitis C status, for a variety of reasons including fear. Fear related to hepatitis C came up in the conversation a few times over the weeks.

John says it's all about fear. The biggest fear is admitting to yourself you might have hep C. Fear of telling people, didn't tell people for a long time, not family no one. Fear of first injection for treatment "Why? Fear of the needle?"

(Researcher)

No going back. As once you've started treatment you have to continue with it.

(John)

Fear of side effects to treatment. Fear now of going for last blood test (since completing treatment). Fear of finding out if I still have it

(Seb)

[Field notes: Week 1]

Yet in the last week of observation *John* explained that *the fear of hepatitis C isn't as bad anymore as people know hep C doesn't kill you* [Week 9]. Hepatitis C can however lead onto diseases such as hepatocarcinoma or end stage liver disease that people do die of, therefore people do need to access treatment and not 'bury their heads in the sand'.

4.2.7 Hepatitis C services

The hepatitis C services and staff were frequently discussed. The group on the whole seemed disgruntled, as they '*didn't know what was happening*' with their care and the doctors they saw kept changing. Doctors were named and described as *good* or *not good*, although reasons for these descriptions were not given. The location of the services were also discussed.

Kath: Has appointment at hospital 'A', but wants to go back to hospital 'B'

[Field notes: Week 1]

Kath has got an appointment at hospital 'C' and doesn't know why. John talks about Kath asking for appointments to be moved from hospital 'A' to hospital 'B' and how now Kath's been given an appointment at hospital 'C'. John says it's further and she'll have to take more time off work.

Later it became clear that the reason for *Kath* attending hospital 'C' was medically in her best interest, as she received a fibroscan (scan of the liver). This equipment was not available at the other hospitals, however the group were not aware of this fact. This prompts questions on the reasons behind this and perhaps suggests improved communication is required between services and service users.

Although mainly dissatisfied with the hepatitis C service, the group did however have a high opinion of the hepatitis C specialist nurse. Indeed they seemingly trusted and went along with their plan of care, unquestioning aspects that concerned them, which were then discussed at the group. One such concern was that they were *being given different treatment to X* (another area of Merseyside). Such concerns over treatment could be discussed with their nurse, but they did not talk to her about this during the period of observation.

4.3 Discussion

As seen from the findings there are difficulties associated with running a hepatitis C support group. Whilst organisations differed on location of a hepatitis C group ('out the way' or convenient), who led the group (staff or peer) and the content of the group (testing or group discussion and buddying), a commonality of people not attending the groups, was found. The reasons behind non-attendance for Group 2 was not uncovered during the observation period but a discussion about this with Group 1 (*John* and *Kath*) illuminated some of the reasons for this in Group 1. *Andy* only attended the group once and *Simon* and *Seb* had stopped coming, *John* said *they've got their own things going on*, *Seb* was *taking drugs again*, *John* was *working and Andy* was *trying to get a house* [Week 8], showing that at that current time, they had priorities other than their hepatitis C. When

discussing the declining numbers *John mentioned that the local services were changing from one organisation to another causing disruption so he would need to go around the services again and put posters up to try and get new members [Week 8].* The changing of services and the difficulties this caused to service users was highlighted throughout the process of gaining access to the field, as well as during the period of observation.

By the end of the observation period, *Kath* was the only group member who was attending. Qualitative research invites us to explore the 'exceptions' as well as patterns of commonality (McPherson and Thorne, 2006; Phoenix and Orr, 2017). Indeed *Kath* was an exception in numerous ways. Not only was *Kath* the only support group member who was observed and then interviewed (as per original study design), she also was the only person who was not dependent on or previously dependent on substances (heroin or alcohol) and therefore was not accessing a drug and alcohol service. Thus Group 1 itself was unusual as it was not connected to a drug and alcohol service, meaning it was open to people who did not attend these services. All other groups and organisations visited for the service user observation and interviews for this research were drug and alcohol services, therefore *Kath* was an exception to all other participants on this research. Throughout conducting this research I discovered that there were no local hepatitis C support groups other than those in drug and alcohol services, showing the lack of support available for people who do not attend these services, and perhaps an explanation as to why *Kath* kept attending this group.

This period of observation has illuminated many interesting points, some which are linked to the original research objectives and others which have emerged during the process. Although the meaning and importance of these findings was not clear at this point in the research, the interviews provided further information and clarification.

Chapter 5 Service user interviews - findings

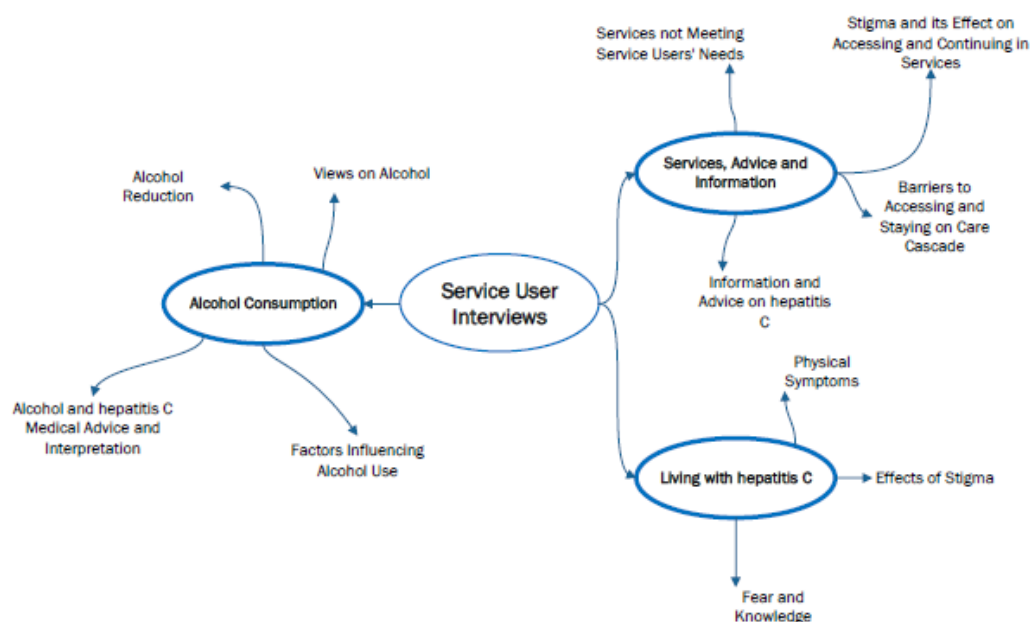
5.1 Introduction

Chapter 5 presents the findings of the service user interviews. In this context 'service users' were people who have injected drugs (either current or previous injecting of psychoactive drugs such as heroin or crack cocaine) and who have had hepatitis C at some point in their lives (either current or previous).

Interviews were conducted at a variety of drug and alcohol services from January to December 2015. Life history interviews were conducted with 21 service users, of which 4 participants had a follow up interview (see Appendix 4 for interview schedule and Appendix 7 for participant characteristics).

The analysis discusses three main findings namely; alcohol consumption, living with hepatitis C and services, advice and information. Figure 4 demonstrates these themes and the corresponding sub themes.

Figure 4 Thematic map for the service user interviews



5.2 Findings

5.2.1 Alcohol consumption

At the time of the interviews, five participants were dependent or high risk drinkers, five were abstinent from alcohol and eleven were drinking amounts classed as lower-risk levels for the general population (i.e. people who do not have hepatitis C), albeit some participants were having the weekly amount on one day rather than spreading the amount across the week as recommended. However as the calendar method enabled lifetime alcohol use to be explored, it found some participants who were currently abstinent or lower-risk drinkers had a previous history of higher-risk or dependent alcohol consumption. Three participants had been dependent drinkers and four participants had been higher-risk drinkers for a period of time during their lives. For some participants this period of higher-risk or dependent drinking occurred prior to injecting drug use (ranging from 8 years prior to briefly overlapping), other participants used heroin and drank at the same time and for other participants drinking came after drug use,

with some of these drinking higher-risk amounts for a short period of time only and others becoming dependent on alcohol.

5.2.1.1 Factors influencing alcohol use

All participants (N=21) were aware that drinking alcohol with hepatitis C increased the risk of liver damage, yet most had consumed alcohol since diagnosis. Only two participants had not consumed alcohol since being diagnosed with hepatitis C, however these participants were abstinent prior to the hepatitis C test and therefore remained abstinent after, so their abstinence was not linked to the hepatitis C diagnosis. Two participants found on testing they had spontaneously cleared the virus. As they had previously had hepatitis C but no longer had the virus, it is not possible to discuss how having hepatitis C affected their drinking, other than to note that this event did not alter their drinking (although one person did stop injecting after this result, however it is not possible to say if this behaviour change was due to the hepatitis C or the groin abscess that had brought this person in contact with health services). *Sadie* had also spontaneously cleared the virus when she was tested, however she explained how she did not understand the result at the time and thought she had hepatitis C, therefore *Sadie* is included, in the 17 participants who drank knowing they had hepatitis C. The participants' narratives showed a mixed response in terms of the recommendation to stop drinking (or reduce if unable to stop) (NICE, 2016b) following a hepatitis C diagnosis. Some participants did reduce/stop drinking, other participants' drinking stayed the same as before the diagnosis and some participants' drinking actually increased during the time they had hepatitis C. This later finding was only possible due to the method employed in this study. As many participants had been living with hepatitis C for several years (ranging from 1 to 19 years) and the calendar method enabled exploration of drinking over their lifetime, it was possible to see that drinking patterns changed over the time participants had hepatitis C. Thus the question of whether being diagnosed with

hepatitis C affects drinking is a more complex one than is previously described in the literature (Chapter 2).

Sadie and *Jack* did not reduce their alcohol consumption following the hepatitis C result. Whilst it is not clear if their consumption increased or remained the same, they explained how they had used alcohol to cope after receiving the test result:

..so I sort of did it on myself and thought look just go and get fucking bladdered everyday...Just go and get bladdered every day, just get wasted and whatever.

(Jack)

Drunk?

(Researcher)

Yeah.

(Jack)

I thought to myself yeah well, I'll just go on right and just do what I've, I thought one little, get permission sort of thing, yeah, drink as much as I can, take as much vodka as I can.

(Sadie)

Both of these participants were consuming amounts of alcohol that would class them as higher-risk drinkers and had received treatment for alcohol use on a few occasions over the years. Therefore these participants would fit O'Leary et al's (2012) findings that those who drank to excess continued to do so following the hepatitis C result. However the research for this thesis found five other participants who did not alter their alcohol consumption after being diagnosed with hepatitis C, which seemed irrespective of the amount drunk. *Neil* for example would go out every

couple of months and binge drink (*'well I went to a barbecue on bank holiday Monday and had 9 cans or 10'*) and *Brenda* just drank at Christmas and continued with that after diagnosis.

Two participants in the study rarely drank alcohol but had a period of higher-risk drinking during the time they had hepatitis C. Thus alcohol consumption increased when they had hepatitis C, however this change in drinking was not linked to the hepatitis C, but to other factors in their life. For *Sharon* this was because she got a new partner who was drinking and for *Ed* this was to cope with numerous family bereavements. *Ed* had been hepatitis C positive for 8 years and *Sharon* for 10 years when they started to drink higher-risk amounts.

Only *Susan* did actually stop drinking, however this was not immediately after receiving the test result but approximately 6 months later, in order to be eligible to receive hepatitis C treatment. Eight participants had reduced their alcohol intake since being diagnosed with hepatitis C, yet the in-depth conversations during the interviews showed this reduction was not wholly attributed to hepatitis C but was actually a decision based on a variety of factors that were of importance to the individual.

I've never really been a drinker Jane [researcher], but especially when I found out I had it [hepatitis C], that's even made me cut down with me dad now, you know what I mean, obviously he's cut down too now that age where he can't drink, he's starting radiotherapy or chemo.

(Pete)

She [girlfriend] was in XXX [rehab unit] for 'er alcohol as well as drugs so it's very, it's not good for me to have cans in the fridge.

(Pete)

[cut down] after I got diagnosed [with hepatitis C].

(Dan)

I might as well move somewhere, where I can just, I don't know any dealers.

(Dan)

I wanna have one night's sleep Jane [researcher] with nothing in me system.

(Dan)

The quotes by *Pete* (who was a lower-risk drinker) explain that the factors affecting his decrease in alcohol consumption were: that alcohol was not his drug of choice; other peoples' (Father and partner) drinking influenced his own drinking; and his positive hepatitis C result. In contrast, *Dan's* (who experienced alcohol dependency) reasons were linked to trying to change his life by stopping all substances as well as the hepatitis C result. Hepatitis C is therefore not a distinct factor in alcohol consumption but intermingled with many other factors occurring in people's lives.

Other participants said they had decreased their drinking for reasons unconnected to their hepatitis C. *Gav* had reduced because he had generally been '*drinking too much*' and had been told to '*cut down*' and *Beth* did not drink very much as even a shandy made her feel '*weird*', which she put down to her other illnesses and medications she was taking.

Thus for the majority of participants, hepatitis C was not the determining factor in drinking practices. For some participants hepatitis C played a partial role in decisions on alcohol consumption but for other participants hepatitis C made no impact on their drinking, regardless of the quantity drank.

This research found that rather than hepatitis C, the main influences on alcohol consumption were: partners drinking, drinking to cope and where participants were in their recovery process from substance use.

The influence of partners on alcohol (and substance use) was mentioned by the majority of participants. Some participants spoke about how their partner's drinking (or drug use) had started their own use.

I'd only have the odd drink now and again, once maybe twice a week, sometimes it'd only be once a week...and then it was when I met this girl, you know, she was drinking, she'd come out of rehab, but then she started drinking again then and we'd go the pub have a drink and then it starts 'oh go the off licence then', and then it got to the stage where I'd wake up in the morning going 'I wanna drink, I wanna drink'.

(Gav)

I was married to a big drinker, but I didn't know and he's an alcoholic, so I drank nothing, then I ended, ended up worse than what he did.

(Susan)

So you've not drank at all and then you started in 2010. Why did you start?

(Researcher)

Urm, I was with a partner who was drinking.

(Sharon)

For Pete his partner not drinking influenced his own drinking.

..me girlfriend doesn't drink, so I don't drink.

(Pete)

However others talked about only being able to reduce or stop alcohol (or drugs) when they were not with their partner anymore.

He went to prison, and I just slowly stopped drinking.

(Sharon)

Yeah, well ur, it was only moderate, I wasn't drinking as much as when me girlfriend was alive, coz we like sort of complemented by each other.

(Kev)

He didn't wanna stop, you know we'd gone through all that where you stop, no I don't wanna stop, I wanna stop, no I'm not, you know, we'd gone through all that and we'd tried like small decreases, but that was the end of it for me, you know, I just thought to myself, I can't, I can't do it. So I ended up throwing him out and he was not best pleased, he said well can't, can't we just carry, I said I can't I can't do it, I can't do it no more.

(Jenny)

These accounts demonstrate the influence partners have on each other's alcohol and/or substance use, showing the complexities of managing their own addiction alongside their partner's. In this research some partners were using the same substances and other partners were using different substances, for example one participant's preference was smoking heroin but his partner was a higher-risk drinker. It is interesting to note that all participants in the study had tried a variety of substances, as had their partners, however their current substance (or last substance in those no longer using) of choice was not always the same substance as their partner.

Studies conducted in other countries (France, Italy, Ireland, USA) have shown alcohol reduction was part of an overall lifestyle change following diagnosis of hepatitis C (Cullen, 2005; Castera et al, 2006; Scognamiglio et

al, 2007, Stoller et al 2009b). In this research some participants changed their lifestyle following the hepatitis C diagnosis.

Started to drink more water, was like one of the things I started doing when I got hep C, drink plenty of water eat fruit and veg and keep away from red meat, isn't it? Yeah keep away from red meat, eat chicken an all that...and I started to walk a lot you know, you know get a bit more exercise.

(Susan)

...my sister's a nurse and she said 'you know the best thing you can do is go on a low protein diet really' yeah and um I know, I sort of did that

(Tom)

changed your lifestyle?

(Researcher)

Yeah yeah tried to keep me fit you know a little bit yeah, walkin to the buses and that yeah,

(Tom)

The topic of living healthily was discussed on three occasions at Group 1, with the group leader advising people to drink lots of water on treatment (week 6) and also advising the consumption of fish oils and healthy food to “*help you live longer*”. However he explained that the healthy eating and wellbeing was all part of a “*journey of starting to look after yourself, when coming off the drugs*” (week 1), indicating that in this research lifestyle advice is not given specifically when diagnosed with hepatitis C but as part of recovery from substance use. This was echoed throughout the interviews. Jenny explained how she started to make changes to her lifestyle as she stopped using heroin but also how the treatment to clear the hepatitis C was the final part of this recovery process from her heroin addiction.

[Talking about stopping heroin] ...because then, I was on a journey there.

(Jenny)

I was with the XXX [drug service] and I was doin healthy stuff then, you know we were going for walks, there was cooking, you know things like that.

(Jenny)

..it [hepatitis C treatment] was getting rid of the, like that was me drug use completely gone then....if that [hepatitis C] was still there, you know if, if that was still there I'd still have that, with me.

(Jenny)

Carrying a bit of your past with you?

(Researcher)

Yeah yeah, it's took, it's all completely gone.

(Jenny)

For the participants in this research the run of events in regards to lifestyle changes and hepatitis C diagnosis is more complex than explained in previous research. Most participants had made changes to their lifestyle before receiving a hepatitis C diagnosis; for example those who attended drug services for Opiate Substitution Therapy (OST) received a hepatitis C test at the drug service, indicating lifestyle changes in terms of heroin reduction took place prior to the test. However the recovery process is not linear and most of the participants had tried to stop using heroin on a number of occasions, some of these attempts prior to the hepatitis C test and others after. It appears for this research that for some participants where they are in their recovery process from substance use affected how

they were able to manage the other lifestyle factors, such as alcohol and diet that are advised in living with hepatitis C.

This finding has shown various factors influence participants' alcohol consumption. Furthermore it has shown that different factors influence drinking at different points in a participant's life, often with multiple aspects having an impact on alcohol consumption at any one time. Hepatitis C is one of the influencing factors of alcohol consumption for some participants, however this was not the case for all participants (although as influences are changing throughout participant's lives, it therefore stands to reason that hepatitis C may become an influence in the future). This finding has also highlighted the complex nature of participants' lives and the difficulties of managing a chronic illness amongst an addiction/s.

5.2.1.2 Alcohol and hepatitis C - medical advice and interpretation.

Throughout the interviews participants discussed the advice they had received around alcohol consumption whilst having hepatitis C. Out of the 18 participants who have/had chronic hepatitis C (3 who spontaneously cleared are not included), 6 said they had received no advice about alcohol from services (hepatitis C service, drug service or GP). However 2 of these 6 people had received information about alcohol and hepatitis C by attending a peer group or a course linked to the drug service. Of those who had not received any advice about alcohol, 2 people (*Rich* and *Steve*) were abstinent from alcohol at the time they were diagnosed with hepatitis C. *Steve* explains:

Did they give you any advice about alcohol?

(Researcher)

Um well I, obviously I was still in treatment [drug rehabilitation] when I went in there [hepatitis C clinic]. My liver functions were out but not majorly so and not so they could have sclerosis or

anything that would, they were just slightly out on the levels and I was, I declared as being abstinent and intending to remain abstinent so I don't know what they might have said if like I'd said I'm still having a drink.....But I mean like they didn't sort of say 'you have to remain abstinent' or anything. But I mean the fact that I've said I don't drink and I'm not intending to drink I think that just sort of covered it straight away so they didn't you know.

(Steve)

However this is not a universal approach as others who were abstinent were given advice:

Did you get any advice about drinking alcohol and hepatitis?

(Researcher)

Yeah don't drink alcohol, it's bad for your liver isn't it.

(Joe)

Conversely, some participants who drank alcohol felt they had not received advice about drinking with hepatitis C. *Ed* for example received a positive hepatitis C test result 19 years ago and had a period of heavy drinking (63 units of alcohol a week for 7-8 months) yet he was unsure if he had ever been given advice about alcohol and hepatitis C.

Have you been told anything about alcohol and hep C?

(Researcher)

Alcohol and hep C, no, no I don't think so. No I don't think so.

(Ed)

Although it is not known if *Ed* has been given advice that he does not recall or whether he has not received advice, an interesting point is made by *Susan*. *Susan*, who was extremely upset when she received her hepatitis C diagnosis, was not sure if she was given information at that time, including if she was given advice about drinking, however she knew she was given information about alcohol and hepatitis C at the hepatitis C clinic which was at least 6 months after the test result, indicating the benefits of ongoing advice.

The majority of participants in the study commented that they had received advice about alcohol and hepatitis C. This advice was however not, ‘stop drinking’, as recommended in clinical guidelines.

So at the time of your hep C test what advise were you given?

(Researcher)

Oh, uh, not to drink, obviously.

(Kath)

Just to completely stop?

(Researcher)

Um, It's not advisable.

(Kath)

It's not advisable to drink?

(Researcher)

Yeah, yeah.

(Kath)

How did you interpret that?

(Researcher)

Oh just stop, if you don't have to don't. I wasn't an alcoholic I wasn't much of a drinker so it wasn't really a major problem for me.

(Kath)

It looks from what we said before, that you reduced, not stopped.

(Researcher)

Yeah, yeah but still if I went out and did sumfin I went to a party or sumfin I still did.

(Kath)

And did you drink less than you did before you got the result?

(Researcher)

Same probably.

(Kath)

Interestingly *Kath's* comments suggest she thought only higher levels of alcohol were an issue with hepatitis C, indicating that the advice she had received was not to completely abstain from alcohol, as clinical guidelines recommend. This is further demonstrated by *Kath*, when she talked about her current hepatitis C appointments.

When you go for your appointments now what are they saying to you? Are they giving you any advice about alcohol now when

you're going?

(Researcher)

They just ask me "what you drinking"?

(Kath)

They ask you yeah?

(Researcher)

Yeah and that I don't drink much. They don't pass any comments really, don't pass any comments.

(Kath)

Demonstrating that although *Kath* is not abstinent, the hepatitis C clinic are aware of this but do not advise her to stop. Although *Kath* only drinks socially (3 or 4 gins once a month - lower-risk drinker for general population) other participants who drink larger amounts of alcohol were also not told to stop drinking. *Jack* was currently alcohol dependent and *Kev* had previously (over 10 years ago) drunk amounts that would class him as a higher-risk drinker but currently drank amounts that would align him to the lower-risk category.

Did they tell you anything about alcohol?

(Researcher)

Yeah don't drink, well, drink but not, excessively.

(Kev)

And what kind of advice do they give you about your hep C?

(Researcher)

Nothing' just ways of like healthy livin', you know sort of, go to the gym, keep yourself healthy, eat, whatever, basically not drink but I drink, that's the problem.

(Jack)

You were told, not drink, none at all?

(Researcher)

No, not basically 'not drink', but you know obviously it's more a problem for ya coz that will damage your liver more if you've already got hepatitis your liver's damaged anyway.

(Jack)

These quotes indicate that across the range of quantities of alcohol consumed, participants were not being told to stop drinking. The only participant that was told to stop was *Susan*, who like *Simon* from Group 1, had to completely stop drinking to receive hepatitis C treatment. However *Kath* had not received the same advice.

Well I was naughty really on the treatment. I don't remember, I just,.. I don't remember them saying it will, it could, I remember thinking don't drink because it's your liver that's damaged, or it, you know, because of hepatitis C, I don't remember them saying don't drink because it [hepatitis C treatment] might not work. D'ya know what I mean? If they said, I'm sure if I'd had a been told, I mean that may not be the reason it didn't work, at all, but um if they'd told me that ur, you know you can take this for 6 months and because you've had a few drinks however, it will have failed and you'll still have it and then have to have treatment again or whatever but um I just remember in my mind it was just don't drink, don't drink if you can help it, because it's your, you now know you've got a condition that affects your liver. Yeah because um, coz I have thought, it has played on my mind afterwards, is that why it didn't work, but um, I didn't drink that much. Oh I don't know, the answer, like I don't know when I got it, I don't know if it didn't work because I had a few drinks.

(Kath)

And have they said when you might have the treatment again?

(Researcher)

Um they said, actually said January this year that they were deciding whether they were going, go ahead with the new treatment. who they're going to give it to probably by the end of this year I can either, if I don't get offered the new treatment, the brand new one, then I can have the old treatment again but for longer.

(Kath)

Try again, and would you drink again do you think or would you...?

(Researcher)

[interrupting] I probably wouldn't, no.

(Kath)

Yeah because in your head you think that's had some impact on it?

(Researcher)

Well yeah it's one of those things that you don't know. If I was say a heavy drinker I'd would say yes definitely, but I mean I know other people that, saying other people, I know a couple of people that I've known from here that have drank during treatment. My ex drank on his treatment, he'd a worse strain than me and he got rid of it.

(Kath)

The lack of clear advice around alcohol consumption led *Kath* to suspect she was in some way responsible for the negative treatment outcome, leading her to make future decisions about alcohol based on her own and peers' experiences rather than clinical advice. *Kev* also demonstrated how he had (mis)interpreted advice he was given.

....but they didn't say stop completely?

(Researcher)

No, no coz you can't stop can ya, when you're drinking all the time, it's um thingio, dangerous to stop but I've slowed right the way down and then stopped.

(Kev)

You have stopped?

(Researcher)

Mm [nodding]

(Kev)

Yeah, you don't drink now?

(Researcher)

No. As I said every now and again.

(Kev)

Yeah I was gonna say, you said before you drank, every couple of weeks, didn't you?

(Researcher)

Its only like 1 or 2 beers. I won't go out and spend a hundred pound on ale, through drink. I'll have like a couple [of super strength cans] or I'll buy meself a 2 little bottle of cider and go and sit in the middle of nowhere.

(Kev)

For Kev his understanding of the message 'stop alcohol' was linked to those who are alcohol dependent, who are at risk of withdrawal symptoms if they stop or reduce suddenly the amount of alcohol they are drinking (NICE, 2010a). There appears to be some confusion here, as his narrative indicated he was not alcohol dependent so therefore could have stopped drinking without experiencing withdrawal symptoms. Also Kev's interpretation of 'stopped' did not actually mean abstinence from alcohol, which was also shown by Kath and was a common finding from the narratives. Indeed eight participants said they had stopped drinking but were still consuming alcohol. I surmise the origins of this discrepancy lie in the interpretation of the word 'drink'. When I spoke about drinking alcohol, I meant any amount of alcohol, however participants interpreted this as drinking excessively, with many participants explaining '*I'm not a drinker*'.

What about alcohol? Do you drink alcohol?

(Researcher)

No I'm not a drinker.

(Beth)

Have you ever drank any alcohol?

(Researcher)

Oh yeah, yeah

(Beth)

A conversation with *Joe* also highlights this:

I've never drunk Jane [researcher]

(Joe)

Never?

(Researcher)

Never drunk no, not a drinker.

(Joe)

You've tried alcohol though?

(Researcher)

Tried alcohol yeah, yeah.

(Joe)

As does one with *Phil*:

...because I don't drink you see. Don't get me wrong if I go out to dinner I'll have the odd pint of lager that's it, a couple of pints and even that's too much.

(Phil)

How often do you have a drink then?

(Researcher)

No it's not a drink drink, it's a drink with a meal.

(Phil)

All three of these examples demonstrate that participants drank, despite saying they had not/did not drink, showing the term was interpreted differently from its original intention. This may be informative for those conducting future research on this topic but also for those discussing alcohol use with service users.

This research has also shown that participants understand the advice on alcohol and hepatitis C to be for those who are drinking ‘excessively’ and not for those who do not drink ‘much’. Although, interestingly when discussing the advice on alcohol consumption for the general population (i.e. for people who do not have hepatitis C), participants did not know the recommended weekly limit of alcohol (drinks per week, units per week, or what constitutes a unit). Therefore when participants said they do not drink ‘much’ they were actually unaware of what safe(r) guidelines are to benchmark their own drinking against. Participants were therefore using other benchmarks (such as other people’s drinking) to judge their own consumption levels.

Although participants were aware that drinking with hepatitis C increased the risk of liver damage, misinterpretations of the effects of alcohol on the hepatitis C virus were evident throughout the narratives. As in Group 1, *Mark and Jack* thought alcohol could cause hepatitis C.

You’re tempting it [hepatitis C] to come back, you know with the alcohol

(Mark)

... it [hepatitis C] can either be there by drink or be there through drugs so, you know that’s what most people don’t understand you know, you can actually get it through drinking without being involved in drugs.

(Jack)

This was surprising as *Jack* had demonstrated a high level of knowledge about hepatitis C throughout his interview and had previously provided training and support around hepatitis C to others. Another misconception was that by reducing alcohol consumption hepatitis C could be cured.

you know you can get rid of it [hepatitis C] yourself if you're not chaotic, um drinking as much, an doin what I'm doin [injecting].

(Kev)

Kev's narrative indicates confusion not only on alcohol use and hepatitis C but also spontaneous clearance of the virus and the role of injecting in hepatitis C.

This research has shown that participants were aware drinking with hepatitis C increases the risk of liver damage, however it appears that healthcare professionals seemingly have not advised the participants to abstain from alcohol. Although the reasons for this are not known, this may be reflective of the inconclusive evidence on the amount of alcohol that expedites hepatitis C. This is discussed in the literature review (Section 2.5.1) and is explored further in the interviews with professionals in Section 6.2. The research has also found that participants interpreted information differently from how it was intended, pointing to the need for clear explanations, checking understanding and revisiting advice on a regular basis.

5.2.1.3 Alcohol reduction

Twelve participants in the study had a history of harmful alcohol consumption (alcohol dependence or higher-risk drinking) at some point in their lives. Five of these participants had received support through a service (either residential or home detox) to reduce the amount of alcohol they consumed, whilst others said they had not accessed a service, but had

reduced their alcohol intake on their own. Some participants did this by simply reducing their alcohol whereas others used substances to help them lower their alcohol consumption. For *Sharon* this was by using a benzodiazepine which she had obtained without attending a service.

How did you stop drinking?

(Researcher)

Um, I just weaned myself down.

(Sharon)

Did you?

(Researcher)

Yeah and took tablets and they helped me.

(Sharon)

What tablets?

(Researcher)

Urm benzos.

(Sharon)

So was it like through a service, that you got the tablets?

(Researcher)

No, no, no.

(Sharon)

You were just using benzos?

(Researcher)

Yeah.

(Sharon)

Other participants had reduced their alcohol intake by using heroin.

So you know you go through withdraw off it, you know withdrawals and that

(Ed)

Off the heroin or drink?

(Researcher)

Off the drink. Still have the heroin or else you go down there as well you know and that experience of withdrawing off the ale, which is horrible you know. I was lucky, I just made a decision, I'm not gonna be like that again, I'm not gonna let it, you know start having cans a day, every day, get like that

(Ed)

How did you stop [drinking] then?

(Researcher)

I just stopped it.

(Ed)

Did ya, just like that?

(Researcher)

Yeah, just like that.

(Ed)

No help from any services?

(Researcher)

No, no like I said I still had me gear [heroin].

(Ed)

Put it this way, I just stopped it, to be honest, I think to be honest the heroin, I know it sounds stupid but the heroin made me stop.

(Phil)

Although both *Ed* and *Phil* had used heroin to help them change their drinking, they had used the two substances in different ways. *Ed* had started on heroin first then had a period of higher-risk drinking (63 units of alcohol a week for 7-8 months) whilst still using heroin and then continued on just the heroin. *Phil* felt he ‘was getting close to becoming an alcoholic’ but then started using heroin instead.

Phil and *Ed* were not under a drug service at the time they were drinking excessively but were aware of alcohol services and decided not to seek help. *Sharon* was under a drug service at the time of her higher-risk drinking (over 100 units a week) but did not want help for her alcohol consumption. *Sharon* also commented in her interview that she was not aware her drinking levels were harmful until she received unequivocal information.

I came here one day and they went mad at me, they said “Sharon you know, you shouldn’t be drinking end of” but I was absolutely bladdered and they said “you know, you’ve got cirrhosis you’ll end up killin yourself” and it did frighten me. So, I mean I could

have had help here with the drinking but I just done it, yeah, yeah.

(Sharon)

Gav, however did want help for his alcohol dependency but was faced with barriers to accessing treatment.

So when they [GP] said, 'you need to reduce your drinking', did they give you help any, refer you to anybody?

(Researcher)

No, they tried to refer me to somebody, and then they said 'well what we can try is a home detox and give you librium', so I said 'OK that's fine, I'm happy with that, the librium' so he phoned up he said 'oh we've got a new nurse starting a young nurse, she's new but she mightn't let you do a home detox', so I said 'why' he said 'well because you're on valium, he said the librium's got valium in', he said 'only a bit, but not much', I said 'well it's not gonna affect me, you know, I'm not gonna go take all the librium tablets' you know, I said 'I will take them properly', you know, but he just that the girl turned around and said 'no I'm not givin him them', so they wouldn't help me with it.

(Gav)

You know when you were saying they were going to do a home detox and then they couldn't, did they suggest you do like a residential detox then?

(Researcher)

No they were saying one time try and get me in XX house [name of alcohol detox unit]. Then they said 'oh there's no places there' so I couldn't go.

(Gav)

Whilst there may be medical reasons for Gav not having a home detox, and waiting lists for a residential detox unit, Gav felt ‘*they wouldn’t help*’ him with his alcohol consumption and consequently did not ask for support again, (although he did managed to reduce his alcohol consumption himself). Although participants may have received support in the form of brief interventions, it is clear from the narratives that participants felt they had not received help and had done it alone.

This research has found that some participants did not receive help to reduce their alcohol consumption, with barriers to accessing support including: the negative impact of previous encounters with services; not realising drinking levels were harmful; and not wanting help for drinking.

5.2.1.4 Views on alcohol

Throughout the narratives, participants talked about people they knew who were alcohol dependent, many of whom had died ‘*from the alcohol*’. Participants often expressed that alcohol was more hazardous to health than heroin.

