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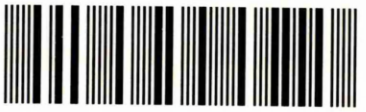

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Non-attendance at Drug Service Hepatitis C Outreach Clinics: Clients and Staff Experiences.

Ray Poll

A doctoral project report submitted
in partial fulfilment of the requirements of Sheffield Hallam University
for the degree Doctor of Professional Studies.

July 2014

Abstract

Non-attendance in the drug service hepatitis C outreach clinic means clients miss essential components of care: being offered lifestyle advice such as limiting their alcohol intake (to prevent further progression of liver disease); a discussion about ways to avoid transmission to others; and referral for hospital treatment, which can be curative.

In the absence of much empirical evidence many suggestions have been given for missed appointments by hepatitis C patients. For example, they forget, lead 'chaotic lifestyles', the infection is 'not a priority' to them and they are 'hard-to-reach'.

This study was undertaken to investigate beneath these 'surface' reasons for non-attendance. Thus, a realist approach was taken. The study comprised three phases of theory development and testing that incorporated qualitative telephone interviews with clients followed by a national survey of staff.

All 28 clients who participated gave 'surface' or 'prima-facie' reasons for non-attendance. However, the study revealed hidden underlying factors (mechanisms). These were categorised under the themes: (i) 'client characteristics' e.g. 'priority' to score drugs and the 'cost of travel' (ii) 'hepatitis C' e.g. 'no symptoms' and fear of treatment 'side-effects' (iii) 'clinic service' e.g. 'distance' to the clinic and difficulty with 'reimbursement' of travel expenses. These mechanisms were produced within a complex context of factors including addiction, welfare policy and stigma. They were often played out in different ways and linked to other mechanisms.

41 out of 142 (29%) drug services in England ran a hepatitis C outreach clinic. There was general agreement with clients about reasons for non-attendance. However, there was some discordance, notably difficulty with walking.

This study revealed a complex picture for non-attendance in a hepatitis C outreach clinic and makes an original contribution to knowledge about the reasons for missed appointments. This in turn has informed changes to practice which may engage more people into care and treatment for example, arranging scans to be undertaken on the day of clinic appointments.

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Chapter 1 – Introduction

This brief chapter describes the background to the study. This is followed by an outline of the structure of the report. But first, a description of the research question is provided. Thus, this chapter comprises of:

- What was the research question?
- Why the study was important; and
- Structure of the report.

1.1 What was the question?

From 2002 a hepatitis C outreach clinic located within a drug treatment service in a city in the North of England was established (followed by another clinic a few years later). Both outreach clinics are run by the Nurse Consultant (and investigator for this study) from the Viral Hepatitis team based within the local acute Trust hospital. The purpose of the outreach clinics was to increase rates of diagnosis and subsequent attendance at the hospital clinic for assessment and consideration of curative treatment. Over time the former has improved (with more testing being done by drug service staff) but non-attendance in the outreach clinic means patients miss the opportunity of referral (by this route) to the hospital for care and treatment. As such, the non-attendance problem that helped stimulate the formation of outreach clinics has remained a problem for those clinics. This situation suggested that a study was required to investigate the problem. If the reasons were known why people did not keep an appointment, it might be possible to consider a solution(s) and improve attendance (locally and nationally).

The key research question was therefore: "What are the reasons for non-attendance at drug service hepatitis C outreach clinics?"

1.2 Why the study was important

There were several reasons why it was important to undertake this study on non-attendance with the hepatitis C outreach clinic. These are now

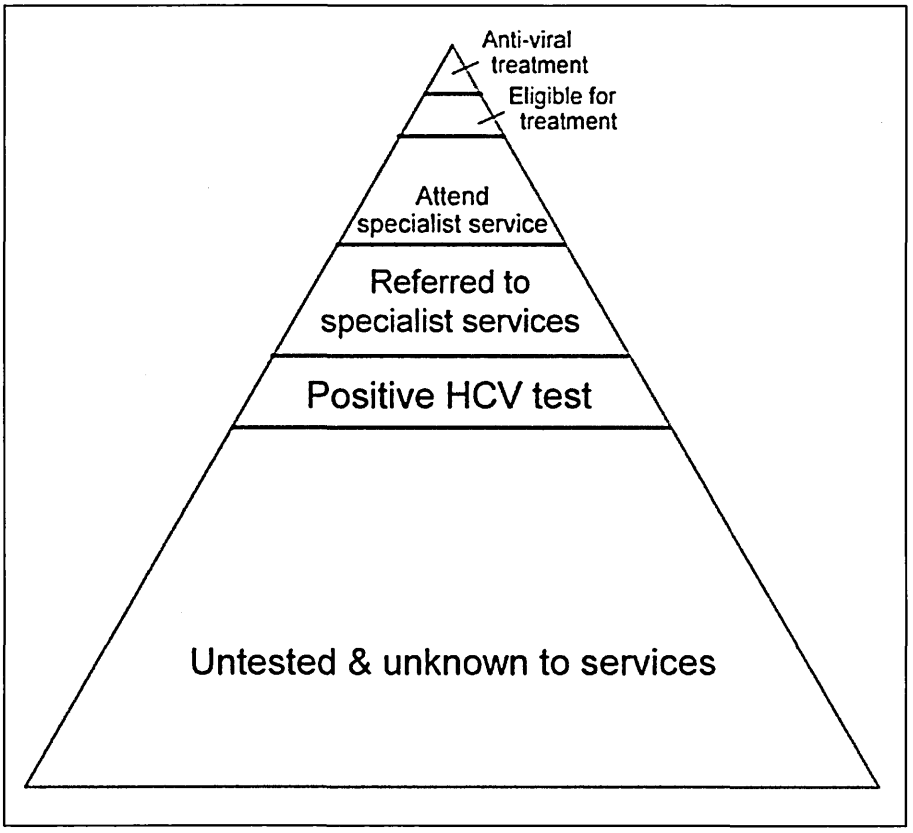
described including some reflections on why it was important for the researcher personally to undertake the study.