I think drink’s the worst to be honest, I’ve seen actually more of my mates die in the last year over drink than heroin, crack anything I’ll be honest with ya. I’ve been to about 7 funerals, 2 of them have been me cousins you know what I mean, over drink, I think it’s terrible, I think it’s the worst like, it’s ruined my family.

(Pete)

..but you know, once you’ve seen what alcohol does to people, alcohol’s worse than heroin, it is, and er, no doubt about it, I’ve lost more mates to alcohol then I have with heroin, you know what I mean.

(Phil)

This perception that alcohol is worse than heroin may explain people's defensive comments, such as '*I'm not a drinker*' when I asked about alcohol consumption. It may also partially provide an explanation for the findings from the period of observation (Chapter 4) where support group members suggested people who are alcohol dependent are 'different' from drug users. Whilst people becoming dependent and dying from alcohol use prompted various emotions such as sadness and fear of their own alcohol consumption, there also appeared to be a level of stigmatisation towards people who were drinking excessively from within their own PWID community. For people who are already stigmatised due to their hepatitis C and history of injecting drug use, a further layer of stigma, could potentially isolate people further. Gav explains how his addictions have affected his relationship with friends.

Well sometimes I'm with other people [drinking] but I might just like, coz I don't want no one seeing me doin it, sometimes I might just get a can and just drink [demonstrates hiding the can as he drinks], you know, just put it in the entry [alley] or something.

(Gav)

Why don't you want people to see you drinking?

(Researcher)

I just, don't know, just the way I was, with other things, I don't want people thinking 'oh look at the state of him again' you know, all that, that's what it is you know. There's some people who do, when you get back to them ways, people look down on ya, you know, well some people do, you know, take yer own friends once I was on heroin no one wanted to know me, you know, no one tried to help me, you know what I mean, but all of a sudden when I starting to getting meself together and looking clean and smart an, oh they were all OK then, but I used to just talk to me [inaudible], coz I thought it doesn't work with me like that, you know, I have this thing he didn't wanna know when I was bad [ill], you know, an all of a sudden when I'm OK and that, you know, they wanna be all matey again.

(Gav)

So if they saw you now, with a can?

(Researcher)

You know now if they see me with a can, I don't care, I'd just say to them 'so what' if I'll have a drink, I'll have drink' what are they gonna do? But they don't say nothing now, they just talk to me coz they know I am not lying, I'll only have 1 every now and again so they're not funny with me then, it's strange.

(Gav)

Gav explains how he lost friends when he was addicted to heroin and would lose them again if he became addicted to alcohol. Many other participants talked about how they had reduced their social circle, by leaving their partners or moving to a different area, to reduce their own heroin use, and 'heavy' alcohol consumption could isolate people further.

5.2.1.5 Discussion

The findings on alcohol consumption have shown that patterns of alcohol use and reasons for drinking are varied amongst PWID. Whilst hepatitis C may play a role in decisions on alcohol consumption for some PWID, many other factors also influence drinking, especially over time. Advice from healthcare professionals on alcohol use and hepatitis C appears to be confusing for some service users, suggesting a need for consideration of language and terminology used. Furthermore service users experience barriers to accessing alcohol support. Dependent or higher-risk drinking, also appear to be discriminated against by other PWID who may not be drinking at the same levels, resulting in decreased support from peers and an increased risk of isolation.

5.2.2 Living with hepatitis C

Participants expressed the impact hepatitis C had on many aspects of their lives, not only in terms of physical health, but also emotionally, and in their relationships with other people. Stigma, fear and knowledge of hepatitis C appeared to be interrelated, impacting on people living with hepatitis C and affecting the support they received.

5.2.2.1 Fear and knowledge

As in the support group I observed (Group 1), participants talked about feeling scared by many aspects of having hepatitis C, however narratives predominately focused on testing and diagnosis. Generally, participants feared being diagnosed with hepatitis C, however some participants feared the test itself.

And how did you feel going for your test?

(Researcher)

Scared. Had palpitations, I thought they were gonna take loads of blood off me and XX [staff member] just went 'dink' on me finger.

(Dan)

And pricked your finger.

(Researcher)

Yeah. I was made up she done that, I always thought a needle to take blood off me.

(Dan)

So you were worried about the needle?

(Researcher)

Because you know just one needle and it might just set me off [injecting drugs again]. She said “no it’s just a prick on your finger”. I was made up then.

(Dan)

Dan shows here that he was not knowledgeable about the testing procedure prior to going for the test, causing him to have an incorrect understanding of the sampling procedure which led to him feel scared. Potentially with a better understanding of the test, *Dan’s* fear could have been reduced.

Steve who proactively sought a test, still ‘*bottled it*’ (to not do something because you do not feel brave enough, (Macmillan dictionary, 2017)) on his first attempt to go for a test.

I think they used to do it in detox, they used to do a test, they use to screen you and I asked about it when I was in there and they said they don’t do that anymore, so when I come out I had to get registered with a doctor and it took quite a while and I think I did have an appointment and I ended up, I bottled it a bit and I went and sat in a bookies all afternoon, didn’t go for the appointment to get the test you know.

(Steve)

Showing that despite wanting a test, fear stopped him from attending for the test. Others attended for the test but were then too scared to return for the results. *Pete* explained how he only received his test results because the nurse followed him up with phone calls.

So I went “OK” and done it [hepatitis C test] an....I didn’t go back for the results. I don’t know why, an they started phoning me and I thought “why are they phoning me like”, you know what I mean, I thought like, you know I thought “am I unlucky enough to have it”

(Pete)

.....then you had to get me in there, I wouldn't go back for me results, I had an inkling you know what I mean

(Pete)

That's really interesting to me, you actually came for the test and then you didn't want the result?

(Researcher)

Yeah.

(Pete)

If I've had a blood test done, I want those results.

(Researcher)

[laughing] Yeah, ahhh, no I was the other way round, only when the nurse said "Pete, we need to meet", an I thought, "bloody hell I better get over there", and as I said it was positive.

(Pete)

Like *Simon's* neighbour in Group 1, *Pete* had not gone for his test result as he was scared of receiving a positive result. For the majority of participants the fear of receiving a positive hepatitis C result was linked to a fear of dying.

..me I was shittin meself [scared] coz I thought it's a death sentence me.

(Jack)

..mine come back inconclusive, right, so I went along thinking, oh I've got hep C, I'm gonna die.

(Sadie)

..I, thought you could, well you couldn't live with it basically.

(Kev)

Yeah, I thought I was dying. I was in tears, yeah had to get um, had to get escorted home, from here coz I was in that much of a state, when I got told. ...hearing what I thought was a death sentence.

(Susan)

Jack explained that his reaction was because he'd been tested many years ago, when there was little information and no treatment for hepatitis C. However the other participants who also thought they were going to die from the hepatitis C, were tested more recently, when knowledge of hepatitis C had increased and treatments exist. Neil explains how he was scared due to lack of knowledge about hepatitis C, and was not given information at the time of testing or when he received his positive result.

Well I, I was very scared coz I didn't know anything about it [hepatitis C] at the time. I didn't know what it was about or I just thought it was like, that it was HIV.

(Neil)

So what information did they give you when they gave you the test?

(Researcher)

Nothing.

(Neil)

Nothing...OK and then then you got the results...

(Researcher)

I even remember the day, like I didn't exist, basically I got told I had hepatitis "get out", I thought I was gonna die, they didn't give us a lot of information, didn't tell me it was gonna be alright, didn't tell both of us [Neil and his partner] about the treatment, no and it.....[paused] weren't very nice.

(Neil)

For many participants the reaction to the test result was linked to fear from misunderstandings and myths of hepatitis C transmission, disease progression and treatment. *Sadie* explained about the information she received following her test.

Um, I had the test right and then it come back inconclusive right, do you know what I felt terrible because, erm, I thought well I didn't really speak anything, and I thought they didn't explain when they said it's come back inconclusive right so it means ..you might have hep C, now nobody said to me come back and get another test done, go for counselling and I just thought to myself, I've got hep C.

(Sadie)

Consequently she thought she had hepatitis C and it was not until 4 years later when she was retested that she understood she had self-cleared the virus, (which happens around the first 6 months after transmission only). Both *Susan* and *Neil* misunderstood the course of the disease progression of hepatitis C, thinking that they were going to die imminently:

I thought I was gonna 'ck' [makes noise] conk out and that was it.

(Susan)

Oh god, it was like.. the floor opened up and I went with it, I fell back [when he received the positive hepatitis C result].

(Neil)

Why was that?

(Researcher)

Well because I was scared an, no one told me nothing so I thought immediately I was gonna die [laughs].

(Neil)

So did you think you were going to die quickly?

(Researcher)

Yeah I thought I was just gonna drop.

(Neil)

When asked about how he felt receiving the positive hepatitis C result, *Pete* did not mention death (perhaps because he knew there was treatment-see below), but still reacted badly to the result.

And I was devastated coz I just thought na not me no, I've got to be seriously unlucky to have this an, she said you're negative for AIDS er HIV, and then she saved the last one hepatitis C and I just looked at her and I just expected her to say neg and it was pos know what I mean and I, I cried in front of her, I did, I was devastated.

(Pete)

This account implies there was an element of surprise on receiving the positive result, again leading to questions about pre-test information and his understanding of the risk factors for transmission, as he had previously shared injecting paraphernalia.

The above quotes raise questions about the information given at the pre and post-test consultations and how this information is received and understood by service users. Only one participant reacted differently from all the other participants when receiving her hepatitis C result. *Kath* explained her reaction was linked to her prior knowledge of hepatitis C.

..oh well I've got it, it's not killed me, type of thing, actually it was a bit of a confirmation as to why I get tired so easily. It was a little bit of it, not relief, it was a little bit that way.

(Kath)

Well I already knew about it. I think if, cause my brother'd been diagnosed with it. And he'd had a years' treatment yeah, so I knew what, that was the first I'd even heard about hepatitis C and he told me, so I didn't feel, I knew about it then.

(Kath)

The effect of having knowledge of hepatitis C was also demonstrated by some of the other participants. Participants who initially thought they were dying when they received their hepatitis C result, talked about how they felt about their hepatitis C once they had improved knowledge.

I'm not bothered, now that I know a bit more about it, it doesn't, you know, I've made a mountain out of a molehill basically.

(Kev)

..you don't, well you can die from it like but, it's not as serious as what I thought it was.

(Susan)

It didn't really bother me, once I knew about it, it didn't bother me. I knew that nobody could catch it off of me like, using a cup or glass.

(Susan)

Largely this fear of being diagnosed with hepatitis C was linked to lack of knowledge about the disease and therefore fear of dying but others who knew there was a treatment, feared the treatment itself (interferon/ ribavarin).

I'm still terrified of having the needles for this interferon, I'll be honest with ya I am terrified of them.

(Pete)

I heard people were telling me ghost stories "oh that interferon, the needles like that [showing size of needle with hands- about 30 cms long] they put it in your belly" and that it's like you're havin chemotherapy, you're being sick for a week.

(Pete)

I always ask doctors about it [hepatitis C treatment], if things were available, so I started learning over it. The treatment scared me coz it goes like a cancer drug, where it can make you lose that much weight you can look worse than when you're on smack and crack anyway.

(Jack)

As well as being scared for their own health, participants also frequently discussed their fears about transmitting hepatitis C to other people, (as shown by Susan's quote above), mainly this fear was for partners or children.

I've got a lot of nieces and nephews, they'd be coming round and I'd be knocking about with them, scared. I'm not gonna do something wrong in the slightest but I am dead scared, you know in case one of them has a fall and I was to pick him up, an you know what I mean, anything like that. I had to go tell me sisters about it and they were shocked and, you know they were really

really upset, that I had that, coz you know I got that hep C, and the way they are, I think they're just being cautious, now that I told them about the hep C, 'listen I'll have to take care about the kids, and if the kids do anything like that, you know it can', you know you're always like that, 'take care about letting the kids play, you know letting your kids', the boys come running and want to jump around me. Me sister's telling them 'ok lads, stop it, leave it alone now' you know and they always used to like [demonstrating play fighting] you know and I couldn't do it with them anymore.

(Ed)

How did that feel?

(Researcher)

That's horrible, you know coz you are attracted to it, they're like, even though me nieces and nephews but they're like your own sons and daughters. Yeah so urm yeah that was a bit of er you know a bit of a punch in the face, you know that I couldn't interact like that with the kids no more.

(Ed)

I was just conscious that I had it, knew that I couldn't get a girlfriend, or I wouldn't you know pass meself off onto a girl if I had hepatitis C nothing like that. Obviously you know come clean about it if you did have it but from the point I knew I had it, I just knew that I couldn't have a relationship I just didn't wanna pass it on myself to a female, an unsuspecting female you know. It's not the kind of, you know, it's not the easiest things to say 'oh by the way I've got hep, do ya still wanna see me?' Do ya know what I mean? So I thought 'well that's me relationship snookered'.

(Joe)

Um also I was seeing a girl at the time and I'd waited for my results before you know, before doing anything and I hadn't told her why we hadn't done anything, oh fucking hell you know I actually have got it.

(Steve)

This fear led participants to restrict behaviours in order to minimise the risk of others contracting hepatitis C. Although there is a small risk of contracting hepatitis C through sexual contact (Athwal and Prince, 2017), this risk seemed disproportionately important, with many participants voicing this as a concern and applying unnecessary restrictions. Also as there is no risk of contracting hepatitis C from social contact, there is no reason to avoid play with children. Participants in this research appeared to be going to extreme lengths to avoid others contracting the virus from them. Indeed the extent of *Kev's* fear about his family contracting hepatitis C from him is demonstrated below:

You know I would, I'd kill myself if me daughter got it [hepatitis C], or me mum or even family.

(Kev)

This reaction seems extreme but perhaps representative of the depth of feelings around having hepatitis C.

5.2.2.2 Effects of stigma

Although most participants expressed a fear of dying when they received their hepatitis C diagnosis, some participants did not fear dying but expressed how they considered suicide. *Sharon* talked about her suicidal feelings leading up to receiving her results and *Dan* spoke about considering suicide, once he found out his result.

Worried sick yeah, felt suicidal. I was just terrified to tell you the truth.

(Sharon)

When I did get it [the positive hepatitis C result], I was walking home on Friday an I felt like killing myself. I was in 2 minds just

to throw meself into the docks.

(Dan)

Both explained their reasons for their feelings.

Yeah. What were you scared of with the hep C?

(Researcher)

My family, friends, everythin, me.

(Sharon)

Yeah, what were you worried about with your family?

(Researcher)

Er how they'd treat me.

(Sharon)

Right, yeah and why did you think they wouldn't treat ya?

(Researcher)

Well hep C you know, it was bad when I got it, you were treated like a leper. There wasn't much heard about it, so, you know, it was bad. People stayed away from ya sort of thing, if they heard you had it.

(Sharon)

Felt like killing meself, after me result Jane [researcher], I'll, I'll be honest I felt like just doing meself in, I thought who's gonna like, no one's goin to like me or talk to me and things like that. Well people look at you anyway, weird, you know, I haven't had the hit [injected heroin] for...last year.

(Dan)

And why were you feeling like that?

(Researcher)

Um...I just felt, I'd let meself down, let the family down. I thought do I tell them, do I have a cup at the side or a plastic cup, do I have to wear gloves or mask, when I go into me mums.

(Dan)

Both felt suicidal in connection to fearing being shunned by others when they found out they had hepatitis C, demonstrating the impact of having a disease that is highly stigmatised. Porter (2014) suggests two reasons for the stigma linked to hepatitis C that are demonstrated in the narratives here. Firstly, as hepatitis C is an infectious disease, people are fearful of contracting hepatitis C themselves and secondly because hepatitis C is associated with injecting drug use which is a stigmatised activity. Both *Sharon* and *Dan*'s narratives describe fear around the infectious nature of the disease, with *Sharon* drawing parallels to leprosy and *Dan* describing (incorrect) methods to reduce the risk of transmission to his family. *Dan* also expressed the double stigma he faced, by having hepatitis C and previously injecting drugs. This double stigma was also expressed by *Pete*, who explained how others ridiculed and how this affected him.

I don't know it's embarrassing as well

(Pete)

What are you embarrassed about?

(Researcher)

Just like about stigma, you know what I mean, "You dirty little junkie" you know all of that, an I can't, how can I say well I've only ever had 3 injections, I was unlucky, you know what I mean.

(Pete)

Interestingly Sharon (and Rach below) thought her feelings around diagnosis were due to when she was diagnosed, suggesting that stigma, although still present, had reduced over the years.

Er, no, not many people talk about it

(Sharon)

No. Why's that?

(Researcher)

I think again they feel like, "oh if I say I've got hep C people won't treat me the same" that's what I feel anyway.

(Sharon)

Right. You still feel that?

(Researcher)

No not so much now, I'm saying I feel that's what people think. Coz that's how I used to think.

(Sharon)

Guess that was a while ago though when you had it first but do you still feel a little bit like that now?

(Researcher)

Erm well if I'm in a group I'm the first to say I've got it now, I can talk about it now easy. I might get a bit upset but I'm the first to say I've got hepatitis C and then people will start saying "oh I've got it, I've got it" you know.

(Sharon)

Yeah, yeah, so do you think there's less of a stigma now or not?

(Researcher)

There's not as much stigma but there's still stigma, definitely yeah.

(Sharon)

Yeah, and all of that, that you were saying before about like people not wanting to touch you and all of that, does that still happen?

(Researcher)

Erm yeah I've had people come me house and they won't have a drink and I feel like it's because, well I know it's because of me hepatitis C, you know what I mean, people have told me, that they've said that too them, they didn't have a drink coz I've got hep C. D'ya know what I mean they must think they can catch it off the cups, some people are very naïve.

(Sharon)

However when *Dan* discovered he had hepatitis C, he reacted similarly to *Sharon* despite being diagnosed 14 years later (*Sharon* was diagnosed in 2000 and *Dan* in Dec 2014). Showing the effects that stigma still has on people who have hepatitis C. Rather than opposing these stigmatised views of hepatitis C, participants appeared to uphold the views, repeating the stigmatised ideas.

How did you feel when they told you you had hep C?

(Researcher)

I was devastated because I'm a mother of 4, erm and me mum and dad have never used drugs. They don't even know why I ended up on it, coz I'd never been around it or nothing like that. Urm I don't know it was like it was like urgghh sort of thing. You know it was like uuuurrghh [visibly cringing - screwing up face and recoiling body]. It was like urgh you know one of them. It was discriminated and it was then back then, maybe people are more aware of it now, there's more awareness about it but years ago there was none of that, so, it wasn't somethin like you'd tell people about, it was somethin you kept to yourselfwell it's caught, caught through dirty needles and dirty spoons isn't it so it is a dirty disease. When you think of it like that, it is. That's the way it is.

(Rach)

once I was on heroin no wanted to know me, you know, no one tried to help me, you know what I mean, but all of a sudden when I starting to getting meself together and looking clean and smart an, oh they were all OK then.

(Gav)

Thus instead of challenging the stigma, participants appeared to concur with the stigmatising views of hepatitis C and injecting drug use, further perpetuating the stigma and feelings linked to the stigma. In the quotations above *Rach* talks about hepatitis C being 'dirty' and *Gav* describes being off heroin and looking 'clean', suggesting a connection between heroin and looking dirty. Perhaps explaining why participants frequently mentioned being clean throughout the narratives, (*'erm I'm always clean looking'* (*Dan*)), as if in defence of not being 'dirty'. For *Beth* the stigma of having a 'dirty disease' stopped her from disclosing her hepatitis C status to anyone in her personal life except her sister (who had also injected drugs and tested positive for hepatitis C).

Well yeah. It's only me and me sister that know I've got hep C. I'm too scared to tell the family.

(Beth)

Why what you scared of?

(Researcher)

I don't know I don't know. To me hep C is like HIV or AIDS, do you know what I mean, it's got that... yeah, yeah, yeah.

(Beth)

Right. Why haven't you told anyone else?

(Researcher)

Oh no I'm too scared, too scared.

(Beth)

What are you actually scared of? You don't have to answer me if you don't want to.

(Researcher)

It's, as I say its, hep C to me it's one of them "Oh disease, urgh don't touch nothing" Do ya know what I mean? And I'm, the cleanest person on the planet, everyone in our house says I've got that OCD, you could eat off the floor, I'm that clean, but yeah it's just a dirty disease and I'm you know that I'm saying oh I don't want to tell anybody who'll go "oh dirty disease" that's the way I think and I don't want them looking at me "oooh".

(Beth)

Right and do they know you injected?

(Researcher)

Yeah, yeah, yeah.

(Beth)

And are they OK with that?

(Researcher)

And they're ok with that, yeah, yeah [laughing].

(Beth)

Hep C's just a different level?

(Researcher)

Yeah.... Oh, but no it'll stay with me to me grave.

(Beth)

Disclosure of hepatitis C and fear of others finding out was a common theme throughout the narratives, with participants expressing how stigma affected access to support. *Rich* felt unable to talk about his hepatitis C even to healthcare professionals, affecting the amount of professional support he could receive and *Phil's* narrative explained how stigma of hepatitis C affected informal support, increasing the risk of becoming isolated.

Many years I didn't care about that. I really didn't care. I tried really forget about I've got something. I tried to not think about that, you know, that was madness.

(Rich)

Why didn't you wanna think about it?

(Researcher)

I was full of shame, guilty to even say something about, you know, to my doctor, to whoever, 'I've got hep C'

(Rich)

How does it feel knowing there's a new treatment?

(Researcher)

Oh it's very good, specially when, you know, you're fed up, you see one thing about having hepatitis you feel kind of like a zombie. That you're infected and you can infect other people. You feel it, that's the only thing, you know, put a bell round your neck ding ding, ding ding, like a leper. And you can't help feeling it and you know when you tell people, people that are clued up are ok but some people that haven't got a clue are kind of "Oh OK" you know what I mean, kind of sitting back as if you're gonna pass it on, which you know its hepatitis B, is the one that you can catch through paper cups or from you know, it's very easy to catch, which anyone can get, any walk of life, hepatitis B in water and anything but hepatitis C is definitely blood to blood, you know what I mean an people don't understand that. It's like when AIDS came on people didn't understand about that either did they, they thought you just look at someone and you can catch it, you know what I mean, an you know it's just a bad thing all round, but you feel like a leper an erm you know you're scared of people. With the hep C for you're worried about them finding out about you know, you just feel really kind of erm, what's the word er cut off by it. You're worried in case people find out kind of thing. You just don't want people to know, you know you tell your close people but you don't want everyone to know do ya? There's no need for everyone to know, you know what I mean, like Joe Blogs down the shop, you know you won't be going in with a syringe full of blood, so you know what I mean, the thing is you're goin in there and you just wanna do your everyday jobs just get on with it, but the thing is, it's like a disability in a way, you can't do things coz of it.

(Phil)

Kath was the only participant who did not feel stigmatised.

You've not mentioned stigma at all out of everything we've talked about.

(Researcher)

No I know a lot of people talk about it, it's weird in the drug world, it's like hepatitis C blah blah blah I think well they're already addicts so why's hepatitis C such a big thing? I mean I don't go around telling people cause most of the people I know or work with they wouldn't have a clue what it was anyway, they just wouldn't. I mean have told a couple in work, that I'm close to, they just didn't have a clue. And um.. so I haven't felt labelled.

(Kath)

Although the reasons for *Kath* not feeling stigmatised are unknown, it is worth noting that she was the only participant who had never been dependent on heroin. Although *Kath* did inject heroin she did not identify with PWID.

Because there must be people like me that haven't, yeah that have caught it in other ways or don't know how they've caught it, non-drug users that have got it.

(Kath)

This suggests that stigma associated with injecting drug use, may be related to those who become dependent. Moreover like the alcohol stigma from PWID who drink lower-risk levels towards PWID who drink at higher-risk levels/are dependent, this indicates that there may be stigma between non-dependent and dependent drug users.

5.2.2.3 Physical symptoms

Throughout the interviews, participants talked about the symptoms of hepatitis C. Whilst some participants experienced no symptoms, others had aching, tiredness or a 'fuzzy head' (forgetfulness and decreased concentration - which was also mentioned in Group 1).

Jaundice ('going yellow') was however the most frequently mentioned symptom, either in relation to their own or other people's hepatitis C. Whilst this was the most commonly discussed symptom, participants seemed unsure of its significance, asking questions such as 'do you definitely go yellow when you've got hepatitis C?', or saying 'I didn't go yellow', showing a lack of knowledge on symptoms of hepatitis C and seemingly questioning their own diagnosis. Despite the uncertainty, jaundice was however used to identify other people as having hepatitis C.

I got it off me bird didn't I. When she got it off a fella....She was using needles, I didn't know. I just got it being with her know what I mean. I don't blame her because you don't know you've got it. I have seen people go yella, I've seen, but I never went yella and me bird never went yella. The lad that she got it off he went yella. He died in the end know what I mean. But like he went yella, but the one he passed it onto was my girl she passed it on to me and but she never went yella and I never went yella....you don't automatically go yella do ya?

(Mark)

but um I remember going quite yellow over some periods, an I remember the attacks of the hep C, I'd be aching an all that but just get through it

(Tom)

I was hearing all the lads in the hostel at the time "oh he's got it, he's got hepatitis". So I was thinking, "I've shared needles, I've shared spoons, with these", you know what I mean.

(Pete)

What were they saying about these people, you know the lads in the hostel?

(Researcher)

Just er .. “see there such and such, dead yellow his eyes, he’s yellow” un you get that off [hepatitis C], it’s one of the symptoms in it.

(Pete)

Whilst there are numerous causes for jaundice, narratives showed jaundice as an indicator of hepatitis C, highlighting those who (potentially) had the virus and causing service users to consider their own risk.

This situation is reminiscent of other infectious disease such as leprosy, where visible symptoms identify people as having the disease, which historically (and currently in some countries) causes others to fear for their own health, and in turn marginalises those who experience the disease, making it harder to seek medical attention and receive treatment which can cure the disease (Seddon and Seely, 2006). Whilst this research did not seek to explore the experiences of those with jaundice, the labelling of those who are ‘infectious’ is evident, with the narrative from *Pete* showing an element of gossip rather than sympathy towards the person who (potentially) has hepatitis C. Within our culture sympathy would be the normative response towards people suffering from a disease, yet this is not evident here, perhaps due to hepatitis C being a stigmatised disease.

Except for jaundice, participants were generally unsure of the symptoms of hepatitis C, questioning if how they were feeling was a symptom or identifying unlikely symptoms.

I haven’t got a clue. I’ve got that many things wrong with me. I

feel, I don't know what's the matter with me, so I don't know whether it's that [hepatitis C]....Haven't got a clue.

(Brenda)

Do you feel ill with it [hepatitis C]? Do you get symptoms?

(Researcher)

Well, I don't know what it is, no one's actually told me how you feel when you've got it, coz there's times, specially in the last 2 months, where I've actually like, it's been when I've had an argument with me girlfriend as well, and she's gone home and I've been there on me own and I don't know whether it's me head working but it's like me blood's boiling inside and urgh it's hard to explain, not like pins and needles going round and I'm thinking "is that the hepatitis C starting to, have a kickin in me", do you know what I mean, am I just worrying about nothing coz I've had a fight with me girlfriend, am I just paranoid coz there's, no like I don't know. You know I, all's I heard was, you go all like, oh you look yellow [jaundiced] you know. Did you hear that about going yellow? Your eyes are yellow and all that like, I've never gone yellow, but as I said, just twice in the last couple of months where I, I've just felt "argh I don't feel right here like".

(Pete)

I know I've got hepatitis C but I don't know what all the symptoms are...I don't know nothing, nothing. I know one symptom I've been told that your stomach swells. That's all. That's it.

(Beth)

Do you think you've got any symptoms?

(Researcher)

I don't know but me stomach has swelled here [indicating umbilical area of abdomen]

(Beth)

Both *Pete* and *Beth* described and worried about symptoms that were unlikely to be linked to the virus ('blood boiling' after an argument and swollen umbilical area of abdomen). *Beth* had learnt about the stomach swelling (presumably ascites) by another patient in a hospital waiting room and *Pete* gained his knowledge of symptoms from other people he lived with in a hostel. Thus they (and other participants including *Brenda* above) had not discussed symptoms with staff involved in their care, but interestingly asked me as the researcher about symptoms.

Kath experienced tiredness which affected her both mentally (forgetful and reduced concentration) and physically. For *Kath* this tiredness was the worst aspect of having hepatitis C, due to its impact on her quality of life.

Tiredness and fuzzy head, I get a lot of that

(Kath)

Fuzzy head as in headache or?

(Researcher)

No just get forgetfulness it's connected. It's like forgetfulness, tiredness, lack of concentration, general unawareness of what I'm doing half the time, you know like leaving things, forgetting things and just tired, like, they'll be something I'll just get these zonk feelings, really tired.

(Kath)

Sometimes I felt like you know work was dead hard, and I thought, should I have to work with this bloody thing [hepatitis C] it gets me so tired, you know, should I be able to work part time or take it easier but financially it just can't be done really.

(Kath)

Yeah I think working full time is not the best idea, but you have to, cause it means your energy is used in work and then I'm really tired when I go home then and then my mood just drops and I can't be bothered with this and can't be bothered with that, always feel like I have to push myself to do the most mundane things, you know pushing myself whereas I remember on the treatment [hepatitis C treatment] I got like a burst of energy. Still had side effects [to hepatitis C treatment] but I started feeling really good at one point and I was thinking bloody hell if I feel like this all the time that would be great.

(Kath)

Unfortunately the hepatitis C treatment did not work for *Kath* so she still had hepatitis C at the time of the interview. Despite *Kath* struggling with fatigue which affected her both at home and at work, *Kath* had only told a few close friends at work that she had the virus. Whilst *Kath* denied experiencing stigma related to the hepatitis C, her lack of disclosure to managers at work, leads to questions on whether another less stigmatised chronic disease would have been divulged and more support provided.

5.2.2.4 Discussion

This section has highlighted some of the challenges of living with hepatitis C. There appears to be a correlation between lack of knowledge and fear. Participants' narratives demonstrated how not knowing about many aspects of hepatitis C, such as testing, treatment, prognosis, disease progress and symptoms, caused fear and worry. Stigma was also omnipresent. This affected participants self-esteem but also impacted on disclosure of a hepatitis C positive status. Ultimately fear, lack of knowledge and stigma were factors that impacted on the support sought and provided, to those living with hepatitis C.

5.2.3 Services, advice and information

5.2.3.1 Information and advice on hepatitis C

One of the objectives of this research was to establish where PWID obtain information on hepatitis C and what that information was. Findings on this topic showed that the service users accessed information and advice from a variety of sources. Television was mentioned by some service users, either from watching medical documentaries, or programmes about celebrities who had hepatitis C.

So what do you know about hep C?

(Researcher)

That it makes your liver bad. It goes worse after um a time. It was on the telly

(Brenda)

Right OK. Why was it on the telly?

(Researcher)

It was something to do with that Baywatch woman

(Brenda)

Oh Pamela Anderson

(Researcher)

Yeah something to do with her

(Brenda)

Leaflets, books and the internet were also mentioned, however the majority of participants had learnt about hepatitis C from verbal sources.

For some participants this was from others with hepatitis C, either informally from friends and acquaintances, or in more formal peer support groups. The majority of participants mentioned attending courses at drug services or in prison and some participants had received training to be peer workers. Verbal information was also received from healthcare professionals.

There were however barriers noted with many of these sources of information. For the internet, there were varied levels of computer literacy amongst participant. Some participants searched the internet, others were receiving training, but many others mentioned that they could not use computers. There was also a level of scepticism of the information available on the internet.

when you read the internet you've gotta think what's the pros and cons, something that's said is gospel one minute can become different the next.

(Phil)

I think those places like the internet you know you can get a lot of information about that, but somebody said to me 'Rich don't read you know nothing what you can find on the website because a lot of bullshit you know so go to a doctor and speak with him about if you've got any questions what's going on or how it is'

(Rich)

and do you feel comfortable doing that?

(Researcher)

Yeah, especially if this doctor person is, you know, a [hepatitis C] specialist

(Rich)

Kev feared using a computer in public due to the risk of stigma and discrimination of having hepatitis C

but I haven't had a look at hep C because I can't get a computer free enough. I don't wanna go in the library and have a look at it

(Kev)

yeah. Why's that?

(Researcher)

because, well, coz people will be saying "oh look at him having a look at that", you're studying, so it's not like, between you and me you could tell I'm doin what I'm doin and you're just on the computer and studying

(Kev)

What do you mean?

(Researcher)

You can tell I use by the vital signs like, I don't know, but yeah

(Kev)

Learning about hepatitis C 'in public' and stigma was also mentioned by Pete.

Well you know, to be honest Jane, I'd take the leaflets and you know, when you're in the waiting room and all that I was too terrified to read them and I didn't want people to see me reading hepatitis you know leaflets, you know the stigma and all that and when you got home then the leaflets went in a cupboard.

(Pete)

Pete also did not read the leaflets in private at home. Later in his interview he explained his partner did not know he had hepatitis C therefore he hid all information about hepatitis C from her.

The efficacy of leaflets is questionable, as *Pete* did not read them and *Kev* had misinterpreted the information.

I didn't know anything about it [hepatitis C] and then I researched, I done some studying into it, well not studying, but me own leaflets and that and then I realised you, you can get rid of it yourself if you're not chaotic.

(Kev)

Tom felt attending groups was the best way to learn about hepatitis C.

Coz there's leaflets and there's posters around isn't there when you go to the services

(Researcher)

Um I think it's only when you do the groups that you learn about it really

(Tom)

A number of participants mentioned receiving information from healthcare professionals, however sometimes service users did not understand what health professionals were saying. This meant that participants left consultations without understanding the information that they had be given about their illness/care. The use of medical terminology rather than 'lay' terms was one such barrier.

So what information did they give you at the hospital?

(Researcher)

I remember this conversation with that woman and she showed me everything on the computer but I have to be honest with you, she spoke with me that language you know, with that crazy amazing words so I just 'ok', 'ok' but I ask 'everything alright with my liver? I don't have to worry for now about that?' she said 'yeah you don't have to worry about that' so that was for me enough you know to calm down

(Rich)

So you didn't understand some of what she was saying?