It is vital to engage people with hepatitis C into health services so as to reduce the risks of those already infected progressing to severe liver disease and to help prevent transmission to others (Department of Health [DoH], 2002). People with hepatitis C may benefit from: specialist medical assessment; advice about lifestyle changes to reduce further harm to the liver and measures required to avoid infecting others; and being given curative antiviral therapy. Alcohol is a co-factor for progression of liver disease and it is important for people with hepatitis C to keep their intake to a minimum (with abstinence being ideal). With increasingly effective drug therapy, the infection can be successfully treated in up to 80% of infected people (National Institute for Health and Clinical Excellence [NICE], 2006; NICE, 2012a; NICE, 2012b). However, the treatment is less effective for some people including those with advanced liver disease or cirrhosis (Ramachandran et al, 2012). Thus, it is important that people at risk of infection are diagnosed promptly and access specialist services for care and treatment without too much delay.

Despite the chance of a cure for the majority of chronically infected people, only about 20% (27,500) were treated in England between 2006 and 2011, with just 3% treated each year (Public Health England [PHE], 2013a) (see Figure 1.1 overleaf). It is predicted, that by 2020, approximately 16,000 individuals in England will be living with cirrhosis or hepatocellular carcinoma (HCC) (liver cancer) if their hepatitis C remains untreated (PHE, 2013a). Not only does this represent a health burden for people with hepatitis C, but also an escalating cost to health services. Both the number of hospital admissions and liver transplants performed has risen as a result of hepatitis C-related disease (PHE, 2013a). There are several possible reasons why people remain untreated: too few specialist nurses to deliver the service; different clinical interpretations of guidelines, with groups of patients treated in some areas and not others; and patients missing

appointments (Stephens, 2012). The latter implies this study on non-attendance was important, and was not just a local problem.

Figure 1.1 The disease iceberg for hepatitis C (reproduced from Parkes et al, 2006)



A review of hepatitis C prevalence and service delivery across the UK found that non-attendance for an initial out-patient appointment was 'high', with the median per 'comprehensive service provider' (CSP) being 10-24% (Parkes et al, 2006). Non-attendance was identified in the review as the main barrier to care, closely followed by staffing capacity and funding for treatment alongside other factors. The authors advised that understanding the reasons for the declining numbers of patients from diagnosis to treatment (as depicted in Figure 1.1), including factors for not keeping appointments, may contribute to more effective strategies aimed at increasing the number of people attending specialist services. This point about effective strategies to improve attendance was of personal relevance to

the researcher who in his clinical role telephones new patients to remind them of their appointment. It was important to carry out the study to understand why some patients did not receive a reminder and of those that did the reasons why they still did not attend. This study not only investigated the reasons for missed appointments but also suggested ways to improve attendance (locally and nationally) which were informed by the findings.

One quarter of CSPs had outreach services, which were largely located in prisons or drug and alcohol services (Parkes et al, 2006). However, there was no indication whether non-attendance was a problem for the latter (since one would not expect there to be a problem with missed appointments in prison). Other outreach clinics, mainly in the UK, have evaluated the numbers of people tested for hepatitis C (and other blood-borne viruses), immunised against hepatitis B and treated for hepatitis C, but they had not researched non-attendance (Skipper et al, 2003; Gordon et al, 2007; Wilkinson et al, 2008; Jack et al, 2008; Zucker, 2009).

As well as impacting on patients, non-attendance appears to have a negative effect on staff workload in terms of unproductive time spent sending out letters informing referrers the patient did not turn up and dealing with calls about missed appointments, which can be a source of frustration and irritation (Hardy et al, 2001; Martin et al, 2005). In his capacity as a clinician running the outreach clinic, the researcher was also motivated to undertake the study because if patients did not attend it was a waste of his time and demoralising. A considerable amount of time was wasted travelling to the drug service for people not to turn up, and it was difficult to undertake other tasks in this environment away from the office whilst waiting for patients to attend. Further, there was the issue of lost revenue to the department since a reduced payment for the appointment is given if the patient does not attend. If the reasons for non-attendance were identified and potential solutions to improve attendance were devised and

implemented, the researcher's time and clinical expertise would be better spent.

In the absence of much research evidence about the reasons for non-attendance in hepatitis C some ideas have put forward by Jowett et al (2001) including: relapse into substance misuse; low socioeconomic status; psychiatric co-morbidity; a lack of social or family support; imprisonment; a lack of understanding about the implications of a positive result and negative beliefs about liver biopsy (an invasive procedure using a long thin needle to remove a small piece of liver tissue) and treatment. Some of these explanations appear limited, largely focusing on individual characteristics. As explanations they lack detail about the reasons for the behaviour of those that miss appointments. In other literature the phrases 'chaotic lifestyle' and 'hard-to-reach' have been used to explain non-attendance by drug users with hepatitis C (Moriarty et al, 2001; Irving et al, 2006; Parkes et al, 2006; Bruggmann, 2012; Hepatitis C Trust, 2013; Mravčík et al, 2013; Scottish Intercollegiate Guidelines Network [SIGN], 2013). These phrases tend to blame individuals for missed appointments and the former particularly may suggest to service staff that there is little that can be done to improve attendance. In response to being 'hard-to-reach' some hepatitis C services (like the one in this study) have established outreach clinics (with some offering treatment). On a personal note the researcher was keen to undertake the study to understand what was meant by a 'chaotic lifestyle' and 'hard-to-reach'. Also, the researcher was keen to know the reasons for missed appointments in a setting that was familiar to clients and where they went for a substitution drug treatment script.