(Researcher)

Yeah exactly

(Rich)

Didn't you feel you could ask her?

(Researcher)

Yeah I feel because, I feel bad, but really that language what this woman spoke to me was little bit you know, I need to read some medical books to understand them

(Rich)

Participants also mentioned that they were not always provided with information that they needed. *Steve* had not received enough advice on transmission, *Pete* had questions about treatment and *Kath* wanted more information on living with hepatitis C. *Kath* also noted the manner in which advice was provided was clinical in nature, lacking a supportive quality.

thought they might mention more about, coz I was living in a shared house and like if I cut myself shaving to me I'd really panic. I didn't really know what to do, I didn't know whether you just wipe the blood up and then you have to sort of like, I thought

they might give you more advice about how, about that sort of thing about blood you know, how to be careful with, with that but I don't think I've ever really had any advice on that, that would be the one thing that really concerned me that I didn't really know how to approach you know

(Steve)

I wouldn't mind just hearing what is this interferon ur, how big is the needle, is it like chemotherapy, alright I know you don't lose your hair but your sposed to feel like crap, for the week after it, sick and vomiting an run down and it lasts you know the course lasts for 6 months

(Pete)

There wasn't much um, basically all I've ever done is just seen X [nurse] at the clinic. Her telling me, I'm gonna be on the treatment for so long, side effects, no I think she's busy, she's clinical in what she has to tell you. I think there should be like, how to manage and what the future could be like and stuff like that. There's not much sort of, I'd say there's no nurturing around it. D'ya know what I mean, it's a bit empty really.

(Kath)

The participants also gave examples of incorrect information they had received from healthcare professionals. These were mainly linked to spontaneous clearance of hepatitis C. *Brenda* was diagnosed with hepatitis C in 2005, so was in the chronic phase of the virus where spontaneous clearance is not possible.

Have you found out any more information about hep C since we last spoke?

(Researcher)

I went to urm XX [hospital] and they said to get tested again coz it can just go away on its own or something. I think that's what they said but I didn't know where to come

(Brenda)

Was it a clinic for your liver?

(Researcher)

No it was for something else, it was to see a specialist for something, think it was me bones or something, they said to get retested

(Brenda)

However, as found in the Section on alcohol advice (medical advice and interpretation; section 5.2.1.2.) participants noted that the timing of information was important. *Jenny* noted that she was only able to focus on hepatitis C when her ‘*mind was clearing from the drugs*’ and ‘*you take little, little bits each time that you go there [services].*’ This indicates that healthcare professionals may need to give ongoing advice to service users.

5.2.3.2 Barriers to accessing and staying on the cascade of care

As discussed previously (Section 2.2 in the literature review) the cascade of hepatitis C care is, testing and diagnosis, being linked in to hepatitis C specialist care, accessing treatment and achieving the desired outcome (achieving SVR). This section considers the first three steps from testing to accessing specialist hepatitis C services and treatment, which was discussed by many participants during the interviews. Many participants gave examples of situations where they had encountered barriers to accessing support for their hepatitis C. Commonalities in experiences were described and are highlighted in this section through discussion of the experiences of two participants (*Steve* and *Beth*).

For some participants the difficulties started at the beginning of the cascade of care, when trying to access a hepatitis C test. *Steve* took the initiative and actually asked for a test whilst in residential rehabilitation

for his drug use, but the service was not provided. Instead he had to register with a GP and attend the GP practice in order to be tested. This could have been a different outcome if *Steve* had not attended the GPs. *Steve* was determined to get tested and the impetus was on him to push for a test, rather than the service being easily accessed and healthcare professionals being proactive in this process.

Other participants wanted to be retested as had been diagnosed many years ago but had not progressed along the cascade of care to receive treatment.

Beth was diagnosed in 2002, and at that time saw hepatitis C specialists in secondary care but did not receive treatment.

And then ...I was going on appointments and I used to go there regularly, go and get me bloods checked and used to send me to scans but when they assessed me she went "you're not fit to start the treatment" [interferon based treatment] and then I just, faded then

(Beth)

And did you stop going to the appointments or did they stop the appointments?

(Researcher)

Well there was nothing they could do because mentally and physically my health was in a, bit of, through drug use and me dad dying and that, I wasn't strong enough to start the treatment so I just never went back

(Beth)

Beth wanted a retest yet despite regularly attending the drug and alcohol service and talking to healthcare professionals about testing, she did not know how to get retested. She also did not want to visit her GP for a test.

when I was talking to the doctor [at drug and alcohol service] before Christmas, I was telling him that I have hep C but it's been years since I've been looked at again and he said that he'd get me tested again in the New Year and we'll go from there but he left. He's gone and there's not a doctor here no more so, I don't know. And 2 weeks ago I was here [at the drug and alcohol service], I was telling them and XX (staff) said "there's a thing [testing] going on tomorrow in a place in town, do you want to call in?" and gets in me car and I didn't have me phone, so when I got home there was a phone call with an unknown number and I didn't have no one's number so I missed that.

(Beth)

Ahh. Yeah. Would you think about going to your GP?

(Researcher)

No, no. Oh I don't like him. I don't like him [Laughing]

(Beth)

Why?

(Researcher)

[Laughing] I don't know, I don't like him. No. No. I'll ask XX [keyworker] and she did say there's a nurse in here who does the bloods and that. I've never seen her, but on me next appointment I'll just say XX [keyworker] make me an appointment to see XX [nurse] then. You know give me any numbers so I can phone.

(Beth)

In the second interview with *Beth* 6 months later, there had been no progress in receiving a retest. *Beth* attended the drug service monthly to meet with her keyworker and receive her methadone script, yet she had not mentioned her hepatitis C and neither had the healthcare professionals, and she still did not know 'where to go' for a test.

So I was going to ask you, since I saw you last, which was June, what's happened about your hep C?

(Researcher)

Nothing

(Beth)

Have you made any enquiries or anything?

(Researcher)

No

(Beth)

Have you spoken to the people here [at drug service]?

(Researcher)

No

(Beth)

Have they spoken to you about it?

(Researcher)

No, no.

(Beth)

So last time you said you might go for another test, have you thought about that again?

(Researcher)

I don't know where to go. I got told there was a nurse in here but I don't know

(Beth)

If the drug and alcohol service were able to provide testing, *Beth* could have been tested at the service when she asked about receiving a retest, but again like *Steve's* example, the service was not available and the healthcare professionals were not proactive.

Beth had previously been under the hepatitis C service at the hospital in 2002. Routine practice is for hospital doctors to write letters to patients' GPs on discharge from hospital, or after an out-patient appointment, therefore *Beth's* GP should know her positive hepatitis C status, but hepatitis C is not mentioned by the GP when *Beth* attends for other issues such as a 'water infection' and *Beth* does not mention hepatitis C to her GP. Also during the interviews *Beth* talked about discussing hepatitis C with hospital doctors, who, although they were from a different speciality (respiratory as opposed to gastroenterology/hepatology), did not sign post *Beth* regarding her hepatitis C.

So what happened then [after she stopped attending the hepatitis C specialists at the hospital], did they keep in touch with you? Or did your GP keep in touch with you?

(Researcher)

No nothing

(Beth)

Or did you keep in touch with them?

(Researcher)

No

(Beth)

You didn't receive letters from the hospital or from your GP?

(Researcher)

Nothing, no and it just never bothered me and I never thought about it and back in 2012 when I was in [hospital], when I had a bad flare up [of COPD] and they'd sent me for an x-ray and that and the doctor come back and he went 'have you got problems with your liver?' and I went 'oh god yeah I was diagnosed with hepatitis C' so I don't know if it's got bad or but they've never like questioned me on it or delved into anything since they've told me I wasn't fit enough for the treatment that was it, that was it, no more clinic nothing.

(Beth)

Right and in hospital in 2012 when he said 'oh you've got hep C' and you said 'yeah I know' are they following that up now

(Researcher)

No, no

(Beth)

No appointments or anything?

(Researcher)

No.

(Beth)

Have you asked them, 'what are you doin about my hep C?'

(Researcher)

No, no. I'm too sacred

(Beth)

What are you scared of?

(Researcher)

it's the way the system is an. We were only talking the other day, not about hepatitis C, about all these you know cancer an all that, the way that I see the system now is unless you've got money no one will investigate nothing, who do you go to, to investigate, if I wanted to look further to see how much more damaged me liver is, how long it's got left, where do I go, what do I do. I don't know.

(Beth)

Well I guess I'd probably go to my GP, but last time you said to me that you don't like your GP, you wouldn't go, can you tell me a bit more about that?

(Researcher)

I don't know, I just, I don't like goin to him.

(Beth)

Is that just about your hep C or you don't like goin to him in general?

(Researcher)

I don't like goin in general. If I, I just don't feel comfortable with him. I've got to be on deaths door before I'll go and it's just I'm in there with what I'm goin for, like if I've got a water infection or what have ya, I'm in and I'm out. If I was to go to a clinic where it specialises for the hepatitis C then I'd feel comfortable

(Beth)

*Right that's really interesting thank you for that information.
Does your GP know that you've got hep C?*

(Researcher)

*Well it's on me medical files in XX [hospital] and every time
you're in hospital they get a copy of..., so I haven't got a clue*

(Beth)

*So they might know, but they don't ask you when you go about
your water infection*

(Researcher)

No, no, no.

(Beth)

Both participants narratives demonstrate asking for a test and it not being convenient to obtain. It may be that *Beth* does not need retesting, however *Beth* wants to speak to a specialist about her hepatitis C, yet healthcare professionals are not facilitating this linking-in with specialist care.

These examples show moments of lost opportunities, where service users ask for a particular service but are not able to receive it easily or quickly. This barrier was evident throughout the wider interviews.

Despite there being over 10 years between *Steve* and *Beth* being diagnosed with hepatitis C, both had an unsatisfactory experience when receiving their test results (as had many other interview participants).

Yeah I knew I was being tested but while I was in the hospital they

didn't come round and say "oh your test has come back and you've got hep C". It was just another appointment months later under a different Dr and just going through my history and "oh you've got hep C" and I said "what?"

(Beth)

And what did the GP do after they told you the [positive hepatitis C] results?

(Researcher)

Yeah they referred me straight to the em, it was quite good actually, they referred me straight to the specialist clinic in the hospital and I had an appointment there within..., I can't remember, I think it was within like 6 weeks, it was that soon and then I went for the appointment there and because I'd only had the one [antibody test], I'd only been clean at that stage for 4 months and I'd had 1 positive test, so it can be acute hepatitis can't it where it can come and go within the 6 months so it was theoretically possible I picked it up in the last month of using. So they wanted to wait 3 months, have 2 positive tests, so I had to go away and come back 3 months later. Went back 3 months later, did the test, went back another month for the results and they'd lost the tests

(Steve)

At the hospital?

(Researcher)

Yeah and they hadn't rang me in between, you know, the months that I'd waited, so I had to do another test and wait another month before I started treatment but, yeah I ended up starting treatment [interferon based treatment]

(Steve)

It appears in Steve's case that staff were taking bloods but not checking for the results, meaning the situation of the lost tests was only established when Steve attended an appointment a month later. Steve had already

waited a few months for his results and then had to repeat the test and wait for results again. Barriers to receiving hepatitis C treatment for people who use drugs or drink alcohol, include professionals' concerns over service users levels of engagement. However in this case, the service user (*Steve*) could have concerns over the healthcare professionals' 'level of engagement', whilst *Steve* himself demonstrated high levels of engagement to stay in the process and eventually receive treatment.

Despite *Steve's* experience with testing, he praised the pathway from his GP to the hepatitis C specialists at the hospital, along with the nurse who provided his hepatitis C treatment, as she would wait for him.

waiting 'til the end of her shift when the appointments were actually finished to deal with me like, they were really good there, they sort of accommodated around my schedule as well yeah

(*Steve*)

Two other participants also experienced a 'good system' from GP to the hepatitis C specialists in secondary care. However it is interesting to note that all three participants had attended the GP actively requesting a hepatitis C test, rather than the GP suggesting testing.

For *Beth* the pathway from primary care to secondary care had not run as smoothly. Whilst she did not attend her GP for a test/referral to secondary care, healthcare professionals (GP and staff at the drug service) had also not facilitated this process. Unfortunately *Beth* was not the only participant who appeared 'stuck', without progressing through the cascade of care. Many other participants talked about not knowing what was happening about their hepatitis C, or what steps to take to start the pathway to receiving treatment, despite attending their GP and regularly meeting with keyworkers and other healthcare professionals (doctors, pharmacists, nurses) at drug services. This lack of linkage to specialist hepatitis C care poses a major barrier for participants to fulfil the later stages of the care

cascade, thus accessing treatment and the opportunity to be cured of hepatitis C.

One participant (*Phil*) had been through treatment (interferon based) before, but the treatment had been unsuccessful and he had not achieved SVR. However he praised the hepatitis C clinic at the hospital:

they were great, they phone you up on your phone and everything

(Phil)

What for?

(Researcher)

To make sure I turn up

(Phil)

Oh to say 'come for your appointment'

(Researcher)

Yeah 'you coming?' Are you definitely gonna come to this appointment? but they were great in the hospital they really were

(Phil)

At the time of the interview he was waiting for treatment with the new interferon free regime (DAA). '*..they reckon about a year or so, I will get the go ahead, [for DAA treatment]*'. Whilst waiting for the treatment he attended the hepatitis C clinic at the hospital '*every 6 months, go down and just talk to them*'. This example shows whilst *Phil* was also not currently moving along the care cascade as he was waiting for treatment, he was well informed and knew what was happening with his care. He was

having regular contact with the specialists and communication from the clinic/hospital was proactive in keeping him in the system.

The quotes above demonstrate difficulties participants faced in navigating the healthcare systems in order to access and be maintained in hepatitis C services. However participants were not assertive in expressing their needs. Seemingly *Beth's* GP and support workers do not regularly ask her about her hepatitis C, she also does not ask them. One reason for this was fear of discrimination, which is discussed in the following section.

5.2.3.3 Stigma and its effects on accessing and continuing in services

Discrimination from professionals working in services was expressed throughout the interviews. Some participants felt they were discriminated against because of their drug use, others felt the discrimination was due to having hepatitis C, and for others the issues were more intertwined, experiencing discrimination against both opioid use (as well as opioid substitution therapy - methadone) and hepatitis C as professionals made connections between the two.

Beth had experienced discrimination from a health professional whilst staying in hospital. The impact of this was that she was wary of talking to other health professional about her hepatitis C.

So last time [previous interview] when you were leaving you said 'oh its really nice to be able to talk to somebody' I think you said you felt a bit relieved that you'd spoken to somebody about it [hepatitis C]

(Researcher)

Yeah, yeah

(Beth)

So can you tell me a little but more about that?

(Researcher)

I don't know because you're someone that's doing research and you know about it, I feel comfortable talking about it to you, where I don't know, I'm scared of people looking at me as if I'm dirty and you know 'oh she's got a disease'

(Beth)

Even the health professionals though and the drug professionals?

(Researcher)

Yeah, yeah, some of them yeah, yeah, yeah...Because when you go into hospital, I mean don't get me wrong they're brilliant some of them but others they're like, I don't know, they just when they hear of methadone knowing you're a drug addict they look at you differently and treat you differently I've found

(Beth)

Right and hep C?

(Researcher)

Yeah yeah because years ago I was in XX [hospital] me toe had swelled up and there was this male nurse there and like 12 months beforehand me sister was in hospital and this male nurse got close to me young sister and I knew him and when he found out I had hepatitis C he run to tell other nurses 'oh she's got hepatitis C' and I thought, d'ya know what I mean, so that's what puts me off telling....you know, other people, because the way he reacted I thought 'oh my god'.....

(Beth)

Sharon felt discriminated against because she used drugs. She had previously attempted to receive hepatitis C treatment but had been unsuccessful. She felt this was because she used drug at that time.

I went to the hospital a couple of years ago and I had an appointment there and they said they only gave it [hepatitis C treatment] to certain people and I felt.....erm how can I put it, victimised and I thought why not me, alright I was using [drugs] but I wasn't a bad user and I was fobbed off definitely, I could have been treated years ago and they didn't do it

(Sharon)

You know when you said certain people got it, who was getting it, who was getting the treatment?

(Researcher)

Er people that didn't use [drugs]

(Sharon)

During the interview Sharon explained how she had recently come out of prison. Whilst in prison she had spoken to staff about her hepatitis C and the prison had referred her to the hospital for hepatitis C treatment. She was due to start treatment the following week, *'I've been passed and I'm going for it, finally'*. Being 'passed' for treatment suggests those seeking hepatitis C treatment need to be accepted and achieve a certain standard/criteria order to receive treatment, a situation not experienced by people requiring medication for other illnesses, such as inhalers for COPD, lipid lowering medications such as statins for hypercholesterolemia or medication to regulate blood sugar levels in diabetes. Whilst these illnesses may require patients to meet certain clinical indicators that treatment is required, such as cholesterol levels for the statins, or blood sugar level for diabetes medications, in Sharon's circumstance the criteria was not that of clinical indicators such as liver function but rather due to

her drug use. As these other diseases can also be caused by lifestyle factors, such as smoking, poor diet and obesity, this raises questions on why hepatitis C treatment is not given to those who take drugs yet these other medications are not withheld from people who smoke or eat unhealthy foods.

Neil felt discrimination during receiving hepatitis C treatment because of the infectious nature of the hepatitis C virus.

Yeah started treatment about 2 years ago. I done 3 months [of 12 month course] and the side effects, it weren't just because of the side effects, some of the nurses in there. I was seeing a different nurse every single time I went in, and they were 2 specific nurses I couldn't tell you who they was, they were like, let's just say I was speaking to you they'd move away [demonstrating moving away from researcher], put on 2 sets of gloves

(Neil)

Why do you think they were doing that?

(Researcher)

I don't know. I think they were, to me I think they were discriminating. I think they were doing because I had hepatitis. Coz all the other nurses they didn't even put gloves on. They want to bloody wear masks.

(Neil)

[conversation about side effects]Do you think if you'd not had side effects, you would have carried on [with the treatment]?

(Researcher)

I think.. the staff put me off a little bit. 50 50

(Neil)

All three narratives show the detrimental effects that discrimination has had on the participants. For *Neil* the discrimination was a contributing factor on why he did not complete treatment, and for *Sharon* and *Beth* their narratives demonstrate how past experiences with professionals where they felt stigmatised and discriminated against, affected how they viewed their current situations.

5.2.3.4 Services not meeting service users' needs

Participants mentioned difficulties they experienced in attending services. For many participants the number of appointments they needed to attend, the distance to services and the cost of travel was a concern.

You know when you think I go from home to there [hospital], that's 3,4,5 quid in a day. I haven't got 4 or 5 quid a day, it's a long way and it, you know, it can be a few times a week. I have that, then I have doctors appointments, then I have peer appointments and it's a lot of money, so yeah I've got a bike but then I can only go so far.

(Jack)

For *Kath*, the barrier to accessing support for her hepatitis C was twofold. Firstly this research found that the all hepatitis C support except Group 1, was through drug and alcohol services, which *Kath* did not attend. Secondly *Kath* worked through the day when services she would like to attend ran.

There's knowledge and there's advice but um,.. it'd be nice to have more like therapeutic things on offer, relaxation or Indian head massage or like stuff that probably makes you feel good, you know. I mean there is, there is things like that but they're always during the day. If you work you can't go to anything. There's nothing really much for people with a condition in the evening time when you work.

(Kath)

Do you think there's any services that other people with hep C might require?

(Researcher)

I don't know, 'coz I mean, the only people I know is like my ex-husband and then Simon and Seb [support group members] from here and they've got a very different lifestyle than me, you know, I've got a family, a job stuff like that. They've got very different lifestyles. Um, so I don't really know, I think, I mean, I think Seb [from support group] accessed all the services and stuff. I feel like, I'm a bit of an outsider in a sense because, I haven't been an addict or an alcoholic. I've been a sporadic user, sort of carried on my life you know working and having kids and doing all the sort of normal things. You know, my ex has had a lot of access to services and done courses and all that and probably Seb [from support group] has and stuff like that whereas that's not really, it's never been part of my life. I've never been on methadone, I've never been to the drug service.

(Kath)

As Group 1, was not run through a drug and alcohol service (and was in the evening), *Kath* was able to access the group. Many participants (including *Kath*) who had attended a hepatitis C support group over the years, commented on how the group had helped them. As explained by *Phil* hepatitis C can make people feel 'cut off', and the hepatitis C support group reduced feelings of isolation.

What support did you get from the support group?

(Researcher)

Um I got um a lot of support because I thought I was the only one with hep C and then I went there and there's loads what have got it, so I'm not the only one

(Susan)

How does it feel thinking you were the only one?

(Researcher)

It was horrible. Terrible.

(Susan)

first time I spoke probably with other addicts about you know, about that [hepatitis C] because when I came to this country I felt I've got only hep C, no one else, no one else, you know, so that I felt different

(Rich)

Why did you come here [to hepatitis C support group]?

(Researcher)

it just came into my head that I felt a bit isolated and I wanted to have somebody to identify with, you know because nobody really knows at work, only a couple of choice friends know, and I just thought, I just wanted the support really.

(Kath)

However, despite service users noting the benefits of hepatitis C support groups, the period of observation (Chapter 4) found that they were poorly attended but also that the number of groups were declining. Some participants felt that financial considerations affected peer support.

I used to take people to the hospital, you know, for their first 3 appointments, just to go like a buddy

(Susan)

Yeah does that still happen now?

(Researcher)

No, no It's all stopped. It's all these cut backs in it, that's the trouble, everythings being cut

(Susan)

Reasons for not attending a hepatitis C group were discussed in the interviews. Having other priorities such as unwell family members and stigma relating to hepatitis C were suggested.

Why don't people come to that hep C support group?

(Researcher)

I think it's the word, you know because of the stigma in it, erm a hep C group ... coz you come in, if you come in and say [to reception] well I'm going to the hep C support group.

(Jenny)

Participants talked about the 'embarrassment' of having hepatitis C, appearing to uphold wider societal stigmatising views of the virus, and being 'scared' of acknowledging their own positive status. However participants in one drug and alcohol service, also said they were unaware of the group, despite posters for the group being around the service.

Did you know there's a hep C support group at this organisation?

(Researcher)

No, no, didn't know about it, I didn't know about it [Note - there's a poster advertising the support group on the wall to her left]. I didn't know, I don't really ask any questions and that..no.

(Brenda)

Do you think you would go to a support group?

(Researcher)

Yeah

(Brenda)

It should be noted that the room where these interviews were conducted was a small interview/counselling room with a poster on each wall. Each poster advertised a different support service. One of the posters was for the hepatitis C support group. In addition, the small waiting room where people sat to wait for their keyworker appointment had numerous posters up (and leaflets). In this room there were three of the same hepatitis C support group poster.

The reasons for not knowing about the group were not established. It may be that posters are not the most effective method to convey information, however *Brenda* commented that she does not '*really ask questions*' and *Beth* who also did not know about the group stated '*I've been given no information on that*'. These comments suggest that keyworkers and service users may not discuss the hepatitis C support group at their appointments.

However having knowledge of the group did not appear to correlate with attendance at the group, as at follow up interviews participants had still not attended.

5.2.3.5. Discussion

This theme has shown the service users' views and experiences of accessing healthcare services and advice/information on hepatitis C . Barriers and facilitators were highlighted. Communication between healthcare professionals and service users on hepatitis C appeared to be a barrier. Examples were given where hepatitis C was not broached by either

healthcare professionals or service user during appointments. In addition when hepatitis C was discussed, professionals used terminology that service users did not understand or healthcare professionals were providing incorrect advice. The timing of verbal advice and the need for ongoing advice was also highlighted by service users.

There appeared to be occasions of 'missed opportunities' where service users asked for a service, such as a test, and the service was not available. Moreover healthcare professionals did not appear to be proactive at these time points and did not take the opportunity to discuss hepatitis C with the service users.

Examples were given where healthcare professionals and pathways between services were praised by the service users, however there were also examples of historical stigma and discrimination which impacted on access to support.

Hepatitis C support groups were valued by many service users, yet many groups were poorly attended. More research is required into the barriers that prevent those with hepatitis C attending.

5.3 Chapter summary

This chapter has explored service users' lived experience and perceptions of hepatitis C and alcohol. Participants' described the complexities of living with hepatitis C alongside using substances, showing how fear, lack of knowledge and stigma affected their access to support, in terms of healthcare services but also wider support networks. Peer support was viewed as beneficial; further work is required to understand why attendance at hepatitis C support groups is poor.

Chapter 6 presents the findings from interviews with professionals working in drug, alcohol and hepatitis C services, exploring working practices and service provision.

Chapter 6 Interviews with professionals - findings

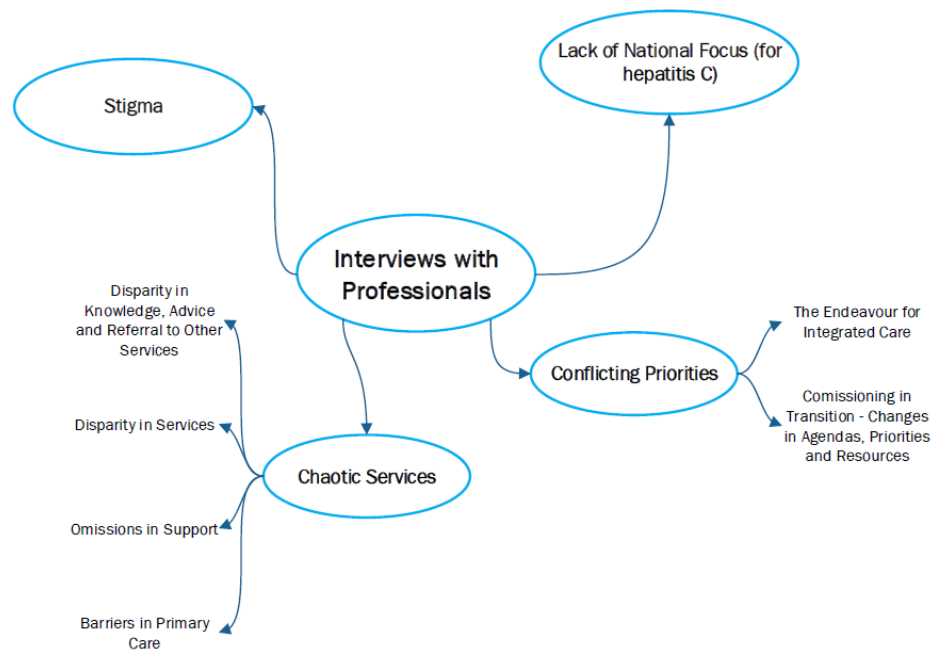
6.1 Introduction

This chapter presents the findings of the interviews conducted with professionals. As explained in Chapter 1, the term 'professional' in this context is used to mean: people who work in the field of hepatitis C, and/or drugs and alcohol; providing their professional experience, as opposed to lived experience of hepatitis, alcohol and drugs, during the interviews.

Semi structured interviews (see Appendix 4 for interview questions and vignettes) were conducted between December 2015 and March 2016, with 12 professionals. 7 were service user facing staff working in drug, alcohol or hepatitis C services, and 5 were public health commissioners of hepatitis C, drug and alcohol services (See Appendix 7 for participant characteristics).

The analysis discusses four main findings, namely: lack of national focus for hepatitis C, conflicting priorities, 'chaotic' services and stigma. The themes and sub themes are displayed in the thematic map (Figure 5) below. Within the findings facilitators were identified, but generally findings constitute barriers to providing services/support for PWID with hepatitis C.

Figure 5 Thematic map for the interviews with professionals



6.2 Findings

6.2.1 Lack of national focus.

During the interviews, the participants who commission services, explained about their role and the services under their remit. This showed the participants had different considerations depending on the geographical area and population they covered. Whilst this was not unexpected, as the purpose of commissioning is to provide services for the local population, the level of freedom in the system and lack of national direction for hepatitis C was evident. Each participant had their own focus around hepatitis C, with no overall national strategy to work towards. One participant (P2) explained how he was going to use questions from ‘a paper’ to audit the hepatitis C service within the drug service he commissioned and as a focus for the organisation’s hepatitis C ‘strategy’.

In fact I was looking at a paper, what it's got here after each section it's got these prompt questions, so I think what I'm gonna suggest, is we take all these prompt questions and put them in like a little basic audit format and then go through it with the service and say 'go away and have a look at these', 'how do you answer these 'yes' or 'no'' and then it gives us a work plan to get things back up to where we want them to be [after retendering].

(P2)

I was wondering what the short and long term strategies are for hep C?

(Researcher)

In what sense?

(P2)

Just like where it's going, where the services are going, what the aims are, what the objectives are?

(Researcher)

Well our aim is to start off with, get the screening up to the highest level that we can, so raise, as this paper asks the question 'Have you asked the question of all the people you need to ask it of.' 'Are you promoting the availability of treatment to the ones that you need to promote it to' and then are we getting those people able to access, so that's what the strategy is. For me it's quite a nice project because its finite pretty much isn't it, there are people that are infected, but relatively speaking they're not a massive number probably, and we've got a treatment. So if we've got a system that is, that can work to prevent people getting infected, if we make sure we've got that still working in the way we need it to work, and that we also then start to work on the people who've already got the infection and clear the virus, so it's a sort of, it's something we're not going to get rid of it altogether obviously, but we can certainly reduce the prevalence, that's got to be the aim, ambition. We did have a hep C strategy but the trouble with strategy documents too often is lots of work gets put into putting them together and, that becomes the exercise but whereas I think what this will give us is a work plan.

(P2)

This suggests a previous local (and not national) strategy for hepatitis C. (The Hepatitis C Strategy for England (Department of Health, 2002) and Hepatitis C Action Plan for England (Department of Health, 2004), were not mentioned, presumably as they are obsolete, there was also no EU strategy for hepatitis C at the time of the interviews and interviews were prior to the WHO Global Health Sector Strategy for hepatitis C). Furthermore local variation in strategic approach was evident when comparing participants from two different areas of Merseyside. Participant P2's strategic approach appears to be very focused on hepatitis C. In comparison participant P3 took a much wider view of hepatitis C as '*one tiny component*' of the '*whole BBV agenda*', as well as considering aspects of the broader health and social care agenda (which are discussed in 'the endeavour for integrated care' section below). This expansive approach caused difficulties for participant P3; expressing during the interview, '*everything just feels a little bit overwhelming*' and '*I can't see a clear strategic approach*'.

Participant P2 also commented on the hepatitis C Action (steering group) commissioning toolkit.

Have you seen the Hep C Action commissioners' toolkit for hep C?

(Researcher)

...we certainly have looked at toolkits in the past, and things like that are quite useful because, you know if something comes on your desk, 'oh right, okay then let's look at this' then something else comes on your desk, but when it comes then it raises the profile of that issue again, it's a bit like this [this research] I suppose. I do remember doing that toolkit, that was before we did the tendering, but it brings it back to people's attention and its gives us a structure and it gives a set of questions for people to reflect on and answer, so yes we did do that and like I say that's I suppose what I'm proposing to use this paper for to create something new as a fresh, coz as, you do it and it gets pushed to

the top of agenda for a while, but then it gets over taken, so you've got to specifically keep bringing something else back to the front of the agenda and keep it going.

(P2)

Whilst the comments emphasise further the autonomy in local decision making, they also suggest a paucity of national formalised monitoring of hepatitis C services (as well as competing demands, which is discussed in the 'commissioning in transition' section below). This lack of national monitoring was highlighted further, as the participants described the national performance indicator for hepatitis C: the proportion of people who were receiving treatment for their drug addiction, who had (ever) received a hepatitis C test. Thus there are no national requirements on people receiving a recent hepatitis C test or an awareness of treatment targets. From the service user's interviews it was clear that some participants had been diagnosed with hepatitis C for many years but had not received hepatitis C treatment, and also that some participants continued to engage in sharing injecting paraphernalia. The participants seemed aware of these issues and had set their own targets, however targets were not the same for each authority.

No well basically in terms of, the only indicator that we've ever been measure against is on NDTMS [National Drug Treatment Monitory System] and that was the proportion of your IDU's that have been tested [for hepatitis C] against drug treatment and there's services up and down the country that are working towards that particular indicator, but that's never a measure of success in my view because the people haven't gone on to access treatment which is what we've asked [nurse] to measure.

(P1)

Okay so within our commissioned drug and alcohol treatment service, substance misuse treatment service there are key performance indicators that we expect to be met, of an offering of screening and I think the standard expectation within the national data set is around the proportion of the active treatment population tested for hepatitis C, we feel that that does not give

a complete picture so locally we have an additional target within our key performance indicators which sets a requirement for the commissioned service not just to meet that percentage of the overall [drug] treatment population who have ever had a test for hepatitis C but for those who have had a test for hepatitis C within the last twelve months because I think that becomes more meaningful. You could have 100% of the treatment population who have ever had a test for hepatitis C but 95% of those might have had a test 5 or 6 years ago so it's currently exposed to, we wouldn't pick any problems or treatment needed up through that if we didn't have this more kind of recent, so I think that is something that we are mindful of. Now we, it's probably fair to say that in terms of performance around those we don't see as higher rate of performance around the shorter time frame expectation as we do on the overall so whilst we exceed the national target and expectation for the percentage ever tested within the last twelve months so it's something we are working hard to improve. What we also, both in national and local target from the proportion to test positive a target for the number offered referral treatment so the treatment pathway so you might think well how effective is that as an indicator of success because having an offer does not necessarily mean that someone will take up that treatment option so I think that is one of the things that we've struggled with, we have a very high return on that target expectation of all people who have a positive test for hepatitis C having the offer of treatment, we don't have as high a completion or success in terms of people commencing and completion...

(P5)

I was going to ask actually, do you have numbers of people who have actually had treatment?

(Researcher)

I don't think the numbers that we have are particularly reliable and that's one of the areas that we are working on with our service at the moment.

(P5)

Offering treatment, but not having 'reliable' numbers on how many have accessed treatment appears concerning. Also from the vignette interviews,

it was evident that service users needed to meet certain criteria (such as not injecting and not drinking over certain amounts) to be suitable for treatment. This seems at odds with the target to offer treatment to all service users with hepatitis C, however this aspect was not discussed by the participants who commission services. Despite questioning the usefulness of this target, this research does highlight local level intentions over and above the national requirements.

More generally, when considering prevention and behaviour change at a population level, one participant (P2) explained how a national level focus is required.

....general population messages which happen and work, but they happen as like national campaigns mostly really, because its only in the national level campaigns that have the resource behind them to get that you know TV adverts sustained year after year of putting a message out, little local campaigns are like pebbles in a pond I think, the ripples, if the ripples do reach the side, they reach the side not enough.

(P2)

I guess with health interventions like that it's probably going to be decades until you see results.

(Researcher)

Yeah and locally all your plans are short term aren't they, whereas a national campaign, you know smoking has been years, decades of targeting smoking and I think we're just getting to that point with alcohol now....

(P2)

Although this participant is not specifically discussing hepatitis C, the difficulties of making an impact at a local level without a national drive are expressed.

6.2.2 Conflicting priorities

Conflicting priorities were seen throughout the interviews, indicating conflict at both strategic and organisational levels.

6.2.2.1 Commissioning in transition - changes in agendas, priorities and resources.

Throughout the interviews, participants referred to the changes that occurred in April 2013 following the Health and Social Care Act (2012), when PCTs (Primary Care Trusts) were replaced by CCGs (Clinical Commissioning Groups) and public health commissioning transitioned into local government. This period of change also saw the move to integrated drug and alcohol services.

..there was a significant shift in focus in terms of the drug and alcohol service from around about 2013 and it shifted the focus of everything really with agencies dissolving, creation of Public Health England, we had to pick up some of the functions of that, the dissolving of the local primary care trust, creation of CCGs, public health coming into local authorities, responsibility for a lot of this specialist commissioning with public health coming into local authorities and within all of that almost unprecedented change there was a change in focus of substance misuse and treatment in services and what that change in focus brought about was an integrated drug and alcohol service.

(P5)

These changes saw hepatitis C services being commissioned by both the CCG and local authorities, with the addition of NHS England (NHSE) who agreed to fund the newest (DAA) hepatitis C treatments for some patients in 2014. One participant explained the impact of these changes on hepatitis C services.

I think what we've got to consider right from the onset is, under the PCT they had the overarching leadership for the whole of the

services now that it's gone you have got the CCG that has responsibility for primary care and hospitals, you've got public health who are responsible for screening, however we have addiction services here with us [public health] as well so we're responsible for making sure those service users get the whole package. ...and then you have got NHSE to throw in the mix here because they have just took on the prescribing costs haven't they, the prescribing cost for the drug [DAA hepatitis C treatments] and that as well so it...NHSE, CCG and local authorities all have a responsibility but that pathway isn't stream lined.

(P3)

The participant explained further the difficulties of trying to get the pathway streamlined in the current climate of changing agendas and differing priorities amongst the strategic bodies.

[Researcher - explains research has gathered service user perspective on the gaps in services] I think the strategic one is your absolute key one because sadly it's a different priority for every, whether it be NHSE, councils, CCG, people miss this and just go 'oh the pathway hasn't changed' and I say 'no the strategic priorities have changed', so if strategic priorities have changed, it doesn't have the same push anymore, they might be prioritising something else, it's not that they are not caring, it's just it's not, for today their agendas have changed and I think that has really been missed, is how all our agendas have changed, and someone like public health where you've put public health back into local authorities, it's taken a massive big sway in another way that I never thought would happen and evenly for them, councils never thought of clinical services, whereas they've got to consider clinical services now.

(P3)

As well as there being different priorities between the organisations, the changes to the commissioning structure also meant commissioners were now responsible for a larger remit, resulting in less resources, different working relationships and seemingly less focus on hepatitis C.

The idea is that what I wanna now be able to do is to influence how we progress our local hep C strategy locally, and largely that

will focus probably just on drug users to begin with to mop up that last 250 [who have not been tested]. But unless we kind of suddenly have a mass influx of migrants with hep C that presents a risk, I can't see us facilitating a specific strategy group for hep C coz everything now is tending to be arm's length, light strokes with a broad brush, in other words it's all kind of, what we were able to do before to drive stuff, we're just not able to do in the same way, because you know, I manage a drug programme of which now hep C is a part, the DAAT [Drug and Alcohol Action team] used to do that, there were 12 people at peak in the DAAT, so I'm looking after the substance misuse treatment system, I'm also the lead for suicide prevention, BME engagement, I've just finished a piece of work on domestic violence, so you're pulling in quite broad range of different stuff really.

(P1)

You know we had a DAAT team, you know at one point there was 12 of us delivering the drug and alcohol programme, there's probably not 12 of us in the public health team anymore, so we haven't got the resources to do it in the same way and that's interesting too because we were effective when we were that team focused on drugs and alcohol very specifically and had a good resource to do it, and I look now at how we, how stuff is falling, this idea of spinning plates, well plates are falling off now, we have to lose some, but there will be a consequence of that because there was a value in those things, we won't reap the consequence straight away, we'll go through a cycle, we're stripping stuff out of the system now, you know hep C is not getting as much attention as it did, so things like this [research] are good to raise profile again.

(P2)

It's funny coz that's one of the other things we were quite connected, different areas would know what was going on, I know [commissioner in another area of Merseyside] well, we'd know what was happening in [other areas of Merseyside], we've lost that as well, we're disconnected from each other now, we do meet up sometimes, PHE still get the commissioners together quarterly I think and it's good to meet up with people and hear what's going on.

(P2)

And I think because it [hepatitis C] has been around for a long

time I think there has been a significant assumption made that we're further on than actually what we are and I think it really became apparent when, with the demise of the PCT and everybody taking a different responsibility but actually it really did sort of open basically our eyes to say, this was fragmented anyway however it's worse now, because actually what you've done is with that fragmentation is really impacted on our service users because our services are now commissioned differently and we don't have the same resources that we used to have, and we don't have the same relationships that we used to have for some of those pathways so it's how do we manage that.

(P3)

These quotes from the participants indicate hepatitis C is not a priority in the 'grand scheme of things'. Furthermore the commissioning process does not permit hepatitis C to be a commissioning priority for the CCG or local authority, requiring it to be commissioned indirectly within a pathway.

So do you meet up with the CCG commissioners about the hep C services and pathways?

(Researcher)

In some instances yeah, so hepatitis C is an interesting one because there isn't actually, hepatitis C is one of those things from a CCG point of view and from a local authority point of view is probably not, doesn't fall into any of the direct priority groups, which for those of us close to it, it's sometimes disappointing but we are recognising that you know it is not always....so you know from a CCG point of view when they set out their priorities, things like cardio vascular disease and respiratory disease they are amongst the kind of top priorities, reduction in hospital admissions and long stays, so it's kind of where does hepatitis C fit in to that, the kind of long term conditions bit of it, so it is very often something that will be commissioned within a pathway rather than a direct provision in itself. From a local authority point of view, from our point of view for example prevention, identification. Prevention of hepatitis C would generally speaking come within the realms of the substance misuse services that are commissioned, now again that's, you know, we don't actually go out to directly commission a hepatitis C service, so treatment or prevention, but it is a focus, so within our substance misuse service - why is that so? I am sure you completely understand that

the vast majority of hepatitis C infections annually are either directly or indirectly attributed to drug use and some of the means by which substances are consumed so it absolutely is an integral part of looking at our drug treatment programmes.

(P5)

Moreover one participant (P1) explained how commissioning of services is complex, especially when working on issues that require joint commissioning. Interestingly some of the participants who commission services met with their CCG counterparts but other participants did not. Those who did not meet with the CCG commissioners seemed less knowledgeable on the treatment section of the pathway, as they did not mention NHSE funding the new DAA treatments and the current system of these treatments being provided by lead sites under the Operational Delivery Networks (ODNs). Although this is understandable as hepatitis C treatment is not under the remit of public health commissioning, it shows gaps in their understanding of the whole hepatitis C pathway.

Is there a commissioner for CCG in [area of Merseyside]?

(Researcher)

No, not, well, they commission acute services, so...

(P1)

It's me not understanding the commissioning process really, you know as a nurse on the ground, you don't really know how it's all

(Researcher)

I don't think half the commissioners do because some of the systems are that complex, it's really strange for example I'm a suicide prevention lead and that's public health's responsibility but CCG are responsible for commission the mental health service as they form that beginning of that continuum, so it's strange, public health work preventively and commission services to test

those at risk of hep C and really we should be pulling in some of those other communities as well, in terms of the actual medical treatment regime presumably CCG's will be commissioning hep C treatment from the hospitals, but who that would be I don't know. But if they commission hospitals then its CCG's will be commissioning the treatment element and no doubt either internally within the hospitals whatever consultants will decide what drugs they prescribe, there may be some influence from with the CCG's as well I don't know.

(P1)

As a newcomer to commissioning, I just thought maybe you all got together, you all talked about what was best for the people in your community and then you all made a pathway that linked up

(Researcher)

common sense would tell you that that's what you should be doing, but for example, alcohol related admissions are a really, really big problem it always has been historically, its improving but if I'm a commissioner working preventatively and I know that alcohol related admissions are costing 2 million pound a year for the hospital I might go to them and say I've got a new service and it's going to save you 2 million pound a year but I'm going to put a 100K in it for next year and I want you to from the money that you'll save. It's alright me turning round and say I'll commission this service which will save more money but if it's not, if those savings aren't being realised within someone's budget it just looks like I'm taking a 100k out the hospital to put it in a community based service so people don't wanna know, there's all this talk around joint commissioning and pooled budgets and it never happens, because people end up, this is my view anyway, you look after drugs and you look after mental health and you look at, and everybody gets a set of performance indicators and a budget to manage against,

(P1)

No we don't link up with them [CCG commissioners for hepatitis C], they sort of left us to it, I think because we had quite a strong DAAT team, anything drug related was just left to the DAAT team to do, and like I say the hep C, the treatment, well the CCG are paying for I presume, they must be coz the hospital are providing it, but we've not had to sit round a table and negotiated that, the treatment pathway has been established, and I think the hepatology consultant from the hospital has championed it from his side and to some extent that has been a bit of a stone that I've deliberately not wanted to draw people's attention to because my concern is if we draw too much attention to it, people might take more control of it and that might make it more restrictive, where at the moment anybody who's wanted treatment has been able to access that treatment, so I don't, so the CCG have just let it get on with it, it hasn't been a partnership work in that sense but it hasn't been obstructive either, so that may not be the classical way of doing it, but I have tended to think, well it's not broke so let's not try and fix it even more than it is. If it gets to a point where people are struggling to get access to treatment then we'd have to get into that negotiation but at this time I'm not aware that it's happening, anybody whose identified and ready for treatment has been able to access the treatment

(P2)

I found it quite interesting. I think 'X' [name of hospital] might have different treatment, lots of new drugs [DAAs] isn't there, and I think 'X' are using some of those, so I wonder how that works and whether people from [area of Merseyside] can be referred over to 'X'

(Researcher)

I think last time, to be honest in all the upheaval of [retendering], I'm not as in touch with that as I was when we've spoken about it before. I do recall that there was some suggestion that for certain exceptional cases, there was the opportunity, people would get referred to 'X', but that wasn't the norm it was for a particular, it was a sort of quid pro quo arrangement between the two hospitals or the two units, the consultants could refer, I think they referred all people from the consultant

(P2)

This section has shown the many challenges facing commissioning of a hepatitis C service within the current commissioning structure. Alongside the changes in commissioning, the government's larger agenda of integrating services (health and social) to improve the fragmentation of care has caused further concern for participant P3 (as discussed below).

6.2.2.2 The endeavour for integrated care

The Government's vision for services to be integrated to meet the increasingly complex needs of patients, has been on the agenda since the Health and Social Care Act (2012). All participants that were interviewed who commission services, talked about the integration of hepatitis C services by explaining their pathway from the drug services to receiving hepatitis C treatment in hospital (and increasingly in the community). However only one participant (P3) mentioned integrating wider services; showing another level of complexity for a strategic approach to hepatitis C.

the whole BBV agenda is really important and that's [hepatitis C] like one tiny component so again it's where's our starting point, should we be going straight for hep C or should there be other things that we're gonna look at as well alongside that. The most important thing is how does that sit with our new alcohol strategy, a homeless strategy, if we are going to ask people to look at integrated pathways, health and social care agendas should these not be priorities in the strategic plans, so that is another conversation that is taking place at the moment.

(P3)

there is no point in public health writing an BBV strategy when actually we know we're probably not going to get all the outcomes of that strategy met and also as well, them being with the council now and not sitting with health you have to then consider the social side, so it's the areas of deprivation, it's someone's housing need so there is an awful lot that you need to tap into, which actually I hadn't considered when I was on the PCT and now being here [local authority] the first thing you know my council colleague says, 'what about this cohort of people?' 'What about this cohort of people?' And again they might have

been a substance misuser ten fifteen years ago but maybe have been left vulnerable, may have mental health issues, may have homeless issues, but the service doesn't come to them so again they are like well it should, and if we are going to address health and well-being this is where we need to start and it's about looking at everybody's needs as an individual which is great, but it doesn't actually answer the question of what we say about the hep C pathway being fragmented, the services being fragmented and I'm trying to sort out that one grey area at the moment, so health and social care broader agenda has got a long way to go in offering collaborated integrated services.

(P3)

As an integral part to integrating health and social care, health and wellbeing boards were established and became operational in April 2013 (Kings Fund, 2016; Humphries and Galea, 2013). The health and wellbeing boards 'are ideally placed within local communities to bring together key partners to deliver better outcomes for individuals, including the most vulnerable, and there is great potential for further joint working' (HM Government, 2017 p. 29). In 'Opportunity Knocks: An Audit of hepatitis C services during the transition' (Hepatitis C Trust, 2013a) a recommendation was made; 'Local authorities should have a designated liver health lead on their local health and wellbeing board, with hepatitis C designated as a clear part of their remit'. (Hepatitis C Trust, 2013a, p. 6). Bearing this in mind, this topic was discussed during the interviews giving an interesting insight into participants' knowledge of this.

What do the health and wellbeing boards do about hep C?

(Researcher)

They leave it to, it's one of those things I suppose that because, I think the DAAT's [Drug and Alcohol Action team] were quite effective, certainly our local DAAT was quite effective, think people got in to the habit of you know just let them get on with it, we don't have to worry about it that's being sorted out over there, which in some ways is quite good because it means we could get on, we were able to just get on and do it, and not have to worry so much about satisfying everybody else, I don't think

it's very big on the health and wellbeing board's agenda.

(P2)

I've read somewhere health and wellbeing boards need to have a representative about hep C, so I thought 'oh I'll interview them' but I don't know who they are.

(Researcher)

I suppose in theory it would be my manger who's the deputy director of public health. They go to the health and wellbeing board, so the director of public health is, yeah does she go? I think she does yeah, or is it chaired by the director of public health? I don't go so I don't know the people but I think also within the public health team, people, my colleagues think 'oh [name] will deal with that' coz I've been dealing with it for a long time and it's been reasonably well managed, so they think well we don't need to worry about that, that's all been sorted out over there.

(P2)

Do you know much about the health and wellbeing boards and hep C on them, is there much...?

(Researcher)

I'm guessing, the health and wellbeing board obviously exists as this tripartite kind of system each with these 3 different strategies which are overlaid to produce a health and wellbeing strategy and I'm sure it'll be mentioned in there, but I'm sure it's not the focus.

(P1)

So you don't know like the named person who would know more about hep C on the health wellbeing board?

(Researcher)

No.

(P1)

I don't know if they have anyone, but um..

(Researcher)

I'm not so sure, I think it depends whether it's a priority or not isn't it you know what I mean, the Impression I get from health and wellbeing boards is that where public health will talk an awful lot about the preventative stuff, GPs are very interested in waiting times, rates of prescribing and so on so, you've got kind of this trichotomy of three different people pulling in different directions and I think that makes it difficult for boards like that to function when they are so distinct and separate, you know those interests.

(P1)

Although the participants suggested hepatitis C may not be a priority for the health and wellbeing boards (as was shown in the HCV Action report 'Health and Wellbeing Boards & Hepatitis C') (HCV Action, 2014), this could not be substantiated as interviews were not conducted with health and wellbeing board members. However, the overall strategic importance of hepatitis C within these local councils can be questioned, if they do not know, a) who represents public health on the board and b) the board's overall hepatitis C agenda.

Not only is the integration of care a government agenda and a concern for commissioning, the vignette interviews showed how these difficulties are

experienced 'on the ground'. When considering the vignettes, participants would attend to the issues posed, but would also exceed this and explain other aspects they would consider when seeing service users. Figure 9 (Appendix 6) shows all the aspects that one participant (P12) would consider for 'Kate' during her first consultation at the drug and alcohol service, and other services she could be referred onto for help. Thus not only is 'Kate's' heroin use, methadone use and hepatitis C assessed, the wider concerns are evident, including her physical, sexual and mental health as well as her living and work arrangements. Regarding her injecting, as well as hepatitis C, consideration would be given to other blood borne viruses such as hepatitis B and HIV, as well as bacterial infections, such as endocarditis and abscesses which would require injection sites to be checked. He (P12) would provide harm reduction advice in terms of safer injecting, advise on injecting paraphernalia provision and tailor the methadone script to reach a level that helped 'Kate' to reduce her heroin intake.

Regarding her social circumstances, as she is currently homeless, staff at the hostel would be contacted to discuss 'Kate's' needs. He (P12) would also ask if 'Kate' was engaged in sex work, with consideration of her sexual health including hepatitis A and referral to a charity that supports sex workers. Although the vignette said 'Kate' did not drink, alcohol was still discussed, with participants explaining that if 'Kate' did start drinking excessively, this would complicate her situation further, adding a layer of difficulty to the management of some of her other health issues. Firstly in terms of any mental health problems, alcohol was a barrier to accessing mental health support, as the mental health *'crisis team would only see her if she turned up there not intoxicated'* (P12), secondly, alcohol (at some levels) is an exclusion for hepatitis C treatment and thirdly, alcohol would affect the management of her methadone. This was highlighted when another participant (P11) discussed vignette 'Ben', as rather than talking about alcohol and hepatitis C, as per study design, this participant talked

at length about the difficulties of managing methadone when service users drank alcohol.

...because of the risk with alcohol on top of methadone, we'd look at reviewing the methadone dose, you know, if they're stable on the methadone, do they need that reducing? Depending on what dose methadone he's on, could it be that he could convert to subutex - because you're less likely to overdose on subutex. So, that he's currently maintained on a methadone script doesn't mean that you have to keep that methadone script. So working with the client, if he's used methadone before he might want to carry on using it, so we really need to look at whether it's the right option for him - mentally and physically. So we'd look at blood testing as well, and we'd see how his liver's coping, mainly we'd focus on if his liver's compromised, then we do really need to look at bringing the dose down, and converting him over to buprenorphine perhaps.

(P11)

Methadone affects the liver does it?

(Researcher)

Well it's because of the way it works. It can stay in the liver longer if the liver's compromised if they're drinking. So we don't really like drinkers on methadone here. We prefer to convert them over to subutex, because they're less likely to overdose. Because methadone is a sedative - like alcohol. So that's the focus the prescriber would look at - really challenge whether we need to carry on with that methadone script the way it is. Look at formulating a plan with them, and how we can change it.

(P11)

...And big risk for him as well is accidental overdose. He's at risk if he's previously injected. It's great that he's methadone only, but a risk is he might return to heroin and accidentally overdose, because he's not as tolerant any more, especially if he goes straight back to injecting. So a lot of risk management around that.

(P11)

So although 'Kate' did not drink alcohol, we could surmise if she drank, she would be at a similar, if not greater, risk than 'Ben' (as she was injecting heroin), of overdosing. The risk of overdose would be another, and arguably more pressing, concern than her hepatitis C (which does not generally damage the liver until many years after being infected) for staff to address. These interviews have shown that for professionals working in drug and alcohol services, supporting service users such as 'Kate' and 'Ben', there are many conflicting priorities to attend to, with some issues requiring more urgent consideration than hepatitis C. Furthermore, substance use conflicts with hepatitis C treatment, as drinking excessively and injecting are exclusions for treatment. One participant explained how she would not even refer service users who injected, for hepatitis C treatment.

If people are still using in the way of smoking a few times I'd still refer them for treatment because they can function on that. Just because they're still using a few times a week doesn't mean they can't function with everyday life, and appointments and stuff, but I wouldn't refer them if they were injecting.

(P7)

And if 'Kate' was referred to the hepatitis C clinic in secondary care:

She wouldn't turn up. They're our highest DNAs. So we would discourage them, even if she's got a diagnosis of hepatitis C, to refer to the hospital at this stage. Because she really needs to engage with - the injecting, she's not going to be treated. But that needs to be addressed. The smoking heroin we can deal with. She's clearly on a methadone script but it's not working, because she's still injecting and smoking. She doesn't engage with the drugs services, so they need to engage with drug services; she's homeless. So the Hep C is absolutely the least of her problems at the moment. The only thing that we would do is if this patient turned up, we would spend quite a bit of time explaining what hepatitis C is, and how it's transmitted, and that she's putting other people at risk, or she's caught it from someone because she's still injecting. So we'd talk about paraphernalia, and not sharing it, and the risks....

(P8)

Her homelessness needs to be sorted. She needs to engage. She doesn't drink alcohol, which is a good thing. So I would say she needs to be told about her hep C, she needs to be told that it potentially can cause cirrhosis. Possibly if she did engage with us, if she did turn up, I would do all her bloods, and I would do her fibro scan. And I wouldn't discharge her - I would try to encourage her to be treated. But whether she would engage with us, I don't know.

(P8)

The narratives suggest that even if 'Kate' did engage with the service, she would not receive hepatitis C treatment as she was injecting drugs. All participants who considered the 'Kate' vignette agreed that 'Kate' would not be given hepatitis C treatment, although it was unclear if it was the injecting per se or the lack of engagement with services which was attributed to injecting. This shows the barriers for 'Kate' to receiving hepatitis C treatment and/or advice from the hepatitis C specialists in secondary care. Therefore 'Kate' would need to have support from primary/community services. Participants felt that many service users did not visit their GP and were more likely to attend the drug services. However as shown in the discussion of 'Kate' and 'Ben', there are many other, more pressing aspects to attend to in consultations at the drug and alcohol services as well as the hepatitis C. As 'Kate' is not attending the drug service regularly, the hostel staff would be instrumental in helping 'Kate' with any concerns she may have. In regards to her hepatitis C, again there may be other issues that would take priority.

We used to try and do an education session [on hepatitis C] for the hostel workers and for the hostel dwellers, so we used to try our best to do some education sessions, so a lot of the keyworkers in the hostels are, you know I'd like to think in each hostel at least a few of them are au fait, whether or not it happens I don't think it does, I think they've got too many other problems going on in the hostels, day to day problems for them to worry about the hep C, I really don't.

Vignette interviews of the professionals' perspectives, have shown barriers in providing hepatitis C support for service users who have addictions, with substance use (injecting heroin or drinking excessively) as well as other factors, such as mental health, physical illness and homelessness, posing 'conflicting priorities' to providing hepatitis C related support.

6.2.3 'Chaotic' services

PWID and/or have an alcohol dependency are perceived by some as being difficult to engage in services and to treat (Zanini et al, 2013; Grebely et al, 2015), due to the 'chaotic' nature of their lifestyles (Sylvestre, and Zweben, 2007). However this research has also found services to be somewhat 'chaotic', which is discussed in more detail below.

6.2.3.1 Disparity in knowledge, advice and referral to other services.

When comparing the participants' narratives of the vignettes, it was evident that they had different knowledge and would give contrasting advice to service users. Furthermore the differences in knowledge resulted in varied criteria for referral to other services amongst the participants. This is demonstrated by considering the 'Rob' vignette.

'Rob' was deemed to be currently unsuitable for hepatitis C treatment, by all participants who considered the 'Rob' vignette. Whilst all the participants noted that his alcohol consumption was too high to receive treatment, one participant (P10) would also inform 'Rob' that his heroin use (smoking) would exclude him from treatment.

..inform about the [hepatitis C] treatments that are available now but again informing that although methadone isn't a problem they probably wouldn't initiate treatment until he was clear of the heroin for a period of time.

(P10)

However, the participants who provide hepatitis C treatment said smoking heroin would not exclude 'Rob' from hepatitis C treatment.

So 'Rob' for example would he be suitable to be referred onto treatment if he is smoking and drinking?

(Researcher)

The smoking of the heroin and the crack if he's engaging and he's not too chaotic with that, I mean you've said he currently smokes heroin twice a month, no that's fine. His drinking, no he's not suitable.

(P9)

This shows that 'Rob' would be given conflicting information on his heroin use in terms of his suitability for hepatitis C treatment. Although the incorrect advice had been given by a participant from the alcohol team, (and 'Rob' would have been given the correct information by the hepatitis C team, if he met with them) incorrect advice could lead to confusion. Furthermore being required to abstain from heroin, could potentially prevent 'Rob' from seeking hepatitis C treatment, and the wrong exclusion criteria for treatment could stop service users from being referred on for hepatitis C treatment. All participants who considered 'Rob' did however agree that he was consuming too much alcohol to currently receive hepatitis C treatment. Indeed, all participants interviewed using the vignettes agreed that alcohol consumption was an exclusion for the treatment, however when questioned on the amount of alcohol people could drink and still receive hepatitis C treatment, there were inconsistencies in opinions.

One participant working in a community drug and alcohol service explained 'Rob' would not even be referred on for hepatitis C treatment because he was drinking. However the participant was not completely sure of the criteria for hepatitis C treatment, initially saying no alcohol, but then suggesting a limit of approximately 2 -3 units a week (glass of wine or bottle of beer).

Yes so if he wanted hep C treatment?

(Researcher)

He'd have to stop drinking.

(P12)

OK and then if he managed to stop drinking?

(Researcher)

If he managed to stop drinking first of all it's the retest. Maybe he hasn't got hep C anymore, ok, so if we retested him and he's still positive for hep C and he'd stopped drinking we would then refer him through. Now we can always get him to see [hepatitis C nurse working in the drug and alcohol service], that's not a problem but she would not be able to refer him into treatment [for hepatitis C] if he's carrying on drinking. It's an exclusion criteria at the [hepatitis C clinic].

(P12)

All levels of drinking?

(Researcher)

I think so. Couldn't swear to that but I think so. I mean if they have a glass of wine, a bottle of beer, at weekends, maybe he'd be able to get away with that but beyond that I don't think so.

(P12)

However, the participants involved in giving hepatitis C treatment provided different answers to the accepted alcohol levels for hepatitis C treatment. One participant (P7) explained 'heavy drinking' is an exclusion, although they did not explain what constituted 'heavy' drinking. She also explained people needed to 'reduce or be abstinent', which appears to be confusing advice. Regardless of this, her advice was not 2-3 units a week as expressed by participant P12.

And what about drinking? Would they be referred for treatment if they were drinking?

(Researcher)

Depends on how much they were drinking. If they were drinking heavily I'd refer them to the alcohol team if that was something they wanted to do. Obviously I can't make them do that. I'd say "this is what's available to you" and obviously I'd give them the risks of drinking with hep C. And the risk of cirrhosis and things. So if they were drinking I'd say "I'll refer you to the alcohol team". "When you've engaged with them, when you've cut down or become abstinent, we'll re-review the situation again and then I can look at referring you for your hep C treatment".

(P7)

Another participant who provides hepatitis C treatment, also considered 'Rob', giving a different explanation on alcohol consumption in the context of hepatitis C than participant P12 and shedding further light on the explanation provided by participant P7. She explained 'Rob's' alcohol consumption would need to be 'reduced' to receive treatment, although she did not express to what level. However her explanation gave further insight into the complexities of this situation, explaining how the stage of liver disease affects the advice given, so if 'Rob' had cirrhosis, then he would need to be abstinent, and presumably, if he did not have cirrhosis he did not need to be abstinent. Thus, this advice was not given to meet a

criteria for treatment per se but as general advice for the health of his liver. Also seemingly more important than an actual amount of alcohol consumed, was engaging with services. The reason for this was not ascertained.

OK, OK, so is the advice really to completely cut out alcohol or to reduce it or what's....?

(Researcher)

Not completely cut it out but we do need it to be, I mean every, you know 5 cans of super strength a day it's far too much, so what we'd have to do is give him some support and see him making some steps to you know to actually engaging and being positive, so I think we'd need to do is, is see him showing willing. If he wants the [hepatitis C] treatment then he has to make some changes in his life as well, so I think it would be unrealistic to say completely come off it, that would be our goal obviously our main aim, if he was cirrhotic then we'd, I'd refer him in to the liver team, we'd keep an eye on him that way and we'd just work with him but at the moment he would not be suitable for [hepatitis C] treatment, we'd have to work with him definitely to get his alcohol reduced and if he was cirrhotic he really needs to be abstinent, so depends on his stage of liver disease you know if he has got any.

(P9)

Later in the interview with participant P9, she elaborated further on hepatitis C treatment and alcohol, explaining how treatment would be given if drinking was within the government recommended units for the general population (21 units a week at the time of the interviews for males, not 24 units as expressed by this participant). This is a vastly different amount of alcohol than the 2-3 units participant P12 suggested. Again however the complexities of this decision was illustrated by participant P9, explaining that this amount of alcohol was only for people who were not dependent on alcohol, with people who were dependent needing to be abstinent. Again a decision not based on the hepatitis C treatment itself, but on the person's pattern of alcohol use.

What level of drinking would you treat [hepatitis C] on?

(Researcher)

So I mean our forms actually just class as heavy, moderate, so moderate is I suppose is within your units and under your units, so for men its 24 units and under isn't it, so we'd also discuss that you know "your safe units are 24 with 3 alcohol free days and that's what we need to try and get you to", but if you are dependent on alcohol then I think the only safe limit is nothing. And then discuss, there are lots and lots of anti-craving drugs out there now, so what we could say is, if we can get you off the alcohol then hopefully we can give you some medication that will stop the craving and help you continue to be abstinent so that's where we wanna be, but if we've got people who aren't dependent and are just drinking maybe 50, 60 units a week but they're not drinking every day to that level, then we'd basically say we need to get you down to 3 days free and within your recommended limits so that's what we're trying to get to.

(P9)

As participant P9 would advise people with cirrhosis to be abstinent, we can surmise that the 'safe units' a week would be for people who do not have cirrhosis. However when another participant (P8) discussed vignette 'Sarah', who did not have cirrhosis, she advised under 7 units of alcohol a week - a lower amount of alcohol than the weekly limit of units recommended for the general population (14 units a week for females and 21 units a week for males at the time of the interviews).

Just re-iterate alcohol should be really no more than seven units per week for a non- cirrhotic.

(P8)

Okay so that alcohol's okay is it, yeah [talking about 'Sarah's' alcohol consumption]?

(Researcher)

Yeah, once a month, two to three gins, that's fine. We'd discourage them to drink, I would discourage them to drink as a matter of habit. Even though that's fine, I would stress the importance of making sure that don't drink for the sake of drinking, maybe try and keep it for special occasions, but that's up to her.

(P8)

So there appear to be discrepancies between participants on the advice provided to service users, but also on the alcohol criteria for hepatitis C treatment which may affect service users being referred for treatment. As shown above, participant *P12* would not refer 'Rob' for hepatitis C treatment as he was not abstinent, yet he may not actually need to be abstinent (if he was not dependent on alcohol or have cirrhosis). Thus 'Rob's' referral for treatment would depend on which member of staff he saw. Fortunately for 'Rob' a hepatitis C nurse was working in the drug and alcohol service where participant *P12* worked, so 'Rob' would see the hepatitis C nurse in the drug and alcohol service, who would then refer him for hepatitis C treatment (once he had reduced his drinking). It is however important to note that the hepatitis C nurses have not always run clinics in the drug and alcohol services, so prior to this current provision, 'Rob' would seemingly not have been referred for hepatitis C treatment.

Regarding 'Rob's' alcohol intake, participants talked about the measures 'Rob' himself could employ to reduce the amount consumed, such as using a drinks diary and slowly reducing the amount and strength of alcohol he drank, but participants also mentioned services he could attend for detoxification. Figure 10 (Appendix 6) shows where 'Rob' would be referred for an alcohol detoxification depending on which drug service he attended.

As can be seen from the schematic for 'Rob', there is variation as to which service 'Rob' would be referred onto. Interestingly there is a difference in referrals between service 1a and 1b which is the same drug service based

in 2 different locations. Drug service 1b would refer onto detoxification staff within their own service but 1a would not refer to this. Although the reasons for this are not known, this shows variation in referral pathways within this drug service. Also, interestingly drug service 2 would refer onto the alcohol team who explained they would not be able to conduct an ambulatory detox (detox via outpatient clinics) for 'Rob' due to his heroin use and would refer him to the inpatient detoxification unit. Thus this referral pathway would require 'Rob' to attend an extra appointment to reach the same end point as other referral pathways. Therefore 'Rob's' care is different depending on which drug service he attended and to a certain extent which staff member he saw at the service.

Although in this section examples so far have focused on alcohol and heroin, there are many instances throughout the interviews where different advice would be given about a topic. An example here shows the different advice provided about household transmission of hepatitis C. The first quote is advice that would be given to 'Rob's' partner who he lives with, and the second quote was information that would be given to a service user at the time of testing.

....and explain the risk of transmission so in terms of routine household contact it's nil basically. In terms of the risk factor, the only risk factor she's got is sexual transmission.

(P12)

Not sharing personal equipment. Anyone who you live with, in your family, could be at risk. They need to get a test. You can't share any toothbrushes or razors, and stuff, with them.

(P7)

Hence there is different advice provided about the household transmission of hepatitis C by the two participants.

Furthermore, throughout the interviews there was evidence that participants did not know the purpose/criteria of other staff/services. This is demonstrated by the following example. Participant *P12* said, '*she [P9] can do HIV screening [at the dug service] but I'm not sure if she does*' but participant *P9* said '*I don't do other bloods I just do a hep screen*', showing that a participant from a drug and alcohol service did not know which blood tests the hepatitis C nurse (working at the same drug and alcohol service) takes from service users. This disparity was also found amongst participants working in the alcohol services, with the example below showing that participant *P10* did not know the criteria for the alcohol detoxification unit, which is later clarified by another member of the alcohol service.