In summary, the study was important because non-attendance in hepatitis C appears to be a national problem resulting in health consequences for patients and increased costs for health services. In the absence of empirical evidence it was important to understand the underlying factors contributing to missed appointments and to develop effective ways of improving attendance.

1.3 Structure of the report

This doctoral project report comprises six chapters. The methodology and methods of the study are contained in Chapter 2. This includes: the study aims and objectives; the rationale for taking a realist approach; an outline of the three phases of the study; the contribution to the study methods made by former service users ('Ambassadors'); and the researcher's use of reflexivity. In keeping with a realist approach i.e. cycle(s) of developing and testing theory, the findings of the study follow in the next three chapters. The literature review ('realist synthesis') opens the findings in Chapter 3. This order is unconventional, as the literature review ('realist synthesis') is presented in Chapter 3, after the methods. This is because the literature review was more than just a background to the study. It formed the first realist cycle of the study. At the end of Chapter 3 is a section about new literature on non-attendance in hepatitis C published after the study. This is followed by the findings from the client interviews (Chapter 4) and the national survey of staff working in outreach clinics throughout England (Chapter 5). Both Chapters 4 and 5 include details on: how the sample was selected; data collection and analysis; and ethical issues. The sixth chapter is a discussion of the findings and their implications for policy, service delivery, education and research. Chapter 6 also includes an outline of the strengths and limitations of the study and how the findings have been and will continue to be disseminated.

Chapter 2: Methodology and Method

2.1 Introduction

This chapter describes the philosophical underpinning of the approach taken in the study. It used a 'realist' methodology and drew on the work of Bhaskar ('critical realism') and Pawson ('realist evaluation') (Collier, 1994; Pawson, 2013). The realist approach taken has several implications for how the data was gathered and analysed i.e. methods. These implications will be made explicit before the methods are described. In order to make sense of the methodology and method that follows it is important to know the question that the study wanted to answer. Thus, the chapter comprises of the following sections:

- Research question
- Aims
- Objectives
- Realism: rationale and implications
- Methodology
- Method

2.2 Research question

What are the reasons for non-attendance at drug service hepatitis C outreach clinics?

2.3 Aims

The primary aim of the study was to identify reasons for missed appointments in hepatitis C outreach clinics by examining the experiences and perspectives of clients and health professionals. A secondary aim was to make policy and service recommendations to improve attendance.

2.4 Objectives

(a) To explore, using telephone interviews, the experiences and reasons for clients missing an appointment with hepatitis C outreach clinics in local drug treatment services.

(b) To analyse the data and provide explanations for why patients do not keep an appointment.
(c) To identify health professionals' experiences and views regarding patients missing appointments with hepatitis C outreach clinics in drug services by conducting a national electronic survey.
(d) To explore whether the reasons given by clients and those given by health professionals match and note the similarities and differences.
(e) To make policy recommendations as to how attendance at hepatitis C outreach clinics in drug treatment services might be improved.
(f) To share the findings and recommendations with clinicians, managers, participants, and patients through presentations, posters and publications.

2.5 Realism: rationale and implications

The study used a realist methodology. The key realist idea influencing the study is that there is depth to appearances, that what we experience is the product of processes and mechanisms beneath the surface. It is associated with specific notions of causation, stratified social reality and theory-led approaches to science which influenced the present study. These are now discussed in more detail.

2.5.1 Causation

The research question of the study was to identify the reasons for or causes of non-attendance at an outreach clinic. There are at least two models of causality (Pawson et al, 2005).

Under a 'successionist' model of causality, causation is explained by a linear and repeated succession of events e.g. one billiard ball hits another and it moves (Clark et al, 2007). Where this pattern is repeated, causation is inferred, often in the form of a hypothesis to be tested. For example, if A events are seen repeatedly to lead to B events then the hypothesis that A leads to B is generated and then tested. Similarly, if intervention A is given to population B and outcome C follows then the hypothesis that A causes C

in B is generated. This model of causality is sometimes described as a 'black box' account because it is more important to observe the repeated effect rather than to know the underlying mechanisms by which the effect is generated (Pawson and Tilley, 1997). It is a model of causality associated with the 'closed' conditions of the experimental method, which is used in order to prevent the intrusion of extraneous variables (Clark et al, 2007). Thus, this model of causality underpins randomised clinical trials (RCTs). The idea of the controlled experiment is to see whether A indeed leads to B in carefully controlled environments in which all other causes of B (or not-B) are removed or allowed for. If under these test conditions A still leads to B then this is evidence for the hypothesis.

However, phenomena or interventions that occur in health care settings are difficult to control to the necessary extent. Further, Pawson (2013) points out that a carefully controlled environment can soon come to bear little resemblance to the actual environment where an intervention is to be used, rendering its results invalid. The social systems in which health care takes place are 'open systems'; in other words, there are many factors involved in A leading to outcome C in population B or not, which must be included in consideration of whether A does lead to C. These factors include wider environmental factors as well the interpretations and actions of the individuals involved (Blackwood et al, 2010). In 'open systems' what usually happens is that A sometimes leads to C and sometimes not: the process by which this occurs must be examined by anyone who needs to know whether A will be effective in a particular situation. The successionist model of causality provides little information about in what populations and under what circumstances phenomena occur (or not) or interventions work (or not) (McEvoy and Richards, 2003). The setting for the present study was not a laboratory but an outreach clinic and was part of an 'open system', the social network of the clients and professionals. The participants were likely to give numerous causes for non-attendance, which might be played out in different ways. Also, the study was interested in identifying ways to improve

attendance which might work under different conditions or contexts. Thus, an alternative model of causality appeared to be necessary.