Yes, what about [alcohol detoxification unit]?

(Researcher)

Do they take them on methadone? I'm not entirely sure where their stance is on methadone.

(P10)

..if they meet all the criteria, if they're alcohol dependent, if they're stable say on a methadone script, if they're stable on it, you know we can take them in [to the alcohol detoxification unit] and you'd get the methadone supervised as they would in the community, so they can still have the detox and still be maintained on the methadone.

(P6)

Although using hypothetical service users, it would appear that there are inconsistencies in the professionals' knowledge, affecting the advice given to service users, as well as referrals onto other services. This finding was 'intra' and 'inter' services. Thus, within a single service professionals could have different knowledge from their colleagues, and across the services there was varying knowledge. Although the latter is perhaps to be expected

to a certain degree, as professionals become specialised in their area of practice, they did not seem to be aware of their limitations and continued with incorrect advice/referrals for the (albeit hypothetical) service users.

There was also evidence of incomplete knowledge at a strategic level. Two participants (*P1 and P3*) were both unsure of the hepatitis C testing carried out at the drug and alcohol services they commissioned. Participant *P3* had incorrect knowledge on the current testing and referral procedures at 'service A', suggesting they could not undertake testing so would refer to the service user's GP. Whilst this may have occurred historically at 'service A', according to the vignette interviews this was not currently the case, as a nurse from the hospital would attend 'service A', conduct venepuncture, send the blood sample to the hospital laboratory, receive the results and refer the service user into the hospital for treatment as necessary. Although this gap in knowledge is perhaps understandable, as the nurse is employed by the hospital and therefore presumably funded by the CCG and not the local council, it shows the participant is not aware of the provision at a service they commission.

Another participant (*P1*) was also unsure of the testing method used at the drug and alcohol service he commissioned.

So at the moment [drug and alcohol service] should be doing [hepatitis C] testing.

(P1)

Dry blood spot testing?

(Researcher)

Well I don't know whether it's dry blood spot testing but they're supposed to do 3 way test, like we used to do, we used dry blood spot testing it was a 3 way test for hep B, C and HIV. As far as I'm concerned that should be continuing in 1 shape or form.

(P1)

Showing a lack of knowledge of the testing his commissioned service provides, despite a backdrop of government reports (PHE, 2015; PHE, 2016b) recommending increases in testing and diagnosis and research into interventions (such as introducing DBS testing into drug services) (Hickman et al, 2008) to increase uptake of testing.

6.2.3.2 Disparity in services

The 'Rob' vignette discussions showed the different alcohol detoxification options available to 'Rob' depending on which services he attended. Disparities were also seen amongst the hepatitis C services provided by the different drug and alcohol services, which for service users would mean receiving different care depending on which service they were attending. One participant (P4), who commissioned drug and alcohol services from more than one provider, explained how the services under his remit worked differently, resulting in inconsistencies in the service provided to service users and fragmented care.

Then the other thing that you have got is the disparity in what they deliver as services as well. So some services users really don't get a really good service because, they might have a relationship with a key worker because they have come through a drugs service, so they will look at them from end to end [DBS test to referral for treatment] however you have got some services which would send a letter back to the GP [requesting hepatitis C testing] then the letter may or may not be read by the GP and then also as well you have got the hospital that delivers the [hepatitis C] treatment element, but that covers the Mersey region footprint so somebody has got to get themselves to the hospital themselves, so the system is quite fragmented at the moment.

(P4)

Thus there are differences in the hepatitis C pathway (from testing to treatment) provided at the two drug and alcohol services he commissions, with one service conducting hepatitis C testing and referring on to the hepatitis C specialists in secondary care, yet the other service requiring GPs to test and refer. The comment about the treatment covering the Mersey footprint, refers to how the newest hepatitis C treatments (DAAs) are provided, which is from a main site for the region (Operational Delivery Networks), requiring some patients who do not live near that specific hospital to travel further than others who live nearer. Increasingly in the literature there are studies considering different models to increase uptake of treatment (Wade et al, 2016). Due to the safety, efficacy and all tablet regimens of DAA treatment, one such intervention is to provide DAA treatments in community settings (Wade et al, 2016).

All participants involved in commissioning of services mentioned providing hepatitis C treatment in the community, however the models of care and timescale were different in each area. Two participants (*P3 and P5*) explained the current plans to start treating hepatitis C in the drug services.

I was at the CCG yesterday and they're very aware that from a clinical service as in treating the hepatitis, they've got to come out of the hospital setting and they have got to come to some services which is great again, they're going to come out potentially of hospital and deliver in the community alongside ideally, some of the addiction services.

(P3)

we are on the verge of having a collaboration with clinical staff from one of our major local hospitals working with the drug and alcohol team in providing satellite clinics in the actual drug and alcohol service.

(P5)

From the vignette interviews, it is apparent that the service participant *P3* is referring to, is to bring the DAA treatments out to the drug services,

however it is unclear from the interview with participant *P5* which treatments (DAA or interferon based treatments) will be provided in his area.

Although both participants discussed the imminent community hepatitis C treatment services, there had already been some treatment in the community. Participant *P3* referred to a previous time when service users could receive treatment at one particular GP practice, also the area covered by participant *P1* had been providing hepatitis C treatment in the drug service (and even service users' homes) for many years.

For us we would have all these different drug providers referring to harm reduction team, they would do the test, test is positive they would go to [nurse] who's based in the harm reduction team but also co-located in X [hospital], so it would be [hospital] that would be doing their treatment. What was good about our treatment pathway was that, that treatment could be conducted anywhere, once people had been initiated onto a programme so if they wanted to go up to hospital every week to get their needle, great, if they wanted to come into the [drug] service and receive their injection there or within the person's own home, so in that way you know it was very flexible in terms of administering the meds.

(P1)

This section shows a disparity in hepatitis C treatment provision in the drug and alcohol services across the areas of Merseyside covered in these interviews.

6.2.3.3 Omissions in support

Narratives explained the gaps and omissions in the hepatitis C service provided to service users, both historically and the present day. The main issues discussed were: difficulties with increasing testing; the complexities of getting service users from diagnosis to treatment; and omissions in advice and support provided. Although no exact cause was identified across the

interviews, generally these shortfalls were considered to be due to issues with staff (training issues, the language staff used, staff's reluctance to discuss hepatitis C).

...were keyworkers actually raising this [hepatitis C] regularly with them [service users] and reviewing it? I thought from my time when I was a practitioner, did I initially when I was very early on in my career, avoid the question of hep C coz it could bring about a technical question from the service user that I didn't feel confident enough, didn't know enough about, pegylated interferon [treatment] or what the genotypes were and so if I steer the conversation away, they wouldn't ask a question and that, because I would be fearful of getting it wrong or admitting I don't know, which then I thought might have an impact. And these are the kind of questions I was sitting there thinking about. So I felt that there was kind of a training issue somewhere in there or, you know a service user turned round and said to me 'I've been and had a word with XX XX' [nurse] 'she started talking and then all I heard was oohrarohhhraoo' because professional people, technical words and it makes no sense to them really and this guy [peer] is just telling me how it is.

(P1)

Convinced, convinced there's been training issues in the past with individuals because as well another thing that we introduced was an opt out arrangement as well you know for testing because when I was a practitioner, although, as I was learning my trade, I was a drug worker you know way back, and I have got to say I think that 70-90 % of my caseload agreed to a test, so I knew that it was how you framed the question sometimes. You'd be like 'look da da da da, you've put yourself at risk, I'm gonna send you for a hep C test is that OK' because that kind of is saying you know you've gotta tell me 'no I don't wanna go' and then we can have that conversation but yeah its rather than asking the question 'do you want a hep C test and not really explaining why or how.'

(P1)

We've had I think a degree of success, getting so far down the path which has been hampered firstly by the reticence of one service to push the issue of hep C with their client group for whatever reason that is.

(P1)

[Nurse] did a good job of supporting people through the treatment, I think what she was less effective at, and I think it's a bit of a perhaps I think a wider criticism of NHS services sometimes is, she was a bit of like her expectation is "I'm here, I'm doing a good job why don't you come and use me". I think sometimes it's got to be a bit more, go out, be more proactive, promote what you're doing more energetically, more proactively and recognise that there is a lethargy within other professionals but also with service users you know, that you've really got to sell it and certainly when we set the pathway up the ideas about hepatitis treatment were quite ambivalent and how effective was it, it's really uncomfortable, it's really upsetting, it's really distressing, over the course of time that pathway has been running there's been great improvement in that treatment it's much more effective, and it sounds like its less intrusive and less difficult for the people who go through the treatment and we've got lots of people around the system now who are benefactors of that, who've cleared the virus and we've worked very hard at pushing it, with our treatment providers but then when we had our organisation system meetings but then I'm not wholly sure that it got fully into the mind-set of the work force and I think that's part of why we were recognising that it really was the time, the tendering was the shake-up, it's really shaken people's previous, you can't stay sitting in the seats like you were before doing the same thing over and over again coz we've fundamentally changed everything.

(P2)

Throughout the interviews it was apparent that funding also affected service provision, causing uncertainty and impacting on which services could be provided. One participant explained how the change in funding stream for public health services from the Department of Health to local authority caused concern.

And the nature of the NHS being that basically you don't know a lot of things so "this might happen" and "we've done this but we don't know", so it's bidding for contracts at the moment.

(P12)

Are you out for tender?

(Researcher)

Well we're eternally out for tender, yes. Well our funding stream is going from the Department of Health to local authority so there might be huge cutbacks, so one thing that might happen for example is that we'll have to reintroduce waiting lists, so if somebody drops out of treatment [for their addiction] well the next appointment is in 10 months.

(P12)

One participant (P9) described how funding affected the hepatitis C testing provision in one of the drug and alcohol services, explaining that although staff have the skills, there are financial constraints on providing this service for service users.

And do they do [hepatitis C] testing in [drug and alcohol service] then?

(Researcher)

They don't, we're currently trying to get that funded, so the only way of testing there at the moment is via X [hepatitis C nurse from secondary care]. They do have nurses that actually can take bloods but unfortunately are not funded for blood borne viruses, so that's something that we're in discussion with at the moment with the CCG.

(P9)

Despite the aforementioned staff related barriers to providing hepatitis C services, it was also evident from the interviews that staff were also facilitators in trying to provide the best service possible for their service users, despite issues with funding. In the example above, funding was not available for the nurses at the drug service to take bloods to screen for blood borne viruses, so a hepatitis C nurse from secondary care goes to the

community drug and alcohol services to run a hepatitis C clinic where service users can be tested (although it is to be noted that this service is not provided every day, with half the week covered at 1 drug and alcohol service and the other drug and alcohol service-which has 2 different locations-has the nurse attending each location for a morning every other week). The staff were also trying to change the service by discussing it with the CCG who commission services. Funding was an ongoing issue, one participant (P11) explained that historically they had a testing service which was stopped. She explained how she had been instrumental in setting up the current testing provision with the hepatitis C nurse from secondary care but how she would also like to drive this further by having further testing and support groups for service users.

And what I'm looking at, because I set up that service with [hepatitis C nurses], we've been doing it for a year and half now, but before that we didn't have a BBV service. We used to have a BBV nurse about ten years ago, and before that, but the funding stopped. So because it's something I'm interested in, it took a while, that I got [hepatitis C nurse] started here. And now that's started, what I'd like to do now is to focus on a bit more peer support. So I'd like to have a support group or something, you know. I'm talking with some of the clients about what they'd like. So that would be nice to offer people.

(P11)

So I'm applying for a grant with [drug company] I think it is, to get some dry blood spot tests, to look at screening more people when [hepatitis C nurse] is not here. And anyone can do that, not just qualified [registered nurses].

(P11)

This effort by staff was also evident when discussing 'Kate's' (vignette) hepatitis C treatment, as staff were aiming to bring hepatitis C treatment out of the hospital to the community drug and alcohol services.

Is there any chance that she could be treated out in the

community anywhere?

(Researcher)

Yeah. So we would like to treat her. We're in the process of trying to set that up. [Hepatitis C nurse] is now employed with us, and is going to go back to treating in [GP practice] and we're just putting a business case together for treating in the community, of which [drug and alcohol services] are the two drug centres. So you're right, so even if she got all these things sorted [drug use, methadone script etc.], she wouldn't have to be treated in the hospital. We'd treat her in the community.

(P8)

Yeah. So that would be her coming to the drug services?

(Researcher)

Yeah. At the same time as she picks up her methadone, she could get her sofosbuvir and daclatasvir or sofosbuvir and ledipasvir [hepatitis C medication] or whatever. So even if she had to come in once a week to pick up her methadone, or to see the drugs team, we could give her the medication at the same time.

(P8)

Again, this shows staff trying to provide services that are more service user focused. This was also evident in the alcohol services, with staff proposing new services to meet service users' needs, but also working voluntarily where there was a gap in services and no funding to fill it.

..my background was with the alcohol team, so I worked with the alcohol team, then I got brought up to the hepatology team to do liver cancers and hep C and I was sort of taken to the liver cancer side of things more than anything else, but one of the members of staff was off for a period of time, so I was doing the hep C clinic, the complicated, complex hep C clinic and the number of patients there who were, you know, who needed interventions as regards their alcohol intake was unbelievable, so I put together a proposal for me to actually have my own separate clinic down at

that clinic at that time, for anyone alcohol dependent or who was significantly drinking that I could deal with them before they started their hep C treatment. So that's going through the motions at the moment

(P10)

And that's your work at [drug and alcohol service]?

(Researcher)

Yeah I work for [drug and alcohol service]. I run the group voluntary because it's not funded

(P6)

Oh, this is in your own time

(Researcher)

Yeah so, unfortunately the [inpatient alcohol detoxification unit], see the problem is we take people away from the drink and away from the drugs, there's a big void left there. So you need something to fill that with and while people are finding out their own identity and what they like doing, that's where the group I run can be there to support you.

(P6)

So you're doing it coz there's nothing else for that point in their....

(Researcher)

[Interrupting] It's not funded yeah. Once people are taken away from the alcohol in the [inpatient alcohol detoxification unit] say, there's nothing for them to do and there's a big void there, so say someone's been drinking and taking drugs for 20 years, 'Ben'

for instance will be taking drugs and drinking for 27 years, all his life basically, so there's a lot of questions need answering there. There's a lot of soul searching and finding yourself, that needs to be done and the best way for that is to have support off other people who are doing the same thing.

(P6)

Thus the participants who worked in services with service users provided examples of how they were trying to improve services, however at a strategic level there was no consensus on how to tackle the issues. Participant P3 admitted there was uncertainty on the direction of efforts;

..and it's where's the starting point, we all know what the problem is but we don't actually know how we are going to go forward, we all have ideas, we all have suggestions but it is around actually we need to take a step back because there's an awful lot of people that weren't screened, that weren't asked the question or if they were asked the question, they didn't go forward and speak to anyone about being diagnosed or being screened or following anything up so, there's a whole host of people that actually five to ten years ago were asked a question, but nothing has happened and that's a real concern for me.....what they've realised was when it come down to it people weren't offered peer support, people didn't understand what they were going for [hepatitis C treatment], people weren't informed about the length of time it [treatment] would take, how poorly you may be [on treatment], who you've got to see and why, and the one thing that was really good when we done that [considered service] it was the fact we needed to go back to basics and if you are going to do anything and make a success of it we need to strip this right down ...

(P3)

Furthermore whilst acknowledging the previous hard work and initiatives to improve hepatitis C outcomes in their areas, the participants explained a lack of empirical evidence on the effectiveness of the interventions on which to now draw.

She [nurse] done amazing work and we were quite surprised that it wasn't documented and I am just assuming it was just timing or miscommunication, it was never written up and it was never

turned in to best practice or, so considering we have strong links with the university everything that we are saying today actually was a lot of what she has done in the past, but it wasn't documented.

(P3)

And in order to deliver that peer mentoring programme with the dry blood spot testing which the signs, although I've got no evidence to evaluate that intervention in the way that I wanted to, the signs were that that was very successful in picking people up.

(P1)

This section has shown that finances affect which services are provided, resulting in some services which are required by PWID, such as hepatitis C testing, being omitted. Despite there being a need for increased hepatitis C testing (PHE, 2018a) and an awareness that PWID are more likely to attend their drug and alcohol service than any other service (P7, P8), testing is not routinely provided by the drug and alcohol services. This section has also shown that staff act as both barriers and facilitators in service provision. Regarding facilitation, staff not only work innovatively to deliver services, but also propose services to funders, to better serve their service users. Despite a paucity of 'evidence' of previous effective interventions and a level of uncertainty on the best way forward for services, all participants who commissioned services did however agree that there was a requirement for greater input from primary care.

6.2.3.4 Barriers in primary care

As well as the disparity in hepatitis C provision available to service users at various drug and alcohol services, there are other people who do not have access to these hepatitis C services at all, as they are not in contact with the drug and alcohol services. The commissioners interviewed were aware

that services were not serving everyone with hepatitis C, requiring more involvement from GPs.

Then you have got the next grey area which is service provision then comes from several different areas coz an awful lot of people might not be in [drug and alcohol] treatment anymore which is a real you know, such a shame, so it's about how you educate and how you get the GPs on-board to look at people's overall health and well-being and that is a real challenge at the moment to say could you look at letters [about hepatitis C testing], could you, you know check if people have come in, and you might have been asked the question five or six years ago [about hepatitis C risk] but what about today?

(P3)

What sort of services are available for people who aren't actually at a drug service? I have spoken to somebody who injected years and years ago and has never really been addicted and has never been on methadone or been in like a treatment programme [for drug use], is there any services for those people?

(Researcher)

I think that is a real gap and I think at the moment, I could tell you what would happen but again it's where that person is kind of going to meet, where the touch point is going to be for access. Because probably that person in that sort of situation is not likely to access a drug or alcohol treatment service where if they have a concern, where might they go? So I think what we need maybe is to have more doctors and nurses in primary care who have sufficient understanding or knowledge so when I say I could tell you what would probably happen it is a bit variable. So you might if you had concern through any potential historical exposure, you were likely never to connect with a drug and alcohol treatment service then probably the only place you would connect with would be through primary care. Now if you were to mention it through your GP or Practice Nurse I think this is where the variability may possibly come in because those more in line would probably advise that you should actually go along to one of the hepatitis C treatment clinics at the hospital and they would be able to organise a test if necessary or any advice but it's not a

pathway as such I don't think it's an ideal situation.

(P5)

The participants agreed it was important for hepatitis C to be considered in primary care, however they talked about barriers to this. These barriers can broadly be categorised into barriers at the staff level, service level, national/population level. 'Staff level', refers to the GPs themselves. Participant *P5* suggested there is variability in practice around hepatitis C amongst GPs/practice nurses, with a requirement for increased knowledge and understanding. In addition to this, two participants (*P3* and *P4*) suggested GPs, as a profession, need guidelines and evidence to encourage change in working practices. Other commissioners mentioned GPs inclination and skills to identify patients' issues and refer accordingly was also a factor. At a service level, service demand including GPs workload and time pressures were mentioned by all participants who commission services. Another participant (*P1*) also touched on the historical culture of issues around drug use being dealt with by drug services and not by GPs. Considering the wider public health view, participant *P5* discussed the barriers to providing population based testing as opposed to focused hepatitis C testing.

So does that [meeting] include GPs as well?

(Researcher)

Not so much GPs coz we struggle to engage GPs I think in terms of, things like the drugs agenda, they've kind of traditionally seen that our [drug and alcohol service] provider is the expert in everything so.

(P1)

So does much [hepatitis C] testing go on at GPs?

(Researcher)

I would doubt it, we looked at some of the NICE guidance round hep C for some of the other groups, you know we were thinking specifically about BME communities and especially with the influx of Eastern bloc migrants and basically, we were trying to create a public health hep C strategy that would include all those at risk groups and this trainee consultant wrote this strategy and a doctor said 'I would never think to ask the question of immigrants around certain things', and he, absolutely uber bright, but it was just time pressures, you know you've got time pressures to see a patient

(P1)

Coz the hep C trust have got a big drive haven't they for GPs at the minute, GP training

(Researcher)

It's what you include as your check list but then its, if we including everybody's cross cutting strategies in terms of you and me and I'm your patient, you're then turning round and saying I've got me checklist but hopefully you're offering all kinds of direction so then it becomes a lot of the skill of the practitioner of being able to respond accordingly to the issues that I disclose as to where you wanna take me with that.

(P1)

this person had been going to the GP for years with tiredness and depression, fuzzy head and it [hepatitis C] wasn't picked up for years so hopefully things are better now

(Researcher)

I wouldn't be that confident because again you know I don't think we have resources to do kind of wide, big scale population sort of screening outside but I think when we are looking at kind of funding streams nationally my suspicion is that we would be reminded of the vast majority of hepatitis C infection rests within a particular population. We do not want to discriminate any population but if we are looking for effective prevention and treatment, that is where we have got to focus our efforts and to

some extent in a climate of shrinking resources I probably have to say I have a degree of sympathy with that because I do know if we effectively direct identification and treatment to within our drug using population, because we don't have any kind of vaccination for hepatitis C, I think from a health projection point of view what we need to do is to shrink that potential pool of infection to such a point where the likelihood of anyone acquiring hepatitis C through practices becomes remote so again it's that back drop for arguing but I don't think we would get there to be honest, that's no consolation for those people who find themselves in that situation...

(P5)

Yeah, yeah, I'm just reading on the hepatitis C Action website, there seems to be a focus on GP training.

(Researcher)

I am a real fan of locating more services within primary care and I think that probably applies to drug and alcohol treatment service but the problem is primary care, GPs are really under the hammer at the moment aren't they, they are not in a position to be taking on more and more, but from a public health point of view where better to deliver population health than within primary care. Those are the people that are seeing their community and I think perhaps not too far into the future we would like to see more involvement than there is now. What have traditionally been turned to specialist drug and specialist alcohol services in community I think any of those given the capacity, and I think that is the problem, that I don't think there is a capacity to do it, but if there were the capacity with primary care, I think primary care would quite comfortably pick up a lot of those kind of services and I think the nature of specialist service would perhaps be up scaled to more sort of kind of hospital treatments

(P5)

If you look at it on a weighting, the place where you need to get a change, to make something change quite quickly, is in primary care and I think that is why one of the significant things that the CCG has spoke about is an education package for GPs, so they would target first of all GPs, with the special interests and do it on the addictions GPs first of all and then see if they could have a lead within each neighbourhood so they have got colleagues to

talk to because the one thing that I have noticed the more clinicians I come across is they are very wary of doing anything that isn't got a policy, procedure and guidelines behind, they like everything, identify for them what we want them to do. So there is an awful lot of training and an awful lot of time needed, questions and answers and that for them really

(P3)

So hepatitis C Action have got a GP training package but I kind of feel like well you would only know about that if you were interested in hep C or you are looking for it....

(Researcher)

We have found that on quite a basic level, if you take alcohol, just to get, within GP practice to do the audit score, audit C is what three questions, the amount of time we have had to go round the houses on that. I suppose to give the GPs some defence they have got a whole host of other issues going on and this is just one, and it's like [P3] said it is having the champions within specific areas who take an interest in that and using their skills and knowledge to try and create something, it's almost like trying to create a model isn't it, it's almost like proof of concept, and saying yeah we know we can make it work but there is tons of practical issues so it's difficult to get there to say we have got a joined up model here.

(P4)

Although barriers were acknowledged, the participants did not have cohesive ideas on how to address and overcome them. Participant P3 explained that the CCG spoke of an education package on hepatitis C for GPs, but participant P2 felt it was the responsibility of the drug and alcohol service to remind GPs about hepatitis C.

And what about GP practices, do you know much about how GP practices test for hep C and refer on?

(Researcher)

Well again the drug service was connected to all the GP practices and we promoted the service through the shared care network and that was the expectation, and those were the frustrations. We have a shared care network that covers all GP practices, the hep C nurse is embedded in the drug service, the shared care workers should be part of promoting the hep C screening to all the GPs, if the GP has somebody on their books, who they think, it didn't have to be a drug user either, you know, if there's somebody that's at risk, so we're promoting it through the direct contact with GP practices in the shared care scheme, but I don't think it was being promoted as much, or as effectively as it could be and equally I'm not convinced that GP, and I do understand the situation the GPs in they, you now general practice, they're jack of all trades, they're looking at so many different things, hep C might not be, it might be a priority for us but it might not be a priority for them and it's a relatively small number of people that it affects, so that they're not as focused on hep C, but then that's the task of the service to keep pushing and keep agitating and keep raising the profile, so it's a constant ongoing.

(P2)

6.2.4. Stigma

Although there were many examples throughout the interviews of staff working to improve services for service users (as shown above), there were also accounts that displayed notions of stigma and prejudice towards PWID. Accounts showed evidence of: stigmatising terminology; personal views aligned with wider societal prejudice of PWIDs rather than professional reasoning; and inequity in service provision. Some actions and opinions were rationalised by financial constraints or by notions of clinical impression/nurse intuition.

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6.3 Chapter Summary

The professionals' experiences of drug, alcohol and hepatitis C provision have provided insight into working in and commissioning these services. Participants gave examples of initiatives to improve services, such as running groups on a voluntary basis and writing bids for new services, however findings largely constituted challenges and barriers to providing services. Difficulties were seen at staff, service and strategic levels. Lack of strategic direction for hepatitis C services, disparity between services, services not providing required provisions, different knowledge, advice and referrals between professionals and discriminatory views about service users were some of the findings. Ultimately the purpose of services is to provide for the people who are using the service, therefore there is value in considering how service users experience services. Chapter 7 compares the findings from the service user observation and interviews with the findings from the interviews with professionals. Thus providing a comparison of the professional and the lived experience of hepatitis C, alcohol and drug use.

Chapter 7 Discussion

7.1 Introduction

This chapter discusses the main findings from the research. Findings from the service user interviews, interviews with professionals and observation of hepatitis C support groups are discussed, considering the lived experience and professionals' experience of alcohol, drugs and hepatitis C. The overall research findings were barriers to service users accessing support for their hepatitis C. As explained in the introduction to this research, 'support' relates to a variety of help, including advice, testing, treatment and management of hepatitis C. Analysis of the results identified four main findings namely, alcohol, knowledge, stigma and services.

7.2 Alcohol

This research set out to explore alcohol use in PWID who have hepatitis C. Within the service user population of this research, findings showed a mixed picture of alcohol consumption. At the time of the research, some participants were dependent drinkers, some were abstinent and others were drinking lower-risk levels (as recommended for general population). Thus like the NTORS study of drug users in drug treatment in England (Gossop, 2002) this study also found that there was wide variation in drinking patterns amongst PWID, including abstinence in some. However the calendar method used in this research enabled lifetime alcohol to be considered, showing that alcohol consumption changed over time. Of those who were drinking lower-risk levels or abstinent at the time of interview, a third had a history of higher-risk or dependent drinking at some point in their lives. Higher-risk/dependent alcohol consumption also had a varied pattern amongst the participants, with some drinking prior to drug use (eight years prior for one participant), others overlapping drink and drugs and others started drinking after the drug use, with some drinking for a short period of time only and others becoming dependent on alcohol.

The majority of participants in this study were receiving treatment with OST (buprenorphine or methadone) at the time of the interviews. Therefore the question of whether PWID swap drugs for drink when on OST varied between participants, showing as per the studies analysed in the literature review that there is variation amongst PWID. Some participants in the research did increase drinking when on OST and their drug use had decreased, others were drinking at dependent/higher-risk levels prior to commencing on OST and others were abstinent on OST. However patterns of alcohol and drug use were found to be complex, with many factors impacting on a person's alcohol consumption over their lifetime.

One aspect the research aimed to explore was whether being diagnosed with hepatitis C affected alcohol consumption. The research found that all participants were aware of the dangers of drinking with hepatitis C, however all (except 2 participants who were abstinent prior to diagnosis) had drunk alcohol since being diagnosed. In response to the advice to stop drinking (or reduce if unable to stop) following a hepatitis C diagnosis, some participants did stop or reduce drinking, as found by other studies in the literature review (McCusker, 2001; Scognamiglio et al, 2007; Tsui et al 2007 and O'Leary et al 2012). However O'Leary et al's (2012) study found that those who drank to excess continued to do so following diagnosis. Whilst this was also a finding in this research, it was not just those drinking higher-risk levels whose drinking remained the same pre and post diagnosis, but also some lower-risk drinkers did not change the amount drunk following their positive hepatitis C result. This study (as in Ompad et al's study, 2002) also found that for some participants their drinking increased. Furthermore as this study explored lifetime alcohol consumption, rather than drinking a short time after diagnosis (Ompad et al, 2002 and Tsui et al, 2009), or a one off cross sectional consideration of alcohol regardless of time since diagnosis (McCusker et al, 2001 and O'Leary et al, 2012), it found that alcohol consumption was not fixed but changed over time.

Whilst hepatitis C was a contributing factor for some participants' drinking, for other participants having hepatitis C had no impact on their alcohol consumption, with partners drinking, drinking to cope and where participants were in their recovery from substance use being the main influences on alcohol consumption over their lifetimes. Elliot et al (2016) suggested an association between understanding about hepatitis C and alcohol and drinking behaviour, however like other studies (Kwiatkowski et al, 2002; Campbell et al, 2006; Noon et al, 2009), this study found that having knowledge on the effects of alcohol and hepatitis C, made little difference to drinking behaviours, especially over time.

For participants who had drunk at higher-risk or dependent levels, this research found that many did not seek help for their alcohol use, instead lowering their drinking by themselves, either by just reducing their alcohol or using substances (non-prescribed benzodiazepine or heroin) to help them reduce. For those who did seek help, narratives suggested that participants had received support in terms of brief interventions, however participants did not recognise this as support. The majority of participants were taking OST for their drug use, therefore it may be that advice and not medication for their alcohol use, was not deemed as support. Furthermore it appeared, as explained by Gossop (2013) that healthcare professionals were focusing on the perceived main substance (heroin) whilst underrating other substances (alcohol).

As per the literature (Nyamathi et al, 2008; Field et al, 2013), this study found that relationships with healthcare professionals was an important factor to accessing support for alcohol use. One participant noted that healthcare staff would not help him to have a home detox and consequently he did not ask for support again. As well as the negative impact of previous encounters with services, other barriers to seeking support for alcohol consumption included not realising drinking levels were harmful and not wanting help for drinking. Furthermore the vignette interviews highlighted that methadone and/or heroin use impacts on alcohol treatment options.

For those who continued to drink, one consequence found in this research (as per literature review) was that alcohol consumption is a barrier to receiving hepatitis C treatment. Historical accounts from the service users showed that they had to stop drinking to receive treatment, and observation of Group 1, confirmed that this exclusion still applied. The vignette interviews with professionals showed a much cloudier picture. Whilst all professionals agreed alcohol consumption was an exclusion for treatment, there were inconsistencies on the amount of alcohol people could drink and still receive hepatitis C treatment, thus abstinence was not suggested for every (hypothetical) service user. However 'heavy' (over recommended weekly units for general population) alcohol use was deemed as an exclusion for treatment, with (hypothetical) service users being advised to reduce or stop depending on their drinking behaviour (i.e. dependent or nondependent) and level of liver cirrhosis. Thus advice was not for treatment per se but rather general advice for the liver. Treating hepatitis C would aid the liver and, as noted in the literature review, treatment is possible in dependent/higher-risk drinkers and SVR rates are not affected by alcohol consumption (Le Lan et al, 2012; Tsui et al's, 2016). Furthermore even if treatment was shown to be less effective in people who use alcohol, it is not equitable to exclude them (Grebely et al, 2015), yet in this study 'heavy' drinkers were found to be excluded.

Terminology around alcohol use was found to be inconsistent throughout the interviews with professional (and the literature). Some professionals considering the vignettes used the terms 'heavy' and 'moderate' alcohol use, yet these are not clinical diagnostic terms and other professionals discussed 'drinking', but on further questioning they meant higher-risk or dependent drinking behaviours. This later finding was also found in the service user interviews, with participants misunderstanding 'do you drink alcohol?' to mean problem drinking (higher-risk or dependent). Therefore, many service users in the research said they had 'stopped' drinking, but were actually not abstinent, instead consuming alcohol at increasing-

risk/lower-risk levels. Service users in this research, like Harris's (2010) study, felt they were given mixed messages about alcohol consumption, which in this study, led to decisions on future alcohol use, being based on their own and peers' experiences rather than clinical advice. Harris (2010) suggests the lack of definite advice on whether to stop drinking or reduce by some healthcare professionals could be due to the lack of evidence on which amounts of alcohol actually affects hepatitis C progression (Bhattacharya and Shuhart, 2003; Hutchinson et al 2005). This finding calls for consistent terminology and clearer messages around alcohol use with hepatitis C, in order to enable support for service users.

7.3 Knowledge

One of the main findings from this research was the level of knowledge services users had about hepatitis C. Some services users had a good knowledge base with a few omissions in their understanding, but others showed a very poor level of knowledge, not knowing the most basic facts.

Routes of transmission were commonly misunderstood within the narratives. All service users who took part in the research had injected drugs at some point in their lives, either currently (at the time of the research) or in the past, however not all were aware that hepatitis C could be transmitted through sharing injecting equipment. Most participants (except one person) were aware that hepatitis C is transmitted through sharing needles, however some were not aware that it is also possible to get the virus through sharing the rest of the injecting equipment such as syringes, filters, spoons, water and tourniquets. This lack of knowledge is concerning, as the advice to not share injecting equipment is fundamental in preventing the spread of hepatitis C (along with other BBV).

Hepatitis C is mainly transmitted through blood to blood contact, however some participants showed a lack of awareness of this, thinking it could be transmitted through saliva, touch or the airborne route. *'Can I get it*

[hepatitis C] from sex, cigarettes? I've been washing cups in boiling water' (Andy). *'Do I have to wear gloves or mask?'* (Dan). Whilst it is possible to get hepatitis C through sex, the risk is small (2% risk of transmission; Athwal and Prince, 2017), with the risk increasing if co-infected with HIV or if exposure to blood occurs, however many participants placed disproportionate concern over the sexual risk making unnecessary restrictions on their lives and increasing the risk of becoming isolated (see stigma section below). *'I just knew that I couldn't have a relationship I just didn't wanna pass it onto a female, an unsuspecting female you know'* (Joe). One participant thought that hepatitis C could be caused by drinking alcohol, *'you can actually get it through drinking without being involved in drugs'* (Jack).

Furthermore many of the service users in this research showed a lack of knowledge about the disease and its natural history. Participants demonstrated a poor understanding of antibodies, spontaneous clearance, genotypes and the generally slow disease progression of chronic hepatitis C. There were also many accounts of incorrect comparisons with HIV. This lack of knowledge impacted on participants' understanding of hepatitis C testing, the management and prognosis of their disease and treatment. For example, misunderstanding that she had antibodies but not chronic hepatitis C, led *Sadie* to think she had hepatitis C for 4 years, before she understood that she had spontaneously cleared the virus many years before; *Kev* thought he could clear hepatitis C himself if he was not drinking and injecting; participants thought there was no cure for hepatitis C ('like HIV'), or that they were going to die very quickly after diagnosis; and lack of understanding about genotypes saw people attending Group 1, discussing wanting treatments that would not be suitable for the genotype of the disease they had.

As in the literature, (Craine et al, 2004; Khaw, Stobbart and Murtagh, 2007; Grebely et al, 2008; Strauss et al, 2008; Swan et al, 2010; Jordan et al, 2013; Harris, McDonald and Rhodes, 2014), this research found that lack of

knowledge about hepatitis C, disease progression, location of testing sites and availability of treatment were barriers to accessing testing and treatment. Although service users in the research had already been tested, there were numerous historical accounts of their experiences of being tested and how their lack of knowledge caused fear of receiving a positive result but also fear of the actual testing procedure. Some participants delayed a test due to fear of having to undergo venepuncture, finding on attending that it was a finger prick test. Most participants explained that they were not aware hepatitis C treatment existed when they were tested, increasing the fear of being diagnosed with the virus. However, throughout the research it was evident that many participants still did not have up to date knowledge about current treatment options. One participant had delayed treatment for years due to fear of interferon injections (amongst other reasons), and had only recently discovered from an old acquaintance that tablet (DAA) treatments were available.

Generally participants' narratives showed low levels of knowledge about hepatitis C, despite being diagnosed with the virus for years (ranging from 1 to 19 years) and attending drug and alcohol services.

Participants got their information about hepatitis C from a variety of sources namely; talking to others with hepatitis C; watching medical documentaries on television; watching television and reading about celebrities with hepatitis C; leaflets; the internet; attending groups and doing courses either at the drug services or in prison, attending hepatitis C support groups; receiving peer worker training or verbally from professionals.

There were however barriers noted with many of these methods. Regarding the internet, levels of computer literacy were mixed, some participants searched the internet whilst many others mentioned that they could not use computers, some participants were sceptical, mistrusting information on the internet and others feared using public computers due to the risk of

stigma and discrimination, (findings which cast doubt over the benefits of PHE's recent largely internet based hepatitis C campaign, for this population). Those who had received peer worker training were demoralised, feeling their knowledge was not valued as there was no structure in place to use peers or to update their knowledge. Leaflets were not read by all participants and there were numerous concerns with verbal information provided from professionals.

Vignette interviews with professionals working in drug and alcohol services, identified that not all professionals had correct knowledge about hepatitis C, providing incorrect advice on transmission and the criteria for hepatitis C treatment. Some of the professionals who commissioned services who were interviewed, suggested that professionals working at drug and alcohol services were reluctant to discuss hepatitis C with service users and required further training. Observation of Group 1, found that group leader *John's* knowledge was not up to date. Unlike the peer workers in the studies analysed for the literature review (Treloar et al, 2015; Bonnington and Harris, 2017) *John* had received initial peer worker training but had never had further training or supervision.

Concerns about the delivery of verbal information by healthcare professionals was also a finding. Some service users felt professionals used medicalised language that was difficult to understand, requiring the use of lay terminology and descriptions. Also the timing of information appeared to be important. For some participants information given at the time of diagnosis was not 'taken in', and others noted not being able to absorb information when they were under the influence of substances. Therefore it may be beneficial for professionals working with PWID with hepatitis C to regularly discuss hepatitis C with service users to check their understanding and to relay any missing information. Findings from this research suggest that hepatitis C was not discussed frequently with service users attending drug and alcohol services. Follow up interviews (ranging from 2 - 6 months after the initial interview) were conducted with 4 service users, finding that

there had been no progress between interviews, in terms of knowledge or progress along the care cascade. Indeed generally throughout the service user interviews, participants seemed to be ‘stuck’, unaware of the management plan for their hepatitis C or how to get retested or how to access treatment. Other participants said they were ‘waiting’ although many did not seem to know why they were waiting or what was delaying them from moving along the cascade to either being referred to specialist hepatitis C care or to accessing treatment. Whilst the reasons for this are not known, it was apparent from the service user interviews, observation and discussions of the ‘Kate’ vignette with professionals, that service users often had many other priorities, such as other health conditions or family commitments and that professionals working with service users also had many conflicting priorities such as providing OST and considering housing needs, that were more urgent than hepatitis C, so it may be that hepatitis C is not a priority. However this research also found that many service users who were taking part in the research, wanted to talk about hepatitis C to the researcher. Service users would see their keyworker at the drug and alcohol service first and then speak to the researcher after, often asking questions about hepatitis C. One participant said this was because the researcher had knowledge on hepatitis C and she felt ‘*comfortable talking about it*’ (see stigma section below) perhaps suggesting that she questioned the keyworker’s level of knowledge and confidentiality.

Whilst knowledge was generally low amongst the participants, the benefit of having knowledge about hepatitis C was demonstrated by a few. One participant did not express fear regarding her positive test result, explaining this was because she was already knowledgeable about hepatitis C and treatment through a family member’s experience. Other participants’ explained they were ‘not bothered’ about having hepatitis C once they were more knowledgeable about the virus, knowing there was treatment, they were not going to die imminently and they could not pass it on to others through social contact.

7.4 Stigma and Discrimination

Stigma was a finding at every stage of this research, during observation at the hepatitis C support groups and throughout the service users and professionals interviews.

The service users' lived experiences of stigma in relation to hepatitis C, showed that stigma affected many aspects of their lives. Stigma was experienced from family, friends and healthcare professionals, but perceptions of anticipated stigma pervaded throughout people's lives. As described in the literature (Butt, 2008; Joffe, 2011), stigma was experienced in relation to hepatitis C being an infectious disease but also due to its association with injecting drug use. Narratives of experienced and perceived stigma from family and friends were often connected to the infectious nature of hepatitis C, *'people come me house and they won't have a drink ..people have told me...they didn't have a drink coz I've got hep C' (Sharon)*.

Many service users talked about the dilemmas they faced around disclosing their hepatitis C status to friends and family members. This was often connected to the fear of stigma and being discriminated against. For some participants this meant they did not tell the majority of their family and friends that they had the virus. Narratives showed the difficulties of living with this 'secret', having to lie or omit information in conversations and hide hepatitis C related materials, such as clinic letters, for fear of others finding out. Not feeling able to talk openly about having hepatitis C impacted on social relationships as well as the amount of support afforded to those with the virus, and may explain why a number of the service users expressed enjoying the interview or 'feeling better' after the interview, *I'm made up I've got a little bit off me chest (Pete)*. Kath expressed how difficult it was to work with the fatigue she felt from her hepatitis C. Whilst Kath did not assign her non-disclosure at work to stigma, it leads to

questions as to whether another less stigmatised chronic disease such as diabetes would have been divulged at work and more support provided.

Rather than service users fighting against stigmatising views, the interviews, as in the related literature (Zickmund et al, 2003; Hill et al, 2014), provided many accounts of internalised stigma, where service users upheld wider societal views of people with hepatitis C being 'dirty' and 'like lepers'. As explained by Goffman (1990) the stigmatised are aware '*...to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility...*' (p.18). This was evident throughout the service user interviews, where the shame of having hepatitis C, and its connotation of being a '*dirty disease*', stopped many from disclosing their status, receiving support and increasing the risk of isolation. '*you feel like a leper an erm you know you're scared of people. With the hep C you're worried about them finding out about you know, you just feel really kind of erm, what's the word er cut off by it*' (Phil).

Participants who attended hepatitis C support groups (Group 1, or previous groups) felt they benefited as they received support, felt less isolated and realised they were not '*...the only one [with hepatitis C]*' (Susan). However, concerns over inadvertently disclosing hepatitis C status and the risk of being stigmatised impacted on the support afforded by support groups. Group 3 did not 'get off the ground', as concerns over hepatitis C related stigma led to difficulties in choosing a location that would maintain confidentiality and not expose those attending as having hepatitis C. Group 2 saw minimal attendance which the service users interviewed thought was due to a variety of reasons including the stigma associated with hepatitis C. Having to report to reception in front of others in the waiting room posed a risk of disclosing a hepatitis C positive status. Furthermore some participants felt unable to access information themselves, such as not being able to read hepatitis C leaflets in a waiting room and not feeling able to use public computers to search about hepatitis C, in case others saw and

presumed they had hepatitis C. Thus concerns over inadvertent disclosure inhibited people from gaining advice and information about the virus, and from receiving support from peers.

Many participants talked about past experiences of stigma with healthcare professionals. Unlike the experiences with family and friends, narratives showed a mix of stigma to both the infectious nature of hepatitis C and injecting drug use. '*...they'd [nurses] move away... put on 2 sets of gloves*' (Neil), '*..when they [hospital staff] hear of methadone, knowing you're a drug addict, they look at you differently and treat you differently I've found*' (Beth). However, narratives from the interviews with professionals did not find any stigmatising views connected to the infectious nature of hepatitis C. It is important to note that interviews were only conducted with healthcare professionals working in services that should be *au fait* with hepatitis C (drug and liver (alcohol and hepatitis C) services) and different results may have been found if interviews had been conducted with people working in other areas of healthcare.

As in other research (Butt et al, 2008; Swan et al, 2010), findings showed experiences of stigma in healthcare caused service users to feel judged, which ultimately posed as a barrier to support. For Neil the experience of stigma from nurses partly contributed to him discontinuing his hepatitis C treatment (although he was also having side effects) and for other participants past experiences of stigma affected how they viewed their current situation, impacting negatively on their health seeking behaviours. Whilst these are historic accounts of stigma within healthcare, unfortunately there was evidence of current discriminatory views amongst the healthcare professionals interviewed. Stigmatising perceptions were related to addiction, especially injecting drug use and narratives showed PWID were indeed *judged* by some of the professionals. Service users were not viewed as individuals but were grouped together based on their lifestyle behaviours. This stereotyping saw people with hepatitis C who had a history of injecting drug use being discussed as a homogeneous group whose actions

and even appearance was attributed to drug use. One professional referred to people with hepatitis C who had a history of injecting drug use as a '*type of people*', however from the observation and service users' interviews, it was evident that whilst there were some commonalities, the service users were individuals with diverse experiences and needs.

The literature review identified that PWID may mistrust staff working in drug and alcohol services largely due to the strict procedures around providing OST (Rance et al, 2012; Harris, Rhodes and Martin, 2013), however the research conducted for this thesis identified that some of the professionals interviewed showed a general mistrust of PWID. Furthermore, safety procedures at services were discussed by one professional, as a means to validate service users' accounts on alcohol use, rather than in relation to the safe prescribing of OST. '*Well you breathalyse her obviously. Ask if she's had problems with alcohol in the past. That might be the case but the thing is she's living in a hostel so as I said 90-95% of residents in hostels are drinkers or users, or both. So you wouldn't just say "ok, she doesn't drink alcohol" (P12).*

One of the main findings from the literature on peer workers, was that service users appreciated the support peer workers provided because they did not judge and were empathetic. Whilst some of the professionals interviewed, did show empathy, it was also evident that other professionals did not have empathy and did judge PWID. In contrast to this, the period of observation at Group 1, found '*John [peer worker] would accompany the group members to their hepatitis C hospital appointments. Group members appeared to value this support, informing John when their next appointments were and checking if he was free to go with them. John would also speak to people over the phone outside of the group time. John's support was sincere, steady and encouraging, without force or nosiness and was without doubt, appreciated by the group*' (Finding by researcher, in Chapter 4, observation findings).

The tone of the entry about the peer worker, in comparison to the professional's (P12) quote, shows the difference in approach between some healthcare professionals and peer workers towards PWID, supporting further the perceived notion that some healthcare professionals judge but peers are supportive.

As well as some healthcare professionals holding stigmatising views, organisational systems and structures also appeared to discriminate against PWID. Testing and treatment are two crucial requirements for people living with chronic hepatitis C who would like to clear the virus. However, this research found these services were not easily accessible for PWID.

Firstly, testing was not provided routinely by every drug and alcohol service. One of the professionals interviewed acknowledged that staff at her service had the skills to perform venepuncture and did collect blood samples for other purposes but were not funded to obtain blood for BBV testing. A recent initiative saw nurses from secondary care visiting the drug and alcohol services to test and refer people into secondary care, however they did not provide this service every day, or even every week at one drug and alcohol service. Testing is provided at GP practices and the genitourinary medicine (GUM - sexual health) clinic. It is however generally acknowledged that many PWID do not regularly visit their GP, and one of the professionals noted that '*the GUM clinic are a bit sick of addicts turning up asking for BBV screens especially if there's no sexual health risk*' (P12). As figures show over 90% of hepatitis C in the UK is transmitted through sharing equipment to inject drug (PHE, 2017e) and the risk of sexual transmission is around 2% (Athwal and Prince, 2017), this leads to questions as to why testing is not readily available where the service is needed most, requiring PWID to attend other services that provide testing, but where, because of their route of transmission, they are discriminated against. Thus the service structure for testing contributes to the marginalisation of PWID and presents barriers to accessing this support.

Hepatitis C treatment was also found to be affected by institutional factors. Some service users in the research noted that they had completed hepatitis C treatment but it had been unsuccessful, so were waiting for treatment again. Although some participants did not know why they were waiting (presumably for DAA treatment), one participant (*Phil*) knew he was waiting to meet the criteria for the new DAA treatment. None of the participants voiced concerns about having to wait for treatment, seemingly content to wait for their turn, but having effective treatment rationed is discriminatory and as Charles Gore (CEO of the Hepatitis C Trust) noted, “*it feels like people with hepatitis C are being picked on*”.

Interviews with professionals also highlighted injecting and alcohol use (at some levels) as barriers to receiving hepatitis C treatment (as found in the literature review). Whilst some professionals discussed concerns about engagement with treatment, one participant focused on people who receive treatment as being ‘good investments’ suggesting that those who consume alcohol with hepatitis C would not be good investments and should not receive hepatitis C treatment. This finding reflects the literature (Reidpath et al 2005; Paterson et al, 2007), noting that institutional stigmatisation occurs when people are not viewed to be worthy of social investment, and not complying with management of care (such as continuing to drink in this example) is deemed undeserving of investment. Contrasting hepatitis C with other diseases, people with asthma who continue to smoke, or those with high cholesterol who do not follow the recommended diet, are not excluded from receiving treatment, so people with hepatitis C should also not be excluded from treatment due to lifestyle factors. Treatment decisions should be based on clinical need rather than judgements on lifestyle behaviours, and as alcohol and hepatitis C in combination can lead to cirrhosis and hepatocarcinoma, there is a clinical need to reduce the risk of this disease progression by treating hepatitis C in those who continue to drink. This section has shown that discriminating against people who drink or inject is a barrier to accessing treatment.

Whilst alcohol was found to be a barrier to receiving hepatitis C treatment, another finding in relation to alcohol was that those who consumed alcohol at dependent or higher-risk levels were discriminated against by friends but also from the PWID community.

Many PWID in this research noted that ‘alcohol was worse than injecting’ drugs and commented strongly that they were “not a drinker”; an evident physical divide was noticed at one organisation with PWID and those who consumed alcohol (dependent or higher-risk levels) sitting in separate groups.

For participants who had injected but were also drinking (dependent/higher-risk levels) the stigma associated with substance use (drugs and alcohol) had caused friends to stay away, but those drinking also saw stigmatisation and lack of support from peers within the PWID community. As discussed previously, hepatitis C and injecting are stigmatised, so for those who also drink there is potential for a ‘triple stigma’ with greater risk of isolation and increased barriers to receiving support.

Furthermore, there was evidence that those who were trying to reduce or stop drinking may also become more isolated. Drinking is ubiquitous in the UK, so those who are trying to stop drinking may curtail social activities where drinking is involved, “*can’t go to the pub and watch football without drinking. Everyone’s drinking*” (Simon). Simon was “*thinking of stopping Sky [television] as people come around to watch football and bring beer*”. Harris’s (2010) study in New Zealand and Australia noted that due to stigma associated with hepatitis C, people found it hard to reduce their alcohol intake without raising suspicion amongst others, sometimes choosing to avoid social events rather than lying or disclosing their hepatitis C status. Whilst this was not found in this research, it was apparent that not drinking/drinking less reduced social activities amongst a population that

are already at risk of social isolation due to stigma associated with their hepatitis C and history of injecting drug use.

7.5 Services

The main finding relating to services, was that there did not appear to be a clear hepatitis C pathway from the drug and alcohol services to hepatitis C specialist support in secondary care. Many of the service users interviewed appeared to have been tested years ago, and have not progressed along the cascade of care. Some participants had reached specialist care but were deemed not suitable for treatment, others were treated but they did not clear the virus. Since then some participants had maintained contact with the specialists but did not know their plan of care and others had lost touch with the specialists and were trying to get back on to the pathway again but faced barriers getting a retest or accessing treatment. Furthermore, the interviews with professionals gave further insight into the issues, with some participants who commission services acknowledging that the pathway was fragmented, with no overall strategy of how to improve the pathway for service users. Some of the professionals who commission public health services were not aware of details on the continuum of the hepatitis C pathway into secondary care, which falls under the remit of CCG commissioners, despite PHE (2017d) calling for those responsible for commissioning to simplify pathways to increase access and uptake of hepatitis C treatment. Professionals working face to face with service users, also demonstrated a lack of cohesion and unstreamlined pathways, with varying referral routes, differing advice and a lack of awareness of other services' provisions.

Finances were also a barrier to service provision, dictating which services could and could not be provided, decisions which were not necessarily in the best interest of service users. Service users expressed frustrations at having to travel for numerous appointments, yet services which could be provided locally at drug and alcohol services were not being provided.

Although professionals discussed potential future plans to provide DAA treatment in the community at the drug and alcohol services, at the time of the interviews crucial hepatitis C testing was not even standard at every service. Whilst initiatives were in place to test and link into specialist care, these services were not every day, requiring service users to return for further appointments.

The recent change in commissioning from the Department of Health to local authority saw a reduction in funding, with professionals noting there had previously been more money, more resources and more healthcare professionals providing hepatitis C support. Therefore services were reduced and as one participant said *'this idea of spinning plates, well plates are falling off now, we have to lose some'* (P2). In addition, professionals acknowledged that *'hep C is not getting as much attention as it did'* (P2), a point that had not eluded service users, with many aware that services were providing less than they previously did. This was especially noted for peer support, with service users comparing previous peer support to the current situation, *"it's all these cut backs in it, that's the trouble, everything's being cut"* (Susan). Furthermore service users and professionals noted the 'eternal' retendering of services caused upheaval and uncertainty on service provision.

7.6 Conclusion

This chapter has discussed the main research findings, highlighting barriers to accessing and providing hepatitis C support. Thus not only have service users' barriers been explored but also the challenges that providers face are evident. For service users lack of knowledge, alcohol use and stigma were the main barriers to accessing hepatitis C testing, treatment and /or management of their disease, but also more informal support, such as from friends, family and peers. For professionals working in drug, alcohol and hepatitis C services, lack of strategy, financial restrictions and lack of cohesion amongst services are challenges to providing services and a

streamlined pathway between services for service users. Whilst it was evident through the professional interviews that efforts were being made to improve services, such as bidding for grants and implementing initiatives to improve testing and pathways into specialist care, there was also evidence of stigmatising attitudes as well as organisational and structural discriminatory practices towards PWID with hepatitis C. Consideration of stigma and discrimination as well as innovative working is required to support service users along the cascade of care to treatment.

Chapter 8 Conclusion

8.1 Introduction

The aim of this research was to explore experiences and meanings of alcohol use for PWID who have hepatitis C and to understand their needs and support requirements. More specifically the research set out to explore lifetime alcohol use, considering the relationship between injecting drug use and alcohol use, and also the impact of a hepatitis C diagnosis on alcohol and drug use. For support requirements, the research aimed to understand where information about hepatitis C and alcohol was obtained and what that information was, as well as exploring PWID perceived service needs (alcohol, drug, hepatitis C and general healthcare).

Research was conducted with both service users (PWID with hepatitis C) and professionals (people working face to face with service users and public health commissioners) enabling exploration of this topic from different perspectives, thus providing the lived and professional experience of alcohol use and hepatitis C.

This chapter concludes the thesis, including; a summary of the main research findings, the strengths and limitations of the research, the contribution to knowledge and recommendations for the future.

8.2 Summary of the main findings

Alcohol consumption varied greatly between participants. A mix of, lower-risk drinking (as recommended for the general population, who do not have liver disease), increasing-risk drinking, higher-risk drinking, alcohol dependence and abstinence, was evident amongst the participants at the time of the research. However it was also evident that alcohol use (and drug use) altered over time for each individual with many factors influencing consumption. The relationship between drug and alcohol use

varied amongst participants. For some participants alcohol use started before drug use, for others alcohol use started or increased when heroin use decreased such as when they were on OST, others had a period of higher-risk alcohol use many years after heroin use had decreased, some decreased alcohol as they decreased heroin and were abstinent from all substances, and others decreased their alcohol use over time unconnected to their heroin use. Thus alcohol use fluctuated over time and for many was irrespective of heroin use.

Considering whether a hepatitis C diagnosis affected alcohol use and drug use, findings about drug use were difficult to ascertain. Most participants had made changes to their lifestyle before receiving a hepatitis C diagnosis; for example those who attended drug services for OST received a hepatitis C test at the drug service, indicating lifestyle changes in terms of heroin reduction was prior to the test. For others hepatitis C testing occurred amongst another event, such as being admitted to hospital with a groin abscess, making it unclear which factor led to stopping injecting.

Regarding alcohol use, all participants were aware that alcohol expedites hepatitis C, however having the virus was not generally the main factor affecting long term alcohol use. For some participants having hepatitis C was a partial factor for changes to consumption, but generally different factors influenced drinking at different points in a participant's life, often with multiple aspects having an impact on alcohol consumption at any one time. Rather than hepatitis C, the main influences on alcohol consumption were, partners drinking, drinking to cope, where participants were in their recovery process from substance use and needing to reduce or stop alcohol for hepatitis C treatment.

All participants (except one, who had not been dependent on heroin) had sought help to reduce heroin use and had received OST, yet of those who had experienced higher-risk or dependent drinking, many did not seek help for their alcohol use. Barriers to accessing support for alcohol were; lack of

knowledge that their drinking levels were harmful, not wanting help for drinking and previous negative encounters with alcohol services. Participants felt they reduced alcohol without support. Whilst some had used other substances to reduce their alcohol consumption, many of the narratives described using harm reduction techniques (such as reducing the strength of alcohol they drank). It was not ascertained where participants had learnt these harm reduction techniques, although it is possible this was from healthcare professionals but participants did not recognise this as support. Healthcare professionals working in alcohol services, use intuition to decide if service users can have certain alcohol treatments (such as a home detox). Professionals felt this subjective assessment rather than adhering to a framework was a facilitator to alcohol treatment for some service users.

Alcohol was found to be a barrier to receiving hepatitis C treatment, however not all levels of alcohol consumption were an exclusion, and messages from healthcare professionals were not always to be abstinent from alcohol as per recommendations. Despite other research studies showing that higher-risk levels of alcohol does not affect SVR rates, and that it is possible to treat people who are alcohol dependent/drinking higher-risk amounts, this population were excluded from hepatitis C treatment in this study (until they changed their drinking). Thus, some service users in this study felt they could not access support for their alcohol use and would therefore also be currently unable to have hepatitis C treatment.

Messages around alcohol use and hepatitis C were mixed. Some participants who drank alcohol felt they had not received advice about drinking with hepatitis C, whilst others who were not told to stop drinking felt advice was unclear. Furthermore this research found inconsistencies and misinterpretation of the terminology used around alcohol. Healthcare professionals used informal terms that were not clinically recognised (such as 'heavy') and service users (and some professionals) misinterpreted terms

which led to confusion. 'Drink' and 'stop' were two such terms, with service users expressing they did not drink or had stopped, when they were not abstinent from alcohol and health professionals said drinking was an exclusion for treatment meaning drinking at higher-risk levels/dependency was an exclusion.

Service users deemed 'Do you drink?' to mean an addiction to alcohol, with discussions showing stigmatising views from PWID to those who do consume alcohol at higher-risk levels. Discrimination of those who were dependent/consumed alcohol at higher-risk levels increased the risk of isolation. Furthermore the ubiquitous nature of alcohol within England, also presented dilemmas for those with hepatitis C, with participants avoiding social activities in order to avoid drinking alcohol. Thus dependent/higher-risk drinking and trying to reduce or stop alcohol, were both found to be exclusionary, increasing the risk of social isolation for PWID with hepatitis C.

As well as alcohol, other barriers to accessing hepatitis C support were identified in this research. Furthermore barriers to providing hepatitis C support were also identified. Barriers were found at service user, service and strategic levels.

For service users, as well as alcohol; lack of knowledge, fear, stigma and having other priorities were the main barriers to accessing support for their hepatitis C, with each of these factors impacting on the other factors and having an accumulative effect. For example, stigma and fear of perceived stigma, affected service users' self-worth, impacting on their willingness to use computers or read leaflets about hepatitis C in public areas or to ask professionals about hepatitis C, which therefore affected their knowledge. Other examples were; not having knowledge on hepatitis C increased fear, other priorities impacted on the time and effort service users gave to getting support to learn, manage or treat their hepatitis C and conversely lack of knowledge led to de-prioritisation of hepatitis C. Many service users

did not discuss their hepatitis C with health professionals due to a mistrust of healthcare professionals based on previous experiences of discrimination or conversely service users trusted healthcare professionals were overseeing their hepatitis C care, unquestioning as other aspects of their life took priority. Ultimately these barriers prevented service users from accessing support and progressing along the care cascade.

Whilst there were many examples of professionals working hard to facilitate services for PWID with hepatitis C, such as applying for grants to fund new services and working in innovative ways to improve services, there were also examples of service level barriers to PWID with hepatitis C receiving support.

Commissioners suggested some professionals working with service users were reluctant to discuss hepatitis C and service users noted poor communication from health professionals as a barrier to support. Language and terminology used around hepatitis C and alcohol was difficult to understand and there were omissions in information provided. Some healthcare professionals provided information but lacked knowledge of hepatitis C, giving incorrect information about transmission and symptoms. Knowledge on services was also incomplete, with professionals not being aware of the services provided by other organisations or sometimes within their own organisation. Furthermore some professionals were unknowledgeable on other services criteria and the pathways between services, resulting in service users not being referred and ultimately not progressing along the pathways to hepatitis C (and alcohol) support.

Professionals working with service users also demonstrated a need to prioritise care, having many aspects to consider which required prioritisation above hepatitis C as were more urgent in nature. Thus other priorities were barriers to providing hepatitis C support.

Finally, although service users talked of historic experiences of discrimination from healthcare professionals there was evidence that some professionals, despite choosing to work in drug, alcohol and hepatitis C services, do currently hold stigmatising views on PWID with hepatitis C. This finding supports service users' perceptions that healthcare professionals judge them, and that stigma still exists, which provides an ongoing barrier to PWID accessing services.

As well as the professionals working within services, the services themselves also posed barriers to PWID accessing support for hepatitis C. One example was that drug and alcohol services did not routinely offer hepatitis C testing, a key service for PWID. Whilst finances drove service provision, decisions could also be deemed as discriminatory, as testing provisions were available in sexual health services despite the small risk of sexual transmission compared to the high risk of transmission from sharing injecting equipment, posing questions as to why services are not directed to where the need is highest.

Regarding finances, the restructuring of public health commissioning from NHS to local authority, saw a reduction in funding as well as resources for drug services and hepatitis C. Professionals who commissioned drug and alcohol services noted they were now required to consider a diverse range of issues with hepatitis C not getting 'as much attention as it did'. The lack of funding was noted by service users, who were aware that services were being cut back, especially peer initiatives. Furthermore hepatitis C pathways were fragmented and there was an overall lack of strategic direction for hepatitis C services.

8.3 Strengths and limitations of the research

This research has added to the current body of literature on alcohol use in PWID who have hepatitis C. However rather than taking a cross sectional approach or considering alcohol use for a short period of time post hepatitis

C diagnosis as per other studies, this study has explored lifetime alcohol use for participants. Thus it has been possible to explore the long term impact a hepatitis C diagnosis has on alcohol use, furthering understanding of the support requirements for PWID with hepatitis C.

As this research was inductive in nature and used methods that encouraged participants to 'talk freely', it not only explored experiences of alcohol and hepatitis C, but also found out a vast amount of information about barriers (and to a lesser degree facilitators) to accessing services. This is a strength of this research as, 1) the findings are topics important to service users. Although PPI was not used as much as initially intended the research did enable the lived experience of service users to be heard, 2) this information should be of interest to those working (in whatever capacity) in the fields of substance use and/or hepatitis C, 3) demonstrates the benefits of using a generic qualitative research design which allows a pragmatic choice of methods to explore topics.

Another strength of this research is that the topic has been explored from three different perspectives, that of service users, professionals working with service users and professionals who commission services. This has enabled a multilayer consideration of the topics, allowing perspectives to be compared and contrasted but has also highlighted how the challenges faced by each group interrelate and impact on the other groups.

A great deal of consideration was given to where participants were recruited from. This decision was made with the research questions, aims and objectives in mind. What did I want to find out and where should I go to find this information? As around 90% of hepatitis C cases in England are transmitted through sharing injecting drug paraphernalia, it was logical to recruit participants for the service user interviews at drug and alcohol services. These services provide both drug and alcohol support so if PWID with hepatitis C were also seeking help for alcohol I would capture this population here and I would also capture PWID with hepatitis C who were

not seeking help for alcohol. If I had attended an alcohol service there may have been some service users who had hepatitis C but the majority would not so it would be difficult to find participants meeting the study inclusion criteria. Also I would not have found the diversity in drinking patterns that I found in this research, as everyone at alcohol services are seeking help for drinking. I also considered recruiting participants from hepatitis C clinics in a hospital however I decided against this as I did not want to solely recruit people who were accessing hospital services. I thought more service users meeting the inclusion criteria would be found at the drug and alcohol service than a hospital and also the sample would be more heterogeneous at a drug and alcohol service. By recruiting participants from the organisations I attended I found barriers to accessing services for hepatitis C and/or alcohol that I would not have found by interviewing those already attending hospital services.

The professionals recruited to this research were chosen based on the speciality and location within which they worked. For the front line staff (vignette) interviews, participants were recruited from drug and alcohol services, a community alcohol service, a hospital alcohol service and a hepatitis C hospital service (which also provided an outreach hepatitis C service at the drug and alcohol services). These services were chosen deliberately as they provided services that were mentioned in the service user interviews and period of observation. By interviewing staff from these services further in-depth information on the emerging themes from the service user interviews was obtained along with providing services a chance to tell 'their side of the story'. Commissioners were chosen based on their geographical locations, which were the areas the research was conducted in. This enabled service provision to be considered from a further angle.

In considering the limitations, firstly it is important to note that the PWID who participated in this research were attending services. Thus the experiences of PWID who do not engage with drug, alcohol and hepatitis C services were not captured in this research, which may have produced

different results. As WHO targets on reducing hepatitis C mortality draw closer, there is an increasing need to diagnose and treat hepatitis C, therefore understanding the experiences and needs of those who do not engage with services is vital. Arguably this population are the most important, albeit the most difficult, to support.

Furthermore certain groups of professionals were not interviewed for this research. Keyworkers at drug and alcohol services, GP's and CCG commissioners may have added further insight into the topics explored. Keyworkers may have been able to provide further understanding on whether hepatitis C is discussed in appointments with service users and why service users appear to be 'stuck' and not progressing along the care cascade. Permission to interview keyworkers was not granted. This is a limitation, however, this was unfortunately out of my control. CCG commissioners' views on the hepatitis C pathway from community services to hepatitis C specialists and treatment in secondary care would have been of interest for this research. GP's were discussed by commissioners in this research, as needing to increase hepatitis C testing and referral into secondary care, but also it was noted by professionals and services users that PWID tend to not to visit their GP. Therefore it would have been of interest to explore GP's perspectives on services for PWID who have hepatitis C. Preliminary discussions about the research did occur with one GP. The GP was keen to help however after consideration of the necessary ethics and site approval required to be able to conduct research at this GP practice it was deemed too difficult to proceed. As the approval process was likely to be protracted and data collection with the service user population had taken longer than foreseen it was decided amongst the research team working within the time constraints of a PhD, to cease the primary care 'line of inquiry'.

To explore general healthcare needs for PWID was one of the research objectives, which was not explored in detail during the course of this

research, largely due to the amount of other information captured during data collection. Interviews with service users and GPs may have been able to provide an insight into this objective.

8.4 Contribution to knowledge

This research has explored experiences of alcohol use and hepatitis C in PWID and their support needs, as per the research aims and objectives.

The main contribution to knowledge from this research is that it explores the lived experience. As discussed in the conceptual framework little is known about the lived experience of alcohol and hepatitis C in PWID as historically research on this topic is quantitative in nature. The only previous study (Harris, 2010) considering the lived experience of alcohol and hepatitis C in PWID was conducted in Australia and New Zealand, so to my knowledge this research is the first study exploring this in England. As PWID are generally considered to be a marginalised hard to reach population, and injecting drug use and hepatitis C are stigmatised topics which are not freely discussed, the insights this study provides into the lives of people with these experiences is valuable for people working in services and policy makers.