The 'generative' model of causality is concerned with opening up the 'black box' and finding the hidden underlying mechanisms which are enacted under certain circumstances or contexts (Pawson and Tilley, 1997). A useful physical science example is that of gunpowder exploding, which, although causally linked with the application of a spark, requires a number of favourable circumstances (presence of oxygen and absence of dampness) that must be present to reach the expected outcome (Pawson et al, 2004). Understanding the causal effects of the social world (an 'open system') requires a similar explanation, one which involves the context as well as the mechanism that leads to an outcome. Pawson and Tilley (1997) have summed up this contextual dependence of generative mechanisms in the 'realist evaluation' of social programmes using the formula:

Context + Mechanism = Outcome [CMO]

Thus, in this study, non-attendance is the outcome. The generative mechanism could be that an individual does not have the bus fare to get to the clinic. The context could be the recent government welfare reforms and getting people back to work resulting in people receiving lower benefits and/or having greater problems with addiction (and needing to fund this). However, it is unlikely that the study participants will give only one explanation for non-attendance but rather will give multiple factors (mechanisms) which may be played out in different ways. Thus, a generative model of causality which underpins a realist methodology was adopted in the study (Pawson et al, 2005).

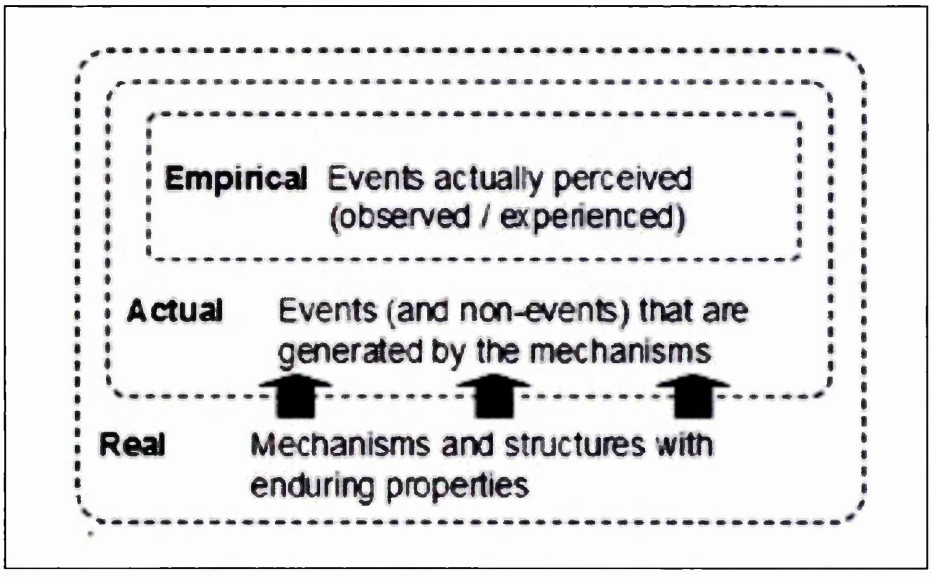
2.5.2 Stratified layer of social reality

The generative model of causality implies that the mechanisms (and contexts) in which the former are triggered are not directly observed but are hidden (Wainwright, 1997). The distinction between what happens and

what we perceive and between an event and the underlying mechanism that cause the event are key features of critical realism – an influential realist philosophy. Critical realism is based on a conceptualisation of three layers of reality, which offers insights into deeper causal mechanisms (Collier, 1994; Mingers, 2002) (see Figure 2.1).

The 'empirical' level is a subset of the 'actual' and consists of phenomena which are experienced by human beings. The 'actual' level comprises things and events that occur but which may or not be experienced by humans. The 'actual' and the 'empirical' levels are contained within the third 'real' domain. This domain embraces the unseen mechanisms that generate events.

Figure 2.1 The three domains of the real (Mingers, 2002; with permission see Appendix 1)



Thus, when a patient is told by his doctor that he missed an appointment with the outreach clinic he experienced the outcome of events in the empirical domain. The event in the actual domain was a cross placed by the name of the patient on the clinic list indicating they had not attended. The mechanism might be, for example, the stigma of hepatitis C which cannot be

directly observed since it exists as an underlying structure in the real domain although its effects i.e. a patient not wanting to be seen at the clinic by others they knew, can be identified. "From the critical realist perspective, understanding the real domain is the proper role of science" (Johnston and Smith, 2010).

This study sought to uncover not only patients' experiences of missing appointments but the events and mechanisms that caused the phenomenon. Some of the reasons for missed appointments by patients were likely to include 'real' concepts such as stigma, poverty and addiction. These concepts which are hidden and exist independently of our minds can be uncovered by realist methodology, such as 'realist evaluation'.

2.5.3 Theory-led approach

In summary, realism is concerned with finding the underlying mechanisms that generate the phenomena we experience, such as missed appointments. It is realist because it believes the world, in this case the social world, to exist independently from our perception of it. Mechanisms are an example of one such thing that we do not experience directly. This is realist ontology (view of reality) (Crotty, 2009). In this, realists differ from constructivists, who do not believe it correct to think in terms of an extra-phenomenal realm (i.e. one of things that are not and cannot be experienced) – rather, they believe we construct the world through our ideas about it. To some extent realists agree with this – our knowledge of the world is something we construct through our theories about it – and those theories change over time. So critical and other sophisticated realists have a realist ontology but a constructivist epistemology (McEvoy and Richards, 2003). Our knowledge of the world is made up of theories, which are fallible. The scientific process is one where our theories are tested and the best ones adopted until a better one is developed.

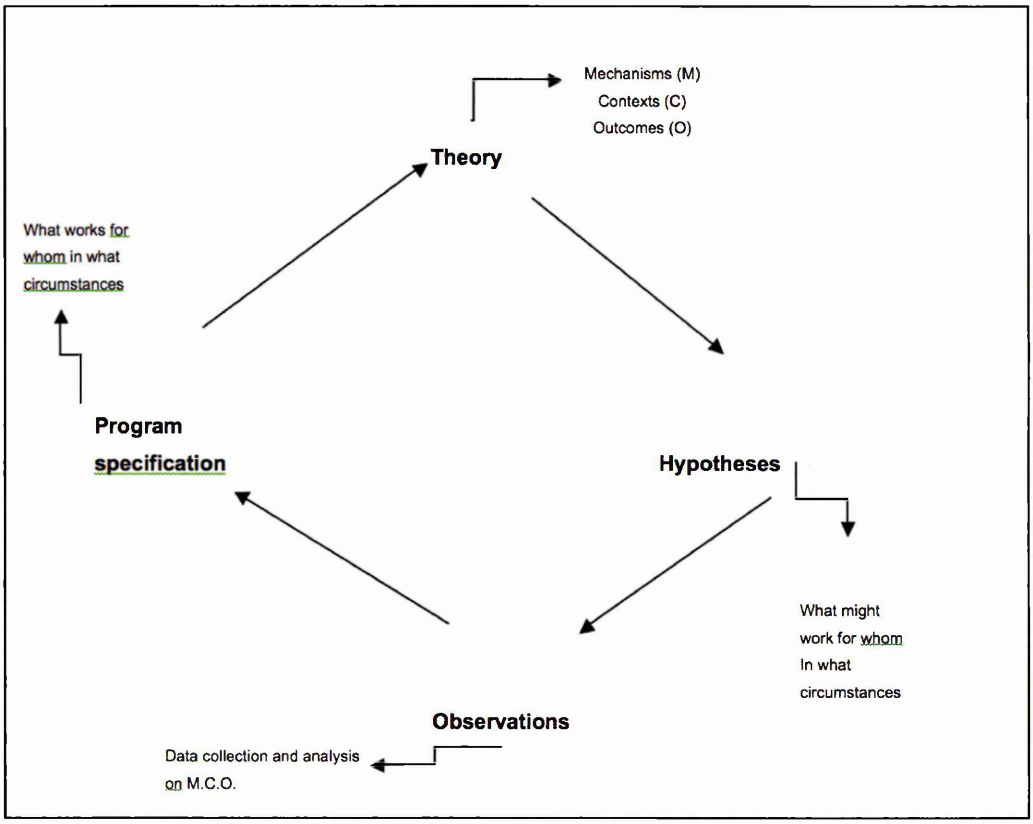
It is for this reason that realist methodology is theory-led. The scientific process under realism is one in which theories are developed, tested and

either adopted, adapted or rejected. Hence, the methodology and methods in this thesis are theory-led.

2.6 Methodology

"Realist research is absolutely conventional, and pleased to be so, in utilising the time honoured research cycle of hypothesis testing and refinement" (Pawson and Tilley, 2004 p10). In Figure 2.2 the 'wheel of science' is couched in realist evaluation terms (Pawson and Tilley, 1997).

Figure 2.2 The realist evaluation cycle (Pawson and Tilley, 1997 p85 with permission; see Appendix 2)



Realist methodology (including 'realist evaluation') has no preference for either quantitative or qualitative methods (Pawson and Tilley, 2004). However, mixed-methods (triangulation) are generally used to develop a more complete understanding of a phenomenon and to test their impact (McEvoy and Richards, 2003; Clark et al, 2007). The precise balance of

methods to be used is decided depending on the context of the study, the theories being tested and the available data.

2.7 Method

2.7.1 Three phases

This study was comprised of three cycles of theory testing. These were, in chronological order:

1. 'Realist synthesis' of the literature;
2. Qualitative telephone interviews led with clients of drug treatment services (see 2.4 'Objectives' (a), (b) and (d)); and
3. Quantitative electronic survey to health professionals running hepatitis C outreach clinics throughout England (see 2.4 'Objectives' (c) and (d)).

Although this study used mixed-methods the biggest component was the qualitative interviews, because little was known about the reasons for non-attendance in hepatitis C outreach clinics. The quantitative survey was used to compare and contrast the findings from the interviews amongst providers' experiences.

2.7.2 User involvement: 'Ambassadors'

The methods and techniques of the study including interview questions were developed with two ex-service users, known as Ambassadors, from the local Drug and Alcohol Action Team (DAAT) (see Appendix 3 – meeting notes). They were invited to comment on the study forms, including the participant information leaflet and interview guide, and the best way of getting participants to speak about non-attendance, including negative things about the service.

2.7.3 Reflexivity

Reflexivity was an important component of the study to help enhance its quality and reliability (Lewis and Ritchie, 2003). It is suggested that these qualities, particularly the latter, are necessary for studies (similar to this

one) with policy implications where some of the findings might be considered replicable in other settings. For example it was anticipated that some of the reasons for non-attendance in an outreach setting and ways to improve attendance might also have relevance for missed appointments with hospital clinics.