Alcohol

This study has found a wide variation in drinking patterns which adds to the current body of knowledge on this topic. Whilst the majority of historic research focuses on ‘heavy’ alcohol consumption within the PWID population (Arasteh and Des Jarlais, Arasteh et al, Hahn et al, Howe et al, cited in Le Marchand et al, 2013) this study has like the NTORS study (Gossop et al, 2002) found that not all PWID drink large amounts, with some people drinking moderate or lower levels (for general population without hepatitis C) and actually some PWID are abstinent. As noted in the literature review, abstinence is a ‘little discussed’ point with Gossop,

(2013) recommending further research on abstinence in drug users. This research adds to this body of knowledge.

The variation in drinking was also evident across the population of people taking OST, adding to the debate as to whether PWID swap drugs for alcohol once on OST (Stastny and Potter, 1991; Staiger et al, 2012; Henriquez-Gonzalez and Patton, 2013). The findings show PWID who take OST are not a homogeneous group and there is variation in lifestyle behaviours and therefore support requirements.

In the conceptual framework, Neale's (1997) work on rethinking theory in homelessness was discussed. Drawing parallels between homelessness and PWID with hepatitis C as both are marginalised hard to reach populations, Neale's theoretical assumptions were considered. One assumption was 'the differences between homeless individuals are multiple and are not adequately explained by theory', the findings on variation in alcohol consumption in PWID supports this theoretical assumption for the study population.

The debate from the historic literature considered whether people decreased (McCusker et al 2001; Scognamiglio et al, 2007; Tsui et al 2007; O'Leary et al, 2012), increased (Ompad et al, 2002) or there was no change (Ompad et al, 2002; Kwiatkowski et al, 2002; Wang et al, 2014; Elliot et al, 2016), to alcohol consumption following being diagnosed with hepatitis C. This research also considered this, again finding variation amongst the sample, however the most illuminating point about alcohol consumption found in this research was that every service user had drunk alcohol at some point during the time they had hepatitis C (except two participants who were abstinent from alcohol prior to their hepatitis C diagnosis) despite recommendations being to be abstinent from alcohol (Royal College of General Practitioners (RCGP), 2007; O'Leary et al, 2012; SIGN, 2013; NICE, 2016b). All of the service users were aware that drinking with hepatitis C increased the risk of liver damage. Descriptions of their experiences,

reasoning and meanings of alcohol demonstrated social, historical and cultural influences on drinking behaviours, such as the role alcohol has in socialising within this country and the stigma associated with drinking amongst PWID (discussed below). Consideration of these influences may mean that people with hepatitis C choose to drink. These findings are important for health providers working with people who have hepatitis C to consider. Furthermore the findings on language around alcohol will be of interest to health providers. The research found that ‘do you drink alcohol?’ was intended by the researcher to mean any alcohol, but interpreted by the participants to mean dependent on alcohol or drinking large amounts. This finding is an important contribution to knowledge, requiring staff to check patients/service users understanding when discussing alcohol. Furthermore this research also found that staff provided varied advice about alcohol and hepatitis C. This was previously found in the literature review, however these studies were based in USA (Blixen et al, 2008; Stoller et al, 2009a) and Australia and New Zealand (Harris, 2010), so this finding from England adds to this body of knowledge.

Grebely et al (2015) suggested people who were drinking should receive hepatitis C treatment. However this research found that people could be excluded from hepatitis C treatment based on certain levels of alcohol use. As there appears to be no scientific rationale for this practice this point requires consideration by those working to provide services for people with hepatitis C, to ensure services are equitable for all.

Knowledge

This research found that there was generally a low level of knowledge on hepatitis C amongst the service users in this research, despite the fact that they were attending services at the time of recruitment. Routes of transmission, disease progression, natural history of the disease, testing procedures, testing sites and treatment were all areas that people required further information on. These findings are important local contributions to knowledge. Although similar findings were cited in the literature review

(Craine et al, 2004; Khaw, Stobbart and Murtagh, 2007; Grebely et al, 2008; Strauss et al, 2008; Swan et al, 2010; Jordan et al, 2013; Harris, McDonald and Rhodes, 2014), these findings will be of particular interest to local providers aiming to increase testing and treatment and to decrease the risk of reinfection. On a wider scale these findings are important as show that the challenges to increase knowledge amongst PWID about hepatitis C still exist.

From conducting the service user interviews it appeared that hepatitis C was not discussed frequently with service users at appointments. Due to circumstances out of my control I was unable to interview staff at these organisations, however the vignette interviews with (more senior) staff from other organisations found gaps in the staffs' knowledge. Provider knowledge is an important factor in increasing testing and treatment (Swan et al, 2010; NICE, 2012c; Jordon, 2013). Locally this finding should be of interest to providers, with a view to increasing hepatitis C testing and treatment.

There is also a need to address agency on the part of service users to take responsibility for furthering their own knowledge. The benefits of peer support in providing information was witnessed at the hepatitis C support group and mentioned in the service user interviews, however these support mechanisms could be utilised further. Peer support (especially hepatitis C support groups) appeared to be diminishing locally, yet the benefits were evident in the literature review and from the findings of this research.

Stigma

Whilst the stigmatisation of injecting drug use and hepatitis C, is well documented in the literature, this research has found that those with alcohol dependency or consuming alcohol at higher-risk levels, experience further discrimination due to their drinking, including stigmatising perceptions from other PWID who do not drink such amounts, increasing the risk of isolation. Participants who injected drugs, had hepatitis C and drank

experienced a 'triple stigma'. Those experiencing this compound stigma appeared to have poorer outcomes in terms of their physical health but also described more experiences of loneliness and social exclusion.

Also exploring the meanings of alcohol use for PWID with hepatitis C, found that those trying to reduce or stop drinking avoided social situations where alcohol would be consumed. Thus both drinking and not drinking was found to be exclusionary and reduce contact with others.

Furthermore, although the literature provides examples of stigma from healthcare professionals towards PWID with hepatitis C, this research has shown that stigma remains a current issue and is still a barrier to PWID with hepatitis C accessing support.

Barriers to alcohol support for PWID were also identified (previous research analysed, was based in Ireland and USA), with one such barrier being previous negative experiences when accessing support. There appears to be a need for non-judgemental support from healthcare professionals towards those seeking support for substance (including alcohol) use and hepatitis C.

Services

The main finding relating to services was that there was not a clear pathway from drugs and alcohol services to hospital based hepatitis C specialists. Again this finding adds to the contribution of knowledge at a local level, but may be transferable and provide insight to other geographical areas of England. Providers, policy makers, commissioners, are all required to 'get on-board' to ensure a less fragmented pathway to specialist hepatitis C care. Many of the service users on this study were 'stuck', having received a positive test result many years before but not progressing along the care cascade into specialist hepatitis C care with the ultimate aim to receive treatment. If we are to eliminate hepatitis C by 2030 the pathways to treatment need to be streamlined.

Treatment also needs to be provided in settings other than hospitals. The professionals in this research discussed future plans of providing hepatitis C treatment in community settings and in particular at the drug and alcohol services, however at the time of the interviews this was not in place and testing was also not available every day at these services. Some of the service users in the research wanted to be retested but were unaware of where to go for a test and wanted treatment but did not know how to get referred for treatment but were attending the drug and alcohol services for appointments. Providing testing and treatment from drug services needs to be considered.

Methodological innovation

The application of the LHC in this research has been appraised at length in section 3.6.6 indicating the benefits and limitations of the method. The main methodological advances are noted here. Firstly LHC's have previously been used with PWID (who may or may not be on OST); to consider alcohol use; to consider substance use; to explore different aspects of hepatitis C; and have been used qualitatively, but have not previously been used to explore these topics in combination. This research has shown that a LHC can be used successfully to explore and understand the experiences of alcohol use and hepatitis C in PWID. The main advantage of the calendar was the dual approach of being able to hear the person's account whilst visualising the data on the calendar. This was helpful for both the researcher and participants to explore the topics in depth.

The vignettes were also innovative as were designed by the researcher based on the findings from the service user interviews and observations. Although vignettes have previously been used with healthcare staff to understand the factors affecting decision making and management of health conditions and to see gaps in services, they had not previously been used to consider hepatitis C and alcohol services for PWID. The vignettes produced interesting and valuable findings. Some of the professionals interviewed asked for more information such as clinical results to aid their

clinical decision making. As these were not available (as were not part of the vignette), this benefited the research further as the participant would then describe the service they would give under a variety of circumstances.

8.5 Future recommendations

A number of barriers to accessing and providing hepatitis C (and alcohol) services have been identified in this research. These barriers require consideration to improve services for PWID. Future recommendations for service users, service providers and policy makers are noted below.

Service users

Peer support locally appeared to be diminishing. As shown by this research and the corresponding literature, peer support can provide information, stop those with hepatitis C feeling isolated and forge links between service users and services. More work is required locally to explore why attendance is poor and to re-establish successful peer networks.

Service providers

Service users lacked knowledge on hepatitis C and found messages around alcohol use to be unclear. There appears to be a need for healthcare professionals to discuss hepatitis C and alcohol with service users, providing additional and more frequent information and advice, and using language and terms that service users understand. Further research is required to establish whether keyworkers working in community drug and alcohol services, discuss hepatitis C with service users and to understand what information is discussed or reasons why hepatitis C is not discussed. The research also found that there were gaps in some professionals' knowledge on hepatitis C, as well as a lack of knowledge on criteria for referral to other services and hepatitis C and alcohol pathways. Furthermore, some service users in this research were not progressing along the care cascade despite regularly attending drug and alcohol services. There appears to be

a training need for professionals working in services, which again would be of interest to explore with further research.

Stigma from healthcare professionals was another barrier for service users accessing services. As historic incidents of discrimination affect current health seeking behaviours, there is a need for professionals to be non-judgemental towards PWID with hepatitis C to build trust in professional/service user relationships, and increase access to support. Professionals may require training on caring for people with addictions (alcohol and PWID), however Paterson et al (2007) note that education and understanding is not a guarantee that this will be integrated into clinical practice.

Locally commissioners need to work with services and service users to establish services and non-fragmented hepatitis C pathways, which enable service users to progress from testing to specialist care and achieving SVR.

Policy makers

Substance use (alcohol at certain levels and injecting drug use) was found to be a barrier to accessing hepatitis C treatment. Further published research is required to provide evidence on treating those drinking and injecting. Furthermore providing hepatitis C treatment to people who use substances needs to be supported by policy.

8.6 Final personal reflections

This research has been interesting, enjoyable and challenging and I have learnt much throughout the process. Although I have worked in clinical research for many years, this PhD has given me the opportunity to design my own research and undertake research methods for the first time. The period of observation was far more challenging than I initially perceived it to be, requiring me to think carefully about many aspects, such as how to access the field, how to dress, how much to interact and how to leave the

field. This experience provided points of learning which I would consider prior to conducting observation again in the future. As a method, the period of observation worked well in building rapport with service users and enabling me to gain an understanding of issues surrounding hepatitis C and addiction, but the observation did not provide service users to be interviewed as per the initial study design. Although there were service users who enquired about taking part in the interviews, they had unfortunately stopped attending the support group by the time I started the interviews. I had missed an opportunity. The learning point from this being to not delay interviewing and seize the moment if people are asking to take part as they might not be available another time. In the future I would not set up participant recruitment in this way.

I enjoyed designing the calendars and the vignettes used in the interviews, as well as reading about how other researchers had developed and used these methods. On reflection the calendars and vignettes worked well but if I used these methods again I would consider involving participants in the design by either doing more pilot interviews or focus groups to aid development as there were points that could have been improved. For the life history calendar the historical events down the side were not used and for the vignettes one professional appeared uncomfortable, changing what he was saying on numerous occasions. There is further research to be done here on asking participants how they experienced using vignettes.

Ultimately regarding data collection I feel privileged to have been able to spend time with participants, especially the service users who spoke openly about their experiences and feelings despite the topics of discussion being personal, emotional, and highly stigmatised. I am also grateful for the services who allowed me to conduct the research in their organisations. There were particular members of staff in the organisations who were very supportive, assisting with finding participants and finding space for me to conduct interviews. This is one aspect of the research that I am proud of as

I worked very hard to build the collaborations with organisations and the relationships with staff.

Initially I planned a PPI approach, working in collaboration with service users on every aspect of the research. Unfortunately, this was not possible however in hindsight this seems ambitious for a PhD project when the group was not already set up and the relationship between the university researcher and group was not established, especially considering the short timeframe for PhD completion. PPI would have required frequent meetings, training, consideration of boundaries and confidentiality between service user researchers and service users participating in the research, gaining access to organisations and so on. However, I would like to undertake further PPI work in the future as believe it is important to have patients/public/service users involved in research.

Although organisations were willing to support this research there are points of learning that I would consider when choosing organisations for future research. In hindsight I should have spent more time finding out about the services prior to commencing data collection. An example being that I was trying to conduct follow up interviews at a service with a 'drop in' not appointment system, so I was unable to know when participants would be visiting the service again. The other service I attended had scheduled appointments so I could see when participants would be returning to the service and then see them for the research at the same time. Another point for future research is that I would also spend more time checking services understood the requirements of the research. For this research despite meetings and explanations of the research requirements, one service misunderstood how long the interviews would take and booked participants in slots that did not give enough time to complete the interviews using the correct technique.

As well as data collection this research has given me the opportunity to learn other research skills such as transcribing, data management using

Nvivo and data analysis. Also during the course of this PhD I have had the opportunity to get involved in many aspects of academia, including attending conferences, presenting at conferences, giving lectures to undergraduates, marking assignments and supervising students. I particularly benefitted from presenting a poster at the INHSU (The International Network on Hepatitis in Substance Users) conference in Oslo in 2016, as had the opportunity to meet experts in the field, authors whose research I had read and have referenced throughout this thesis.

Lastly, this research has been challenging throughout, requiring personal qualities of perseverance and resilience to reach completion. The motivation behind completing this research was the desire to understand and improve situations for people living with hepatitis C which I intend to continue exploring in the future.

8.7 And finally...

Hepatitis C disproportionately affects populations who are marginalised and have poorer access to healthcare and health outcomes. Despite hepatitis C being preventable and curable, millions of people around the world are living with the virus. In the UK thousands of people have chronic hepatitis C. Yearly surveys of PWID, suggest that only around half are aware of their hepatitis C antibody positive status; a figure which has remained stable over the last 6 years. And historically only around 3% of people with chronic hepatitis C accessed hepatitis C treatment. Whilst the introduction of DAA medications has seen an increase in the numbers treated over the last few years, the fact remains that many people are undiagnosed and therefore untreated. However even if people are diagnosed, they may not go on to access treatment.

The WHO has set targets to eliminate hepatitis C (and B) by 2030. If the targets are to be met and hepatitis C eliminated, concerted efforts are required to increase diagnosis and treatment. Understanding barriers to

accessing and providing, testing and treatment is vital to increase uptake, along with understanding the barriers that prevent those already tested from linking into hepatitis C specialist care. In the words of Public Health England:

“much work has been done, but there is still much to do”.

(PHE, 2018a p.5)

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Appendices

Appendix 1 Ethical Approval

From: Williams, Mandy
Sent: 30 July 2014 12:05
To: Evely, Jane
Cc: Hay, Gordon
Subject: Ethical Approval

Dear Jane

With reference to your application for Ethical approval

14/EHC/050, Jane Evely, PGR, Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services (Dr Gordon Hay).

Liverpool John Moores University Research Ethics Committee (REC) has reviewed the above application and I am pleased to inform you that ethical approval has been granted and the study can now commence.

Approval is given on the understanding that:

- any adverse reactions/events which take place during the course of the project are reported to the Committee immediately;
- any unforeseen ethical issues arising during the course of the project will be reported to the Committee immediately;
- the LJMU logo is used for all documentation relating to participant recruitment and participation eg poster, information sheets, consent forms, questionnaires. The LJMU logo can be accessed at <http://www.ljmu.ac.uk/corporatecommunications/60486.htm>

Where any substantive amendments are proposed to the protocol or study procedures further ethical approval must be sought.

Applicants should note that where relevant appropriate gatekeeper / management permission must be obtained prior to the study commencing at the study site concerned.

For details on how to report adverse events or request ethical approval of major amendments please refer to the information provided at <http://www.ljmu.ac.uk/RGSO/93205.htm>

Please note that ethical approval is given for a period of five years from the date granted and therefore the expiry date for this project will be July 2019. An application for extension of approval must be submitted if the project continues after this date.



Mandy Williams, Research Support Officer
Graduate School, Research and Innovation Services
Kingsway House, Hatton Garden, Liverpool L3 2AJ
t: 01519046467 e: a.f.williams@ljmu.ac.uk

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Appendix 2 Participant Information Sheets

Participant Information Sheet – Gatekeeper
LJMU REC No.:

Version 1.0, 28th July 2014



LIVERPOOL JOHN MOORES UNIVERSITY PARTICIPANT INFORMATION SHEET

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Name of Researcher and School/Faculty: Jane Evely, Faculty of Education, Health & Community

Service users from your organisation are being invited to take part in a research study. You are being invited to take the role of a gatekeeper for part of this research. Before you decide, it is important that you understand why the research is being done and what it involves. Please take time to read the following information. If there is anything that is not clear or if you would like more information, please ask. Feel free to talk to other people about the study, such as colleagues, service users and friends.

1. What is the purpose of the study?

We are interested in talking to people in drug treatment/support services who have injected drugs and have been diagnosed with hepatitis C at some point in their lives. The overall study aim is to increase understanding of injecting drug users' health care needs with view to improving services. We would like to understand more about alcohol consumption in injecting drug users. We would also like to understand where information about alcohol is obtained, what this information is and how this information is perceived by people who inject drugs or have done in the past.

2. What will the study involve?

The research will be in two steps:

- 1) Period of familiarisation
- 2) Interviews

Period of familiarisation

The researcher who is from John Moores University, will spend time at the drug treatment/support centre, where the participants will be recruited from. The purpose of this being for service users to spend time with the researcher outside of the interview, with a view to establishing rapport and trust, to facilitate openness in the interview.

At a suitable meeting the researcher will introduce herself and explain the research. The researcher will then continue to attend forums that are already in place at the centre, with a view to building relationships with service users. This will enable people to ask any questions they may have about the research which may crop up over a period of time.

The researcher will record any topic related observations at the first appropriate opportunity. These observations will not include any personal or identifiable information, just general observations; building an understanding of context. Throughout this time, service users will be able to approach the researcher to volunteer to be involved in the interviews.

Service users and staff are able to opt-out of this process at any time by informing the gatekeeper or the researcher. This decision will be accepted without question. The option to opt-out will be explained by the researcher at the initial meeting and on an ongoing basis when meeting new people (staff and service users).

Interviews

After the period of familiarisation, there will be one-to-one interviews with service users who meet the study's inclusion criteria. Service users will be required to sign a consent form to take part in the interviews. (Please read the service user participant information sheet for further information).

3. What is the role of the gatekeeper?

The gatekeepers role is to:

- 1) be aware the researcher will be undertaking a period of familiarisation and documenting general observations (not personal or identifiable)
- 2) inform the researcher if a service user or staff member wishes to opt-out of the period of familiarisation
- 3) sign a consent form acknowledging the period of familiarisation. (Please note gatekeepers are signing to acknowledge the researcher is conducting a period of familiarisation within their centre and are not signing to consent for service users and staff to participate. Staff and service users are able to opt-out if they require. Also gatekeepers consent is not for the interview stage as service users themselves will be required to give consent for participation in the interviews).

4. Why have I been chosen to act as a gatekeeper?

You have been chosen to act as a gatekeeper as you have been identified by the centre/service, to be the most suitable person to fulfil this roll.

5. What will happen with the information collected?

All observations collected during the research will be anonymised (people will not be able to be individually identified). Information will be stored securely in The Centre for Public Health at Liverpool John Moores University. Audio files will be stored in a password protected computer and paper copies will be stored in a locked filing cabinet, in a locked room. Only the researcher and supervisor will have access to the information.

It is expected that results of the study will be published in academic journals, reports and/or results presented at conferences but individual details will not be mentioned and organisations will not be named without prior consent from the organisation.

This study has received ethical approval from LJMU's Research Ethics Committee (*insert REC reference number and date of approval*)

Contact for further information

If you need further information or are worried about any aspect of the study, please do not hesitate to contact Jane Evely, the researcher working on the project.

Contact Details of Researcher: Jane Evely

j.e.evely@2014.ljmu.ac.uk

0151 231 4441

Contact Details of Academic Supervisor: Dr Gordon Hay

G.Hay@ljmu.ac.uk

0151 231 4385

Contact Details of Independent Person: Dr Conan Leavey

C.Leavey@ljmu.ac.uk

0151 231 4544

Note: A copy of the participant information sheet should be retained by the participant with a copy of the signed consent form.

LJMU REC No.:



LIVERPOOL JOHN MOORES UNIVERSITY PARTICIPANT INFORMATION SHEET

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Name of Researcher and School/Faculty: Jane Evelyn, Faculty of Education, Health & Community

Please take time to read the following information. Please ask if there is anything that is not clear or if you would like more information. Feel free to talk to other people about this study, such as friends, family, colleagues or your support worker. This is a voluntary project, and when we have discussed the study, if you would prefer not to take part, your decision will be accepted without question and will not affect the support you receive. If you decide to take part you can withdraw from the study at any stage.

1. What is the purpose of the study?

The overall study aim is to increase understanding of injecting drug users' health care needs with view to improving services. We would like to understand more about hepatitis C and alcohol consumption in injecting drug users. We would also like to understand where information about alcohol is obtained, what this information is and how this information is perceived by people who inject drugs or have done in the past.

2. What does the research involve?

The research is in two parts. The first stage is a period of familiarisation and the second stage is an interview. This leaflet is about stage one of the study only. A separate information leaflet and a consent form to sign, is available for a small number of people (around 10) who take part in the interviews.

Period of familiarisation

The researcher, who is from Liverpool John Moores University, will spend time at the drug treatment/support centres. The purpose being for service users to spend time with the researcher, to getting to know each other prior to the interview, with a view to facilitate openness within the interview. The researcher will also be able to learn about the service provided by the centre.

People will be able to ask any questions they may have about the research which may crop up over a period of time.

After each day the researcher will take notes about the observations she has made. These notes will not include any personal or identifiable information.

Service users and staff can opt-out of this process at any time by informing staff or the researcher. This decision will be accepted without question.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. You are free to opt-out at any time without giving a reason. A decision to withdraw will not affect your rights or any future treatment/service you receive.

4. What will happen to me if I take part?

LJMU REC No.:

If you decide to take part, you do not need to do anything different to usual. The researcher will just be in the centre and may attend meetings that you attend and will record events that occur through the day.

5. Will my taking part in the study be kept confidential?

Yes. All information collected during the research will be anonymised (you will not be able to be individually identified) and remain confidential (nobody other than researcher and supervisor will see your information). Information about you will not be disclosed to anyone, however if you disclose to the researcher that you intend to seriously harm yourself (e.g. suicide) or others (e.g. serious assault), this information will need to be shared with support staff at the drug and alcohol service you attend. Information collected will be stored securely in The Centre for Public Health at Liverpool John Moores University. Audio files will be stored in a password protected computer and paper copies will be stored in a locked filing cabinet, in a locked room. Only the researcher and supervisor will have access to the information.

It is expected that results of the study will be published in academic journals, reports and/or results presented at conferences but your individual details will not be mentioned.

This study has received ethical approval from LJMU's Research Ethics Committee (*insert REC reference number and date of approval*)

Contact for further information

If you need further information or are worried about any aspect of the study, please do not hesitate to contact Jane Evely, the researcher working on the project.

Contact Details of Researcher: Jane Evely

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0151 231 4385

Contact Details of Independent Person: Dr Conan Leavey

C.Leavey@ljmu.ac.uk

0151 231 4544

Note: A copy of the participant information sheet should be retained by the participant with a copy of the signed consent form.



LIVERPOOL JOHN MOORES UNIVERSITY PARTICIPANT INFORMATION SHEET

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Name of Researcher and School/Faculty: Jane Evely, Faculty of Education, Health & Community

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it involves. Please take time to read the following information. Please ask if there is anything that is not clear or if you would like more information. Feel free to talk to other people about taking part in this study, such as friends, family or your support worker. This is a voluntary project, and when we have discussed the study, if you would prefer not to take part, your decision will be accepted without question and will not affect the support you receive. If you decide to take part you can withdraw from the study at any stage.

1. What is the purpose of the study?

We are interested in talking to people in drug treatment/support services who have injected drugs and have been diagnosed with hepatitis C at some point in their lives. The overall study aim is to increase understanding of injecting drug users' health care needs with view to improving services. We would like to understand more about alcohol consumption in injecting drug users. We would also like to understand where information about alcohol is obtained, what this information is and how this information is perceived by people who inject drugs or have done in the past.

2. Why have I been chosen?

We are interested in talking to people in drug treatment/support services who have injected drugs and have been diagnosed with hepatitis C at some point in their lives. This could mean that you currently have hepatitis C or that you previously had hepatitis C which has now gone (either through naturally clearing or treatment). We would like to talk about alcohol consumption, so would therefore like to speak to people who drink alcohol now or have drunk alcohol in the past. We are aiming to speak to around 30 people in total.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason. A decision to withdraw will not affect your rights or any future treatment/service you receive.

4. What will happen to me if I take part?

If you decide to take part in this study it will not affect your usual support in any way. The research will involve a one-to-one interview with a researcher who is from Liverpool John Moores University. The interview will explore your alcohol and substance use over your lifetime. You may have the opportunity to take part in follow up interviews to explore your comments further (there will probably be no more than 3 interviews in total).

The interviews will be audio recorded and later transcribed verbatim (typed up, word for word).

5. Are there any risks / benefits involved?

Benefits

It is unlikely that the study will be of direct benefit to you immediately, however the information will be shared with teams responsible for drug and alcohol services and hepatitis C services in Merseyside, which may lead to improvements in services in the future.

All study participants will be given a £10 voucher for each interview they attend.

Risks

During the interview, we will discuss your history of alcohol and substance use. You do not have to talk about any topic, or answer any question, that you do not want to. After the interview you will still have the chance to ask any questions you may have about the research. You can withdraw from the study at any point. If you wish to discuss personal issues raised by the research, we recommend that you talk to your support worker, for ongoing support. Taking part in the study will not affect your current treatment/support.

6. Will my taking part in the study be kept confidential?

Yes. All personal information collected during the research will be anonymised (you will not be able to be individually identified) and remain confidential (nobody other than researcher and supervisor will see your information). Information about you will not be disclosed to anyone, however if you disclose to the researcher that you intend to seriously harm yourself (e.g. suicide) or others (e.g. serious assault), this information will need to be shared with support staff at the drug and alcohol service you attend.

Information will be stored securely in The Centre for Public Health at Liverpool John Moores University. Audio files will be stored in a password protected computer and paper copies will be stored in a locked filing cabinet, in a locked room. Only the researcher and supervisor will have access to your information.

It is expected that results of the study will be published in academic journals, reports and/or results presented at conferences but your individual details will not be mentioned.

This study has received ethical approval from LJMU's Research Ethics Committee (14/EHC/050, 30/07/2014)

Contact for further information

If you need further information or are worried about any aspect of the study, please do not hesitate to contact Jane Evely, the researcher working on the project.

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LIVERPOOL JOHN MOORES UNIVERSITY PARTICIPANT INFORMATION SHEET

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Name of Researcher and School/Faculty: Jane Evely, Faculty of Education, Health & Community

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it involves. Please take time to read the following information. Please ask if there is anything that is not clear or if you would like more information. Feel free to talk to other people about taking part in this study, such as friends, family or your colleagues. This is a voluntary project, and when we have discussed the study, if you would prefer not to take part, your decision will be accepted without question. If you decide to take part you can withdraw from the study at any stage.

1. What is the purpose of the study?

The overall study aim is to increase understanding of injecting drug users' health care needs with view to improving services. More specifically we would like to understand about alcohol consumption and hepatitis C in injecting drug users and their health care needs surrounding this.

2. Why have I been chosen?

We are interested in talking to people who work in drug, alcohol and liver services, about the services provided to injecting drug users with hepatitis C. We have already interviewed around 20 people attending drug services who have injected drugs and have been diagnosed with hepatitis C at some point in their lives. We would now like to talk to staff who work in these services. We are aiming to speak to around 12 staff in total.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason.

4. What will happen to me if I take part?

If you decide to take part, the research will involve a one-to-one interview with a researcher who is from Liverpool John Moores University. The interview will take approximately 20 minutes, depending on your answers.

The interviews will be audio recorded and later transcribed verbatim (typed up, word for word).

5. Are there any risks / benefits involved?

Benefits

On completion of the study, overall results will be shared with teams responsible for drug and alcohol services and hepatitis C services in Merseyside, which may lead to improvements in services in the future.

Risks

During the interview we will discuss the service where you work. (Please see section 6 below regarding confidentiality).

You do not have to talk about any topic, or answer any question, that you do not want to. After the interview you will still have the chance to ask any questions you may have about the research and you can withdraw from the study at any point.

6. Will my taking part in the study be kept confidential?

Yes. All information collected during the research will be anonymised (you will not be able to be individually identified) and remain confidential (nobody other than researcher and supervisor will see your information). Information will be stored securely in The Centre for Public Health at Liverpool John Moores University. Audio files will be stored in a password protected computer and paper copies will be stored in a locked filing cabinet, in a locked room. Only the researcher and supervisor will have access to your information.

It is expected that results of the study will be published in academic journals, reports and/or results presented at conferences but your individual details will not be mentioned and the organisation where you work will not be named. It is important to note however, that although your organisation will not be named, it may be possible to identify the organisation due to the small number of organisations providing drug, alcohol and hepatitis C services in Merseyside.

This study has received ethical approval from LJMU's Research Ethics Committee (14/EHC/050, 30/07/2014)

Contact for further information

If you need further information or are worried about any aspect of the study, please do not hesitate to contact Jane Evely, the researcher working on the project.

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j.e.evely@2014.ljmu.ac.uk

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C.Leavey@ljmu.ac.uk

0151 231 4544

Note: A copy of the participant information sheet should be retained by the participant with a copy of the signed consent form.

Appendix 4 Interview schedules

Service User Interviews
LJMU REC No.: 14/EHC/050

Version 2.0, 28th July 2014

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Interview schedule

Stage 0: Preparation prior to the interview – period of familiarisation

Prior to the interviews the researcher will spend time at the drug treatment/support centres specified in the ethics application, namely; << REDACTED >>. The purpose of this being for service users to spend time with the researcher outside of the interview, with a view to establishing rapport and trust, to facilitate openness in the interview. The specific practicalities of getting to know the service users will be discussed with professionals and volunteers who have a service user engagement background at each organisation. This may be for example within planned discussions with user forums at the drug treatment/support centres. Gatekeeper consent will be obtained prior to commencing the period of familiarisation.

At a suitable meeting/forum the researcher will introduce herself and explain the research. This will include the purpose of the study, the methods to be used (period of familiarisation and interviews), requirements of the participants, confidentiality, the inclusion/exclusion criteria, the risks and benefits and right to withdraw. The researcher will then continue to attend forums that are already in place at each centre, with a view to building relationships with service users. This will enable people to ask any questions they may have about the research which may crop up over a period of time. The researcher will record any topic related observations at the first appropriate opportunity. These observations will not include any personal or identifiable information, just general observations; building an understanding of context. Throughout this time, service users will be able to approach the researcher to volunteer to be involved in the research.

Service users and staff are able to opt-out of this process at any time by informing the gatekeeper or the researcher. This decision will be accepted without question. The option to opt-out will be explained by the researcher at the initial meeting and on an ongoing basis when meeting new people (staff and service users).

When the interviews commence, the researcher will provide a participant information leaflet to the service user and again a verbal explanation of the study will be given. Potential participants will be advised to take the leaflet away, read the leaflet (or have the leaflet read to them) and discuss with friends, family or their support worker if they would like to. Potential participants will then be given a minimum of 24 hours to decide if they would like to take part. However, as the service user will have been aware of the research over a period of time, if they wish to agree there and then, the researcher will organise a time and date for the interview. Interviews will be arranged at a time convenient to the participant.

Stage 1: The interview – participants' history

The life events calendar will be introduced at the beginning of the interview. The calendar will be placed between the participant and researcher and a verbal explanation of the calendar and how it will be used in the interview will be given. The calendar will be used as a tool, to assist the

participant to recall their alcohol and substance use history. Completion of the calendar will be a collaborative effort between the researcher and participant.

The first step will be to record participants demographics on the calendar. This will be the participant code (For example, ID#: WI01, demonstrating the 1st participant from Wirral) and their gender. Age will also be recorded for each year on the calendar, so therefore their current age will also be recorded. The next step will be to plot on the calendar any important 'life events', such as births, jobs, relationships, periods of illnesses and so on. Pre-prepared stickers of these events will

be used as required for each participant, sticking them on the calendar at the correct time point. Each year on the calendar is split into 3 monthly slots (Jan-March, April-June, July-Sept, Oct-Dec), so the sticker will be placed in the relevant quarter. The purpose of the stickers along with the historical events (down the side of the calendar) is to try and trigger memories. The third step will then be to ask participants to explain their alcohol and substance use over time. Each substance (including alcohol) will be allocated a different coloured pen and a horizontal line will be drawn on the calendar marking the time they used that particular substance. A short vertical line will be drawn at the start and end of using a substance. However it is important to note that the main focus of the interview is on the participants' history not the calendar itself. The calendar will be used to 'trigger' memories, but if the participant is talking freely they will not be interrupted to complete the calendar. Participants will be asked to begin when they first used substances/alcohol and move forward to the present day.