Reflexivity is a means of making the researcher's position within a study transparent from both an 'epistemological' and 'personal' perspective (Willig, 2001). As described earlier (see 2.5.3 'Theory-led approach') this study took a constructivist approach in acquiring knowledge about the reasons for non-attendance; with telephone interviews being the chosen method. It was important to ensure that the researcher was aware of any factors or interactions that that could have affected the client interviews, either negatively or positively. With this in mind a 'post telephone interview reflections form' was completed after each interview, which included the questions: 'How well did the interview go?'; 'What could I have done better?'; 'Did anything new come up?' and 'Any other comments?' (see Appendix 4). Personal reflectivity is about being mindful regarding how ones' values, experiences, interests, beliefs, political views, goals and social identity have shaped the research (Willig, 2001). Thus, the researcher also kept a reflective diary, which included his thoughts and feelings and how these might have impacted on carrying out the study and its findings.

Chapter 3: Literature Review

3.1 Introduction

This chapter presents the methods and findings from a 'realist review' (or 'realist synthesis'). A brief description of the new literature published after the study follows the findings. In keeping with the process of a realist review (Pawson et al, 2004) this chapter is comprised of the following sections:

- Realist reviews
- Starting point of the theory-led literature review
- Theoretical framework
- Scope of the review
- Search for evidence
- Data extraction
- Findings and synthesis
- Discussion - Theories about non-attendance in hepatitis C
- New literature
- Conclusion

3.2 Method

3.2.1 Realist reviews

The method of realist review is different from other reviews (particularly 'systematic reviews') because it seeks to uncover evidence of the wider contextual factors that cause underlying mechanisms to generate an observed outcome (Pawson et al, 2005; Coughlan et al, 2013). The focus is therefore different from 'systematic reviews'; these focus primarily on input and output, where the input is an intervention such as a drug therapy. A 'systematic review' looks only for evidence of the effect of the input rather than the mechanisms by which the effect occurred. 'Systematic reviews' thus give priority to RCTs and meta-analysis as these are the studies where the effect is least likely to have been affected by confounding variables. This works well in closed (or nearly closed) systems, such as a human body or a laboratory. It is less useful in open systems, such as society, where

numerous mechanisms interplay when an intervention is made. For example, a measure to reduce car crime, the introduction of closed circuit television (CCTV) to a car park, may work or not for a large variety of reasons. The realist researcher is interested not just in whether it works or not - the answer is almost always that sometimes it does and sometimes not. The realist researcher must consider what works and, by what mechanisms in order to make recommendations about when the intervention is likely to be effective (Pawson and Tilley, 1997). Pawson suggests that this interplay may be represented as a context-mechanism-outcome [CMO] configuration (Pawson et al, 2005). Thus, a realist review using the CMO configuration explores the literature for theories which may best explain the phenomenon under study e.g. non-attendance, across a range of contexts. The literature is used to test initial ideas largely for the purpose of developing a better theory.

It is anticipated that the steps in this review can be followed by another person, thus making it transparent, auditable and replicable. As such, it is a review using systematic searching techniques although it is not a 'systematic review' as described within the prevailing typology of reviews (Grant and Booth, 2009).

3.2.2 Starting point of the theory-led literature review

Many patients with hepatitis C (notably former or current injecting drug users) do not attend hospital clinics, and miss out on specialist care and curative treatment (Jowett et al, 2001; Morrill et al, 2005; Parkes et al, 2006; Maghlaoui, 2012). Many suggestions have been given for this high default rate, including: relapsing substance misuse; low socioeconomic status; co-morbid mental illness; lack of family or social support; a lack of understanding of the implications of a positive test result; negative perceptions of liver biopsy and treatment; and being sent to prison (Jowett et al, 2001). In more general terms it is sometimes suggested that people miss appointments because they lead 'chaotic lifestyles', the infection is 'not a priority' to them and they are 'hard-to-reach' (Moriarty, 2001; Irving et al,

2006; Parkes et al, 2006; Hepatitis C Trust, 2013; Mravčík et al, 2013; SIGN, 2013). These ideas constituted the theories that led this realist, theory-led literature review.

Further, by taking the approach of looking beyond the lifestyle of individuals to explain non-attendance and explore the role of 'upstream' influences suggested that the 'social model of health' would be a helpful framework for the study (Dahlgren and Whitehead, 1993).

3.2.3 Theoretical framework

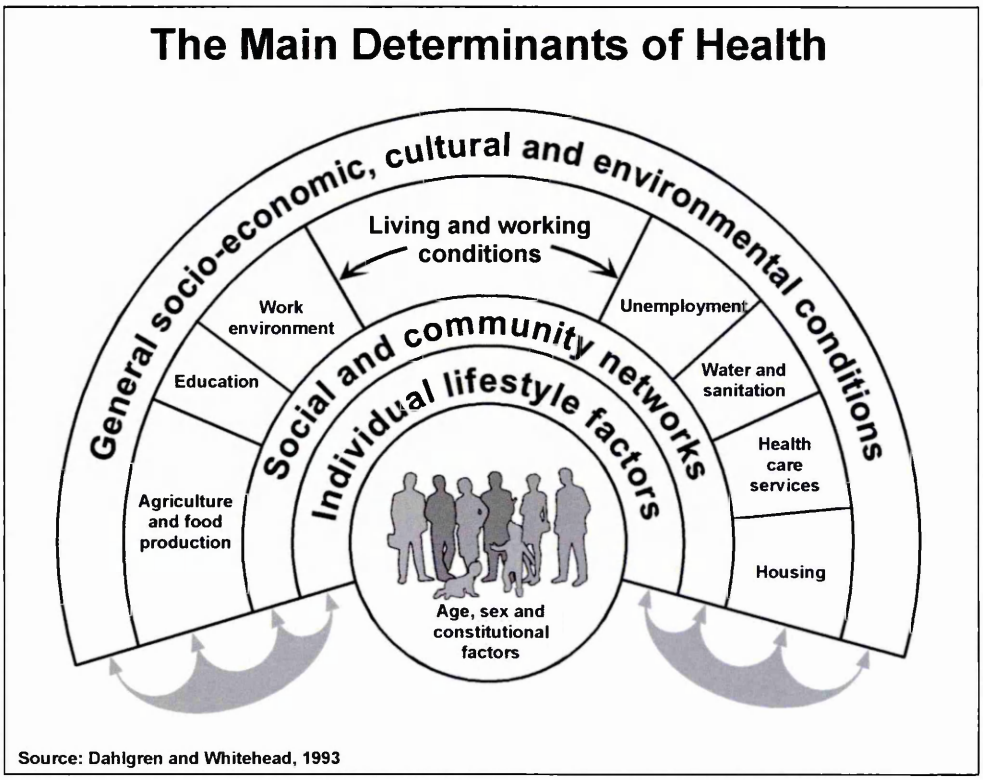
Two theoretical perspectives form the theoretical framework for the study. They were used to develop the study and provided a lens through which to analyse the findings. Thus, they are revisited and discussed further in Chapter 4 – 4.3.2 'Theoretical framework'. The two theories are briefly discussed here and their adoption justified.

The social model of health

This model acknowledges the wider social and environmental influences on health, including the poor uptake of services by some people. It conceptualises the determinants of health as rainbow-like layers of influence (see Figure 3.1 overleaf). The characteristics of individuals that influence health are largely fixed and depicted at the core. The surrounding layers of factors that influence health may be modifiable by policy or practice. For this study it was important to understand the 'causes of the causes' (layers of influence), including the wider socioeconomic and environmental determinants that contributed to missed appointments to help inform effective ways of improving attendance. This model of the determinants of health not only emphasises the interactions between layers but between factors within layers. This was also a feature of the complexity of non-attendance with the hepatitis C outreach clinic with some factors being linked to others. Finally, within the model the determinants of health can have a positive effect on health or be seen as a risk factor for ill-health. The factors or reasons for non-attendance given by the participants could either

lead to attendance or non-attendance depending on how they interacted or were played out.

Figure 3.1 The main determinants of health (Dahlgren and Whitehead, 1993 with permission; see Appendix 5)

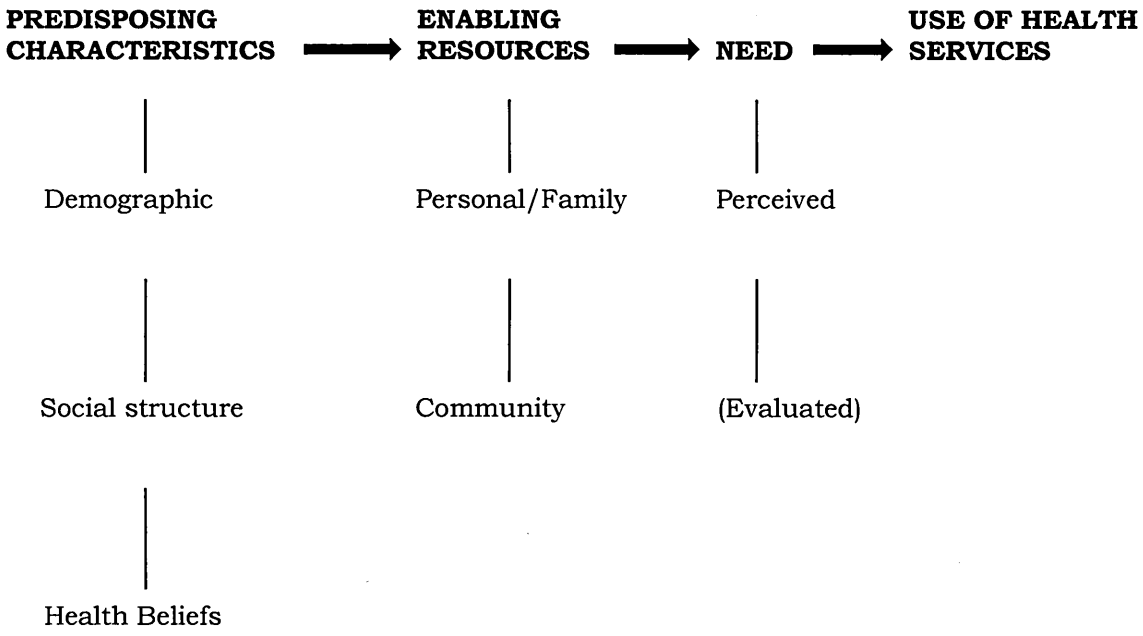


The model of access to medical care

This model developed in the 1960s was intended to: help understand why families use health services; to define and measure equitable access to health care; and to assist in developing policies to promote equitable access (Andersen, 1995). The model originally focused on the family as the unit of analysis but subsequently changed to the individual. This change was due to problems of developing measures at a family level that took into account the potential heterogeneity of family members. In addition, the model was designed to explain the use of formal personal health services rather than to focus on the interactions that occurred as people receive care, or on health outcomes.