Once the participant feels they have completed their history, if they have not already mentioned when they had their hepatitis C test/s the researcher will ask this and will then plot this on the calendar. It is important to note, participants will be aware that events around their hepatitis C diagnosis will be discussed as this will have been explained as part of the informed consent process prior to commencing the interview. The researcher will then ask questions and cross reference information given by the participant, to facilitate further discussion and understanding of certain events. These questions/conversations will be different for each participant depending on the issues raised in their individual histories. Examples of questions may include:

-What did you mean by....?

-Was that after/before (an event such as a birth)?

-How did you feel about....?

-Is there anything else you'd like to add about?

-You talked about..... (an event, place, person) how was that important?

-How much/often were you taking..../drinking then?

-Can you explain why you were taking..../drinking then?

-Can you explain why you changed from ... to... then (one drug to another or drugs to alcohol)?

-Can you explain why you have stopped/stayed on (a drug or alcohol)?

Stage 2: The interview - questions

Once the participant's history has been discussed follow on questions will be asked. Again these questions may be different for each participant depending on what has already been discussed. Examples of questions may include:

- Can you tell me about the time/s you had your hepatitis C test, what happened and how you felt?
 - Can you tell me about any advice you received at the time of your hepatitis C test?
 - What advice were you given about alcohol and hepatitis C? Why do you think that advice was given?
 - Did you have further questions about hepatitis C? What were these? Where did you get the answers?
 - Did you have further questions about drinking with hepatitis C? What were these? Where did you get the answers?
- Where and/or who do you get information about your health from? (this can be from more than 1 place/person)
- Can you tell me your thoughts on what health care services are required by people who inject drugs?
- Can you tell me your thoughts on what alcohol services are required for people who inject drugs?

The interview will be finalised by the researcher asking the participant:

- Do you have any questions about the research or would you like to add anything else?

Stage 3: Follow up interview(s)

After initial analysis of the interview, if more information is required the researcher will contact the participant by telephone or see them at the centre, to arrange further interviews. It is unlikely there will be more than three interviews in total for each participant. The participants will be aware of the potential for follow up interviews from the onset, as this is mentioned on the participant information leaflet and signed for on the participant consent form. Follow up interviews will probably be shorter in duration than the initial interview.

Note: All interviews will be audio recorded and transcribed. Participants will be aware of this as it is mentioned in the participant information sheet and signed for on the consent form.

Experiences of alcohol use and hepatitis C among current and recovering injecting drug users in Merseyside: Implications for treatment services.

Interview schedule (Staff)

Approval to conduct staff interviews will be sought from service managers or research departments (if applicable) at drug, alcohol and liver services. Following this approval staff will be informed of the study and are then free to volunteer to take part. If a staff member expresses an interest in participation, a participant information sheet will be provided, along with a verbal explanation of the study. If they then decide to take part, interviews will be arranged at a time that is convenient to the participant. During the interview a verbal explanation of the study will be given again and 2 copies of the consent form will be signed.

Interviews with staff who have direct contact with service users, will use written vignettes based on hypothetical service users, to gain an understanding of the services provided to people living with hepatitis C. Staff will not be asked to give personal views on the vignette but will be asked to discuss what the service would do for the hypothetical service user. Staff will be asked to discuss a number of things such as; what the service would do for the hypothetical service users; what advice/information the service user would be given; how the service user would be referred to their service and what service they would refer onto. The information gathered during this process will then be compared and contrasted to the findings from the service user interviews.

Participants will be asked to discuss 2 or 3 vignettes (depending on time and the relevance of the vignette to the service). Interviews are expected to take approximately 20 minutes, depending on the answers given.

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Vignette 1

Rob is a 45 year old man with a medical history of COPD and hepatitis C (diagnosed in 2000). He previously injected heroin and crack cocaine but stopped injecting 10 years ago. He has been on a methadone script for 15 years and is currently on 40mls of methadone a day. He currently smokes heroin around twice a month and drinks 5 cans of 9% Skol super strength lager a day. He lives with his partner in stable accommodation (a secured tenancy with a registered social landlord). His partner does not know that he has hepatitis C. She would like to start trying for a baby.

Questions for staff at drug service

- Rob has been at another drug service in a different area of Merseyside and he has just moved. He comes to your service, what would your service do for Rob on his first appointment with you?
- Rob has been coming to your service for his methadone script for years, what does your service do for him at his routine appointments?
- How would Rob have been referred to your service?
- What other services would Rob be referred on to? (Prompt – for his alcohol? for his hepatitis C?)
- What information/advice would your service discuss with Rob?
- How would that information be given?
- Rob would like treatment for his hepatitis C. Can you explain what your service would do? (Prompt - Would he be retested or can you access previous test results? Where would he go for the test? How would he be referred for the test? If the test is at the drug service what information would he be given before the test? How would he find out the results? What information would he be given when he got the positive test result? Please explain how he would be referred to the hospital for hepatitis C treatment?)
- What other services could Rob attend for his hepatitis C? (Prompt – Are there any support services or any educational services?)
- What information/advice would your service give Rob about his alcohol consumption? (Prompt - What advice is given about drinking alcohol when you have hepatitis C? What advice is given about drinking alcohol and being considered for hepatitis C treatment?)
- What information/advice would your service give about transmission of hepatitis C?
- Rob and his partner have been using condoms but are going to start trying for a baby. Rob is concerned about giving his partner (and baby) hepatitis C through sexual contact. What advice would be given?

Questions for staff at hepatitis C/liver clinics

- How would Rob be referred to your service?
- Rob would like treatment for his hepatitis C. Can you explain what your service would do? (Prompt - Would he be retested or can you access previous test results? If he is tested at the hospital what information would he be given before the test? How would he find out the results? What information would he be given when he got the positive test result?)
- What information/advice would your service discuss with Rob?
- How would that information be given?

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- Can you explain the factors taken into consideration when deciding if Rob should commence treatment? (Prompt – Rob smokes heroin, how would that be considered when discussing treatment? And if he injected heroin, how would that be considered in relation to hepatitis C treatment? Rob drinks 5 cans of Skol super strength every day, how would that be considered when discussing treatment?)
- What would the follow up arrangements be?
- What other services would Rob be referred on to? (Prompt –for his alcohol?)
- What other services could Rob attend for his hepatitis C? (Prompt – Are there any support services or any educational services?)
- What information/advice would your service give Rob about his alcohol consumption? (Prompt - What advice is given about drinking alcohol when you have hepatitis C? What advice is given about drinking alcohol whilst on hepatitis C treatment?)
- What information/advice would your service give about transmission of hepatitis C?
- Rob and his partner have been using condoms but are going to start trying for a baby. Rob is concerned about giving his partner (and baby) hepatitis C through sexual contact. What advice would be given?
- What lifestyle advice would Rob receive? (Prompt - Is this given in relation to the hepatitis C or the hepatitis C treatment?)

Questions for staff at alcohol service

- How would Rob have been referred to your service?
- What would your service do for Rob?
- What information/advice would your service discuss with Rob?
- How would this information be given?
- Can you explain the factors taken into consideration when deciding Rob's treatment options? (Prompt - brief interventions, pharmacotherapy, residential rehabilitation)
- Can you explain the factors taken into consideration when deciding if Rob should receive medications for his alcohol consumption?
- What would the follow up arrangements/course of treatment be? (Prompt - for brief interventions? for pharmacotherapy?)
- What other services would Rob be referred on to?
- What would your service do in regards to Rob's hepatitis C?

Vignette 2

Kate is a 35 year old female with a 3 year history of injecting drug use. She currently injects and/or smokes heroin daily. She is on a methadone script although she only attends the drug service sporadically. Kate has had periods of homelessness but is currently living in a hostel. She says she finds it hard to get to the drug service as it is not near the hostel. She currently does not drink alcohol.

[After initial discussion]

Kate had a hepatitis C test 2 years ago at her previous GP practice. The blood was sent to the laboratories at the hospital. The test showed that she has hepatitis C. Kate does not know this as she didn't go back for the results.

Questions for staff at drug service

- This is Kate's first appointment at your service. She gets put on the methadone script. What else would your service do for Kate on her first appointment?
- The next time Kate comes to the drug service is about a month later. She has come for her methadone script, what does your service do for her at this appointment?
- How would Kate have been referred to your service?
- What other services would Kate be referred on to?
- What information/advice would your service discuss with Kate? (Prompt – what kind of harm reduction advice would be given? Where could Kate access needle and syringe programmes?)
- How would that information be given?

Questions after second part of vignette

- What would your service do in regards to hepatitis C testing for Kate? (Prompt- Would your service be informed of the results from the GP? Would Kate be retested or can you access previous test results? Where would she go for the test? How would she be referred for the test? If the test is at the drug service what information would she be given before the test? How would she find out the results? What information would she be given when she got the positive test result? How would she find out the results?)
- What information/advice would your service give Kate about alcohol and hepatitis C? (Prompt – Can they explain how they ask about her alcohol use. Do they take a lifetime alcohol history?)
- What information/advice would your service give about transmission of hepatitis C?
- What other services could Kate attend for her hepatitis C? (Prompt – Are there any support services or any educational services?)
- On receiving the positive hepatitis C result Kate thinks she would like to receive hepatitis C treatment. What would your service do for Kate?

Questions for staff at hepatitis C/liver clinics

- Kate has been tested at the drug service and is hep C positive. Kate would like hepatitis C treatment. Can you explain what your service would do? (Prompt - Would she be retested or can you

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access previous test results? If she is tested at the hospital what information would he be given before the test? How would she find out the results? What information would she be given when she got the positive test result?)

- What information/advice would your service discuss with Kate?
- How would that information be given?
- Can you explain the factors taken into consideration when deciding if Kate should commence treatment? (Prompt – Kate injects and smokes heroin, how would that be considered when discussing treatment? Kate attends the drug service sporadically how would that be considered when discussing treatment? Kate lives in a hostel, how would that be considered when discussing treatment?)
- What would the follow up arrangements be?
- What other services would Kate be referred on to?
- What other services could Kate attend for his hepatitis C? (Prompt – Are there any support services or any educational services?)
- What information/advice would your service give Kate about alcohol consumption? (Prompt - What advice is given about drinking alcohol when you have hepatitis C? What advice is given about drinking alcohol whilst on hepatitis C treatment?)
- Kate received residential rehab for alcohol 10 years ago, how would that be considered when discussing treatment?
- What information/advice would your service give about transmission of hepatitis C?
- What lifestyle advice would Kate receive? (Prompt - Is this given in relation to the hepatitis C or the hepatitis C treatment?)

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Vignette 3

Ben is a 42 year old man who is currently drinking approximately half (35cl) a bottle of vodka a day. He previously injected heroin but is now maintained on a methadone script. He started drinking 2 or 3 cans of Fosters/Carlsberg (3.8-4%) lager a day when he was stopping heroin 2 years ago, but since then has changed from lager to vodka. He lives alone.

Questions for staff at drug service

- Ben has been coming to your service for his methadone script for a few years, what does your service do for him at his routine appointments?
- What information/advice would your service discuss with Ben? (Prompt – for his alcohol consumption? regarding testing for blood borne viruses?)
- How would that information be given?
- What other services would Ben be referred on to? (Prompt – for his alcohol? for blood borne virus testing?)

Questions for staff at alcohol service

- How would Ben have been referred to your service?
- What would your service do for Ben?
- What information/advice would your service discuss with Ben?
- How would this information be given?
- Can you explain the factors taken into consideration when deciding Ben's treatment options? (Prompt - brief interventions, pharmacotherapy, residential rehabilitation)
- What would the follow up arrangements/course of treatment be? (Prompt - for brief interventions? for pharmacotherapy?)
- What other services would Ben be referred on to?
- What would your service do in regards to Ben's history of injecting drug use? (Prompt – How would your service test/refer on for test, for blood borne viruses?)

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Vignette 4

Sarah is a 52 year old woman with a medical history of depression and hepatitis C genotype 1a with no cirrhosis. She thinks she got hepatitis C by injecting heroin a 'few times' in her twenties. She has never been addicted to heroin, so has never been on methadone or attended drug services. She drinks alcohol socially. Sarah goes out with her friends about once a month and has 3 or 4 gins. In 2012 she received treatment for hepatitis C which was unsuccessful. She works full time and is a single mum to 2 teenage children.

Questions for staff at hepatitis C/liver clinics

- Sarah would like hepatitis C treatment again. Can you explain what your service would do?
- What information/advice would your service discuss with Sarah?
- How would that information be given?
- Can you explain the factors taken into consideration when deciding if Sarah should commence treatment?
- What would the follow up arrangements be?
- What other services would Sarah be referred on to? (Prompt – for her depression?)
- What other services could Sarah attend for her hepatitis C? (Prompt – Are there any support services or any educational services?)
- What information/advice would your service give Sarah about her alcohol consumption?
(Prompt - What advice is given about drinking alcohol when you have hepatitis C? What advice is given about drinking alcohol whilst on hepatitis C treatment?)
- What information/advice would your service give about transmission of hepatitis C?
- What information/advice would your service give about living with chronic hepatitis C?
- What lifestyle advice would Sarah receive? (Prompt - Is this given in relation to the hepatitis C or the hepatitis C treatment?)
- What advice/help is given for the symptoms of chronic hepatitis C?

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Interviews will also be sought from people who do not currently work directly with service users but are instrumental in drug, alcohol and hepatitis C services in Merseyside. These are people such as commissioners, people on health and wellbeing boards and those who historically worked in hepatitis C in Merseyside such as leaders of the peer to peer initiative and hepatitis C support groups. These interviews are to gain an overall understanding of current and historical drug, alcohol and hepatitis C services.

Examples questions:

- Can you tell me what services are available in your area for people who inject drugs or are in recovery? (Prompt - prevention and harm reduction, testing and diagnosis, treatment, chronic disease management)
- Can you tell me what alcohol services are available in your area?
- Can you tell me about the hepatitis C services in your area?
- Who is the commissioning lead for hepatitis C in the local authority?
- Who is the commissioning lead for hepatitis C in the CCG?
- Please can you explain the processes involved in commissioning the hepatitis C services in Sefton/Liverpool/Wirral. (Prompt - services = prevention/harm reduction, testing and diagnosis, treatment, chronic disease management-such as alcohol reduction, hepatitis B vaccination)
- Who is involved in this process?
- Can you explain what the local authority's/NHS commissioners long and short term strategies are for tackling hepatitis C in Sefton/Liverpool/ Wirral?
- Can you explain what factors relating to hepatitis C are considered when commissioning drug services?
- Can you explain what factors relating to hepatitis C are considered when commissioning alcohol services?
- Can you explain how the local authority commissioners/NHS commissioners assess the current and future burden of hepatitis C?
- Can you explain how hepatitis C outcomes are monitored and measured? (Prompt - numbers tested in community services, numbers tested in acute settings, numbers accessing hepatitis C treatment , number of people clearing the virus, number of people re-infecting)

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- Can you explain the hepatitis C pathway from testing to treatment for people tested in GP practices in Sefton /Liverpool/Wirral
- Can you explain the hepatitis C pathway from testing to treatment for people tested in drug service in Sefton/Liverpool/Wirral
- What arrangements are in place with local NHS commissioners/local authority commissioners to tackle hepatitis C?
- What services are available in Sefton/Liverpool/Wirral for people with hepatitis C who do not attend drug services? How do these people get tested/supported/educated?
- If there are any difficulties with commissioning hepatitis C/drug /alcohol services, can you explain what these are please? And what works well?
- Can you tell me how liver services and hepatitis C in particular are considered by the health and wellbeing boards?
- As you previously worked in hepatitis C services, can you explain how hepatitis C services have changed over time and why the changes occurred? Is there any gaps in provision now?
- Where are the provision of care for people with hepatitis C? Is there any gaps in provision?
- What is being done to promote hepatitis C testing in GP practices and drug services?
- What approaches are in place to increase uptake of hepatitis C treatment?
- There is much discussion about the provision of hepatitis C services (treatment and testing) in community settings, in the future. What plans do local authorities/NHS commissioners have around this? (What training is in place for GP's?)
- Can you explain how the outcomes in the outcomes frameworks (Public health and NHS) are met when considering drug/alcohol/hepatitis C services?
- Can you explain about the tendering process and any impact this may have on the services provided to service users
- What impact will developing hepatitis C services have on the local population?

All interviews will be audio recorded, transcribed verbatim and imported into Nvivo.

Appendix 5 Calendar figures

Figure 6 The LHC with participant's age and personal events added

ID #.....





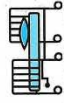

Age	Year	Jan - March	April - June	July - Sept	Oct - Dec	Historical context
39	2009					*Barack Obama President of USA *Michael Jackson Died
38	2008					*Liverpool European Capital of Culture (Liverpool 1, ECHO arena opened)
37	2007					*Liverpool celebrated its 800 th birthday *Smoking ban in all enclosed public places in England
36	2006					*World Cup Germany *Creamfields dance festival moves out of Liverpool
35	2005					*London bombings *Liverpool FC won UEFA Champions League Final
34	2004					*Tsunami in South East Asia
33	2003					*2 nd War in Iraq
32	2002					*Commonwealth Games Manchester
31	2001					*Terrorist attack on the twin towers in New York USA (9/11)
30	2000					*Millennium

Figure 7 The LHC with lines drawn to depict drug or alcohol use

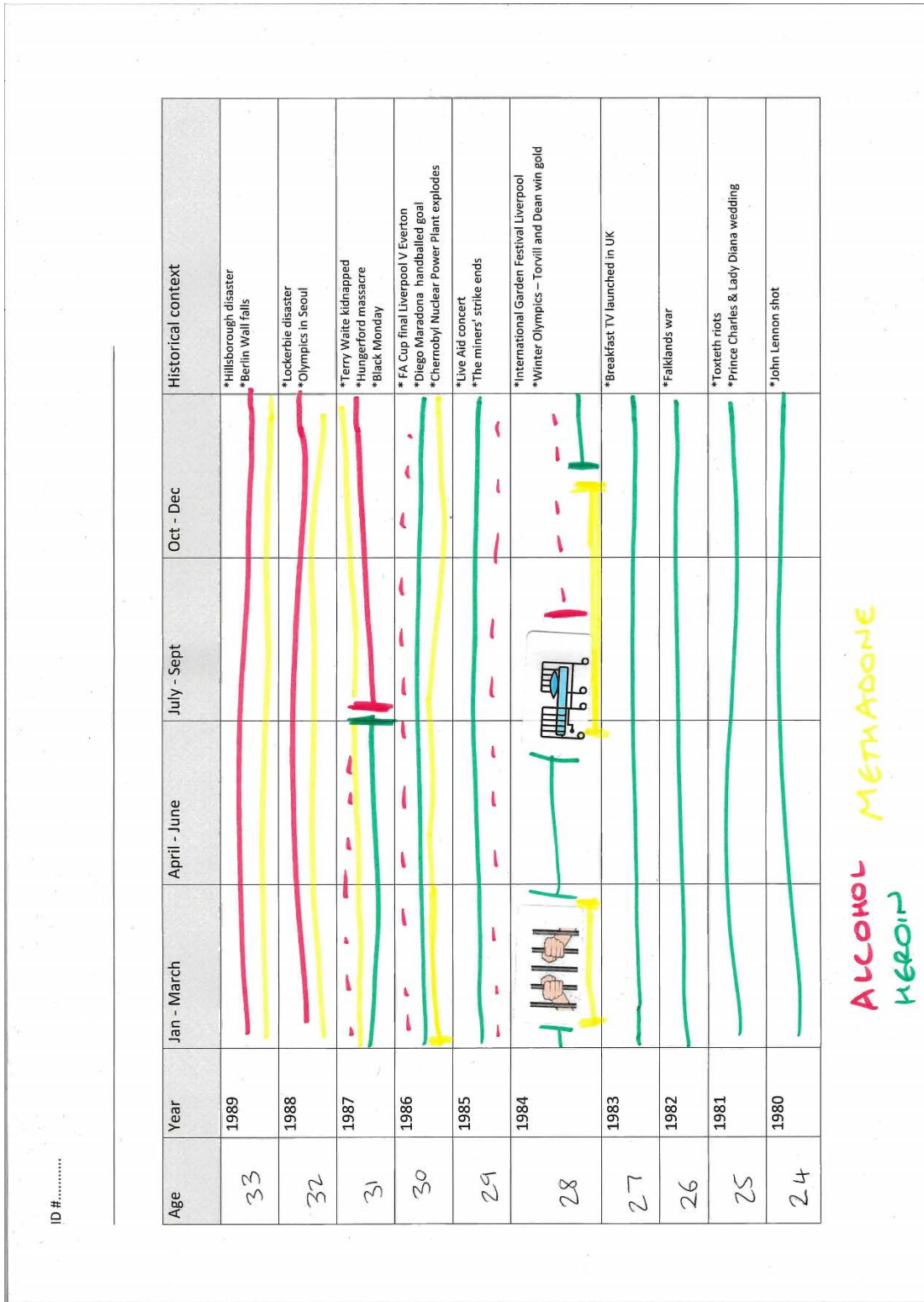


Figure 8 Example of a participant's timeline

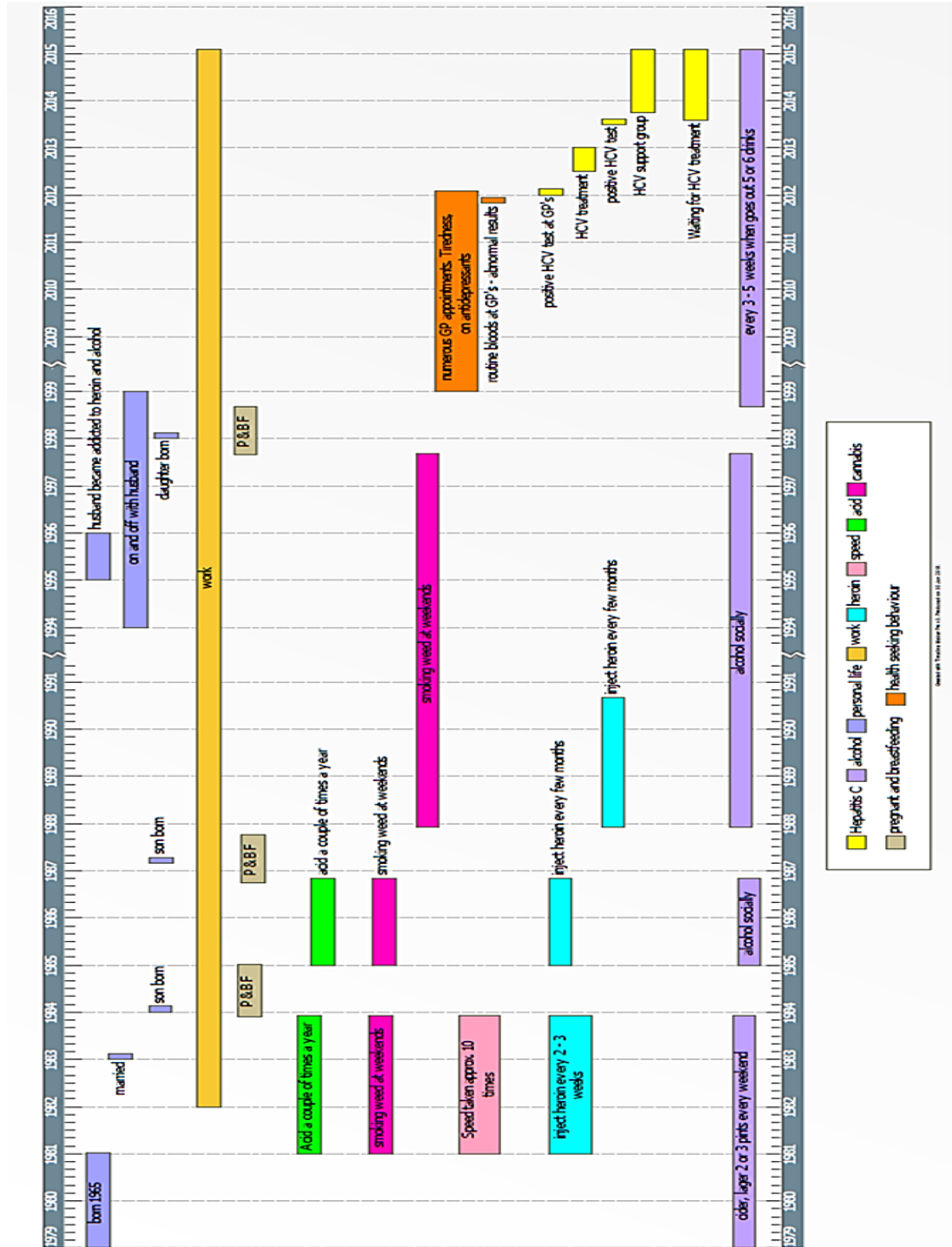


Figure 9 Issues identified for 'Kate' and related services

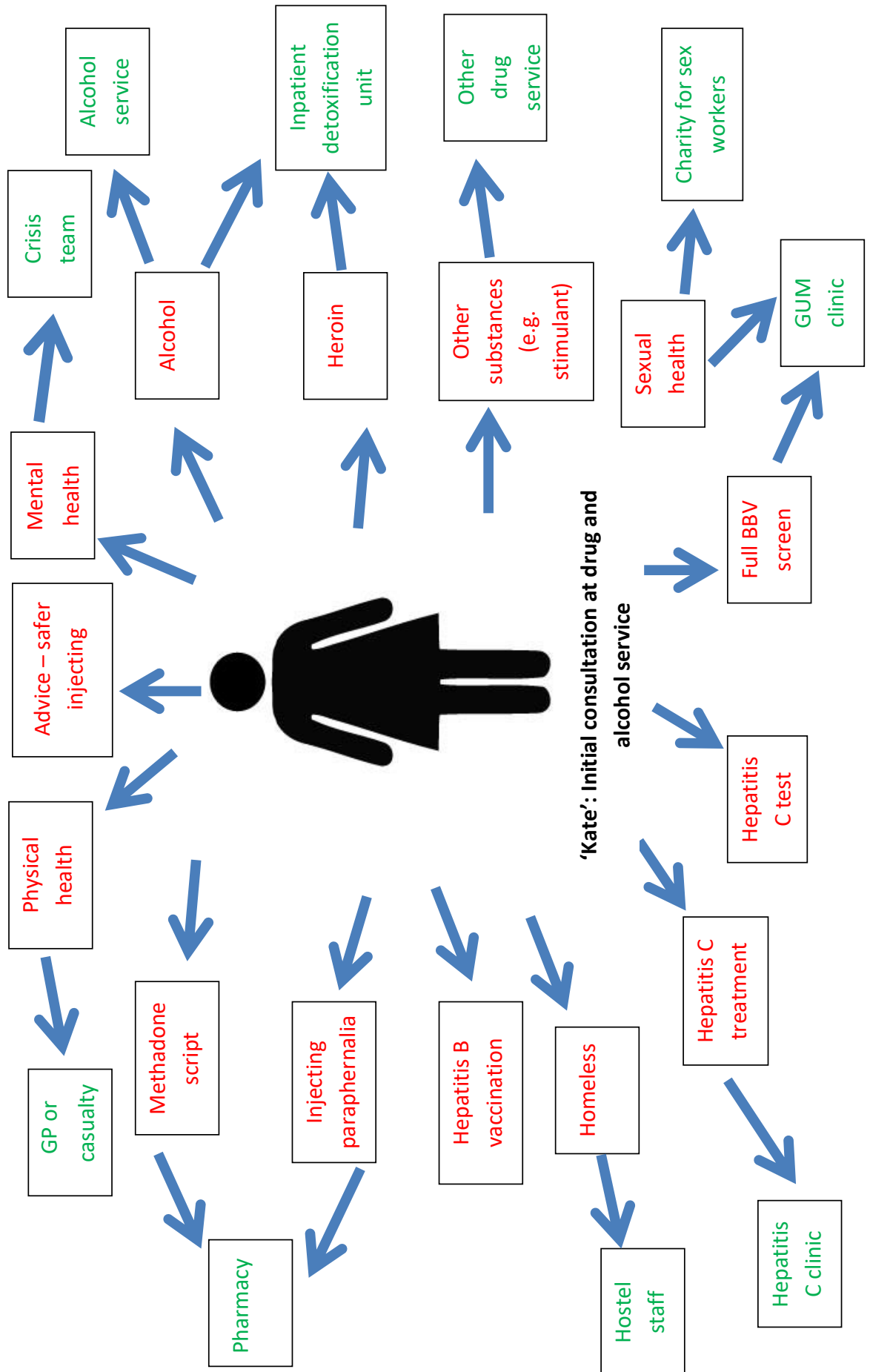
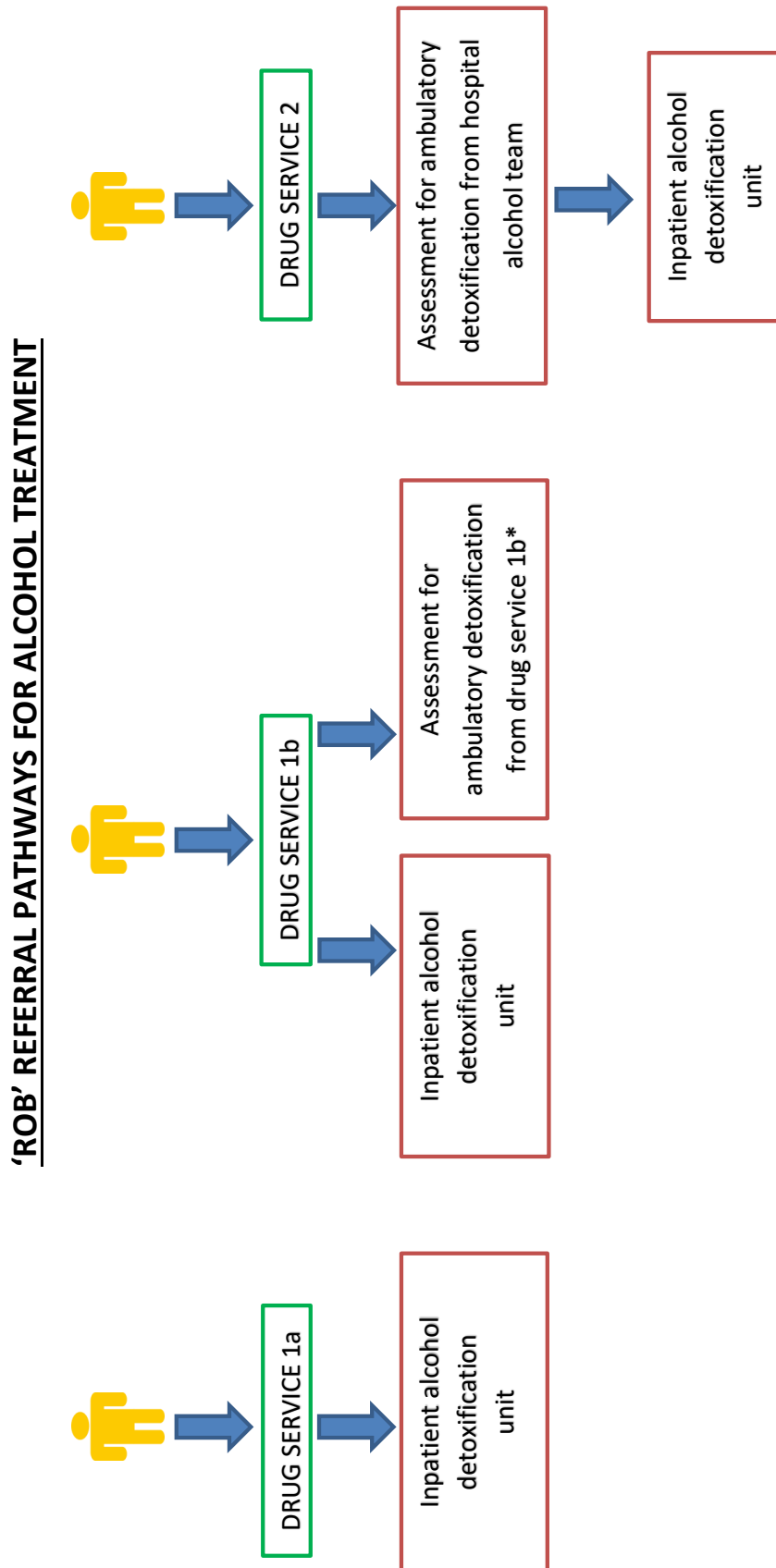


Figure 10 Referral pathways for alcohol treatment for 'Rob' depending on which drug service he attended



*Interviews were not conducted with the alcohol detoxification team from drug service 1b, therefore the treatment decision is not known (i.e. whether Rob would receive an ambulatory detoxification at drug service 1b or if he would be referred to another service such as the inpatient detox unit)

Appendix 7

Table 2 Respondents' gender, age group and respondent type

Pseudonym	Gender	Age Group	Respondent Type
Andy	M	-	Observed
Beth	F	45 - 54	Interviewee
Brenda	F	45 - 54	Interviewee
Dan	M	45 - 54	Interviewee
Ed	M	45 - 54	Interviewee
Gav	M	35 - 44	Interviewee
Jack	M	45 - 54	Interviewee
Jenny	F	> 54	Interviewee
Joe	M	45 - 54	Interviewee
John	M	-	Observed
Kath	F	45 - 54	Observed / Interviewee
Kev	M	35 - 44	Interviewee
Mark	M	45 - 54	Interviewee
Neil	M	45 - 54	Interviewee
Pete	M	35 - 44	Interviewee
Phil	M	45 - 54	Interviewee
Rach	F	35 - 44	Interviewee
Rich	M	35 - 44	Interviewee
Sadie	F	35 - 44	Interviewee
Seb	M	-	Observed
Sharon	F	45 - 54	Interviewee
Simon	M	-	Observed
Steve	M	25 - 34	Interviewee
Susan	F	45 - 54	Interviewee
Tom	M	45 - 54	Interviewee

Table 3 **Professionals' participant numbers**

Participant	Place of work
P1	Commissioner
P2	Commissioner
P3	Commissioner
P4	Commissioner
P5	Commissioner
P6	Alcohol service
P7	Hepatitis C service
P8	Hepatitis C service
P9	Hepatitis C service
P10	Alcohol service
P11	Drug and alcohol service
P12	Drug and alcohol service