The original model, used in this study, is depicted in Figure 3.2 below. It proposes that peoples' use of health services is influenced by three components: their predisposition to use services; factors which enable or impede use; and their need for care. The model may be used to explain or predict peoples' use. For example, each component might be seen as making an independent contribution to predicting use of health services. Alternatively, the model offers an explanatory process or causal ordering where the predisposing factors might be external (particularly the demographic and social structure), some enabling resources are necessary but not sufficient conditions for use, and some need must be defined for use to actually take place.

Figure 3.2 Model of access to medical care (Andersen, 1995)



This study was investigating the reasons that contributed to non-attendance. The components and factors in this model of access to medical care were found to be relevant to this study. For example, within 'predisposing characteristics' and its sub-theme 'health beliefs', the participants suggested that there was no point in turning up for an appointment because they believed the treatment was not effective and they would die anyway. For 'enabling resources' the participants reported not

having the money to travel and relied on someone to give them a lift to get to an appointment. Finally, under the component 'need' the participants indicated that they could delay seeking medical care because they were not unwell.

3.2.4 Scope of the review

Like all literature reviews, a realist review should start with a clear question (Coughlan et al, 2013). The original research question underpinning this review was, 'what are the reasons for non-attendance at drug service hepatitis C outreach clinics?' However, initial scoping of the literature suggested that there was little published on this subject. Therefore, the search aim was adjusted to take in a wider range of literature that was relevant although not precisely focused on the hepatitis-C topic. Thus the three main objectives for this review were to:

- Examine whether initial ideas (theory) about non-attendance are reflected and supported by empirical data;
- Uncover what other relevant theories are present in the literature in related areas; and
- Set out initial theories for testing using primary research (in keeping with the principles of realism).

3.2.5 Search for evidence

Initial scoping of the literature found four articles using the combination of the terms 'non-attendance and outreach and hepatitis C' (Moriarty et al, 2001; Skipper et al, 2003; Gordon et al, 2007; Zucker, 2009). However, only one outreach clinic identified its non-attendance rate of 23% (similar to the local hospital service); it did not explore reasons for missed appointments (Moriarty et al, 2001). Thus, the research question for this realist review seemed not to have been addressed in relation to hepatitis C outreach settings.

In the absence of direct empirical data the search was broadened in two directions. The first was a search for papers on hepatitis C and non-

attendance in non-outreach settings. This resulted in three papers being found (Tiffen and Sheridan, 2002; Kerzman et al, 2009; Cousins et al, 2011). One of these was rejected because it was from a non-Western country and the findings not transferable to UK settings (Kerzman et al, 2009). The second was a search for papers on missed appointments by patients in other groups with similar characteristics and conditions. In England the majority of those infected with hepatitis C are former or current injecting drug users [IDUs] (PHE, 2013a). The infection mainly affects younger adult white males (PHE, 2013a; Mohsen and Trent HCV Study Group, 2001). Drug users may consume large amounts of alcohol, have psychological or mental health problems and are at risk of contracting HIV (Watson et al, 2007; National Treatment Agency for Substance Misuse, 2012; PHE, 2013b). Taking these factors into account, the literature review was extended to include papers on non-attendance in the field of substance misuse, HIV, sexual and mental health.

The key search term was 'non-attendance'; alternative or similar words were identified to ensure that papers using these were also picked up. For example, terms around missed appointments, failure to attend and non-engagement were used. The search terms were put into each database to see whether they matched a relevant Medical Subject Heading (MeSH) but none were found. Thus, a text word search was used. Where appropriate the truncation symbol - * - was used to replace one or more letters to encompass singulars and plurals and various derivations of the same word. For example, miss* appointment* or non-engage*.

The full search can be found in the appendices (see Appendix 6). The databases searched were, in chronological order: Medline; Cinahl; Scopus; and Web of Science. The citations from each database were put into separate folders within 'RefWorks®' and folders were combined systematically with duplicates removed (see Figure 3.3). Google® (with the additional term 'pdf') was searched last primarily for relevant 'grey' literature.

Initial searches also identified unrelated papers for example dissimilar medical specialities and non-Western countries (see Figure 3.4). The literature focus needed to be on populations with similar demographics to where the researchers outreach clinics were located. Thus the exclusion criteria were refined (see below). This revision of the exclusion criteria was found not to omit previously identified relevant papers about non-attendance (Tiffen and Sheridan, 2002; Neale et al, 2008; Cousins et al, 2011) (see Figure 3.5).

Some papers were identified via backward and forward citation tracking, and two were obtained via the specialist nurse in Scotland who sent the references of an MSc dissertation addressing what motivates patients with hepatitis C to attend appointments (see Figure 3.5).

Inclusion criteria

The inclusion criteria for papers were:

- Published in English
- Published from 1980
- About adults
- Had a focus on reasons for non-attendance
- Empirical papers, letters and comment pieces

Exclusion criteria

Papers were excluded if:

- Not about one of the following areas related to Hepatitis C: substance misuse; HIV; and sexual and mental health
- Not about reasons for non-attendance
- All persons <18 years old
- Demographically too different from the population of interest e.g. from a non-Western country

50 papers were initially included, and 18 were excluded largely because they were the wrong patient group (see Figure 3.6). A summary of the main papers relevant for this literature review can be found in the appendices (see Appendix 7). Five papers were found from a search of the 'grey' literature.

The author of one article (Mark Hayter) was approached by e-mail to ask if he was aware of any other papers not identified (Hayter, 2005). He replied that the list was comprehensive but suggested inclusion of literature on tuberculosis (TB) outreach services and non-attendance. However, after discussion, the project supervisory team decided not to follow this advice as TB is an unrelated medical speciality and those affected are typically culturally too different from the predominantly White population affected by hepatitis C in Western countries and, particularly, the UK.

Figure 3.3 Flowchart of database search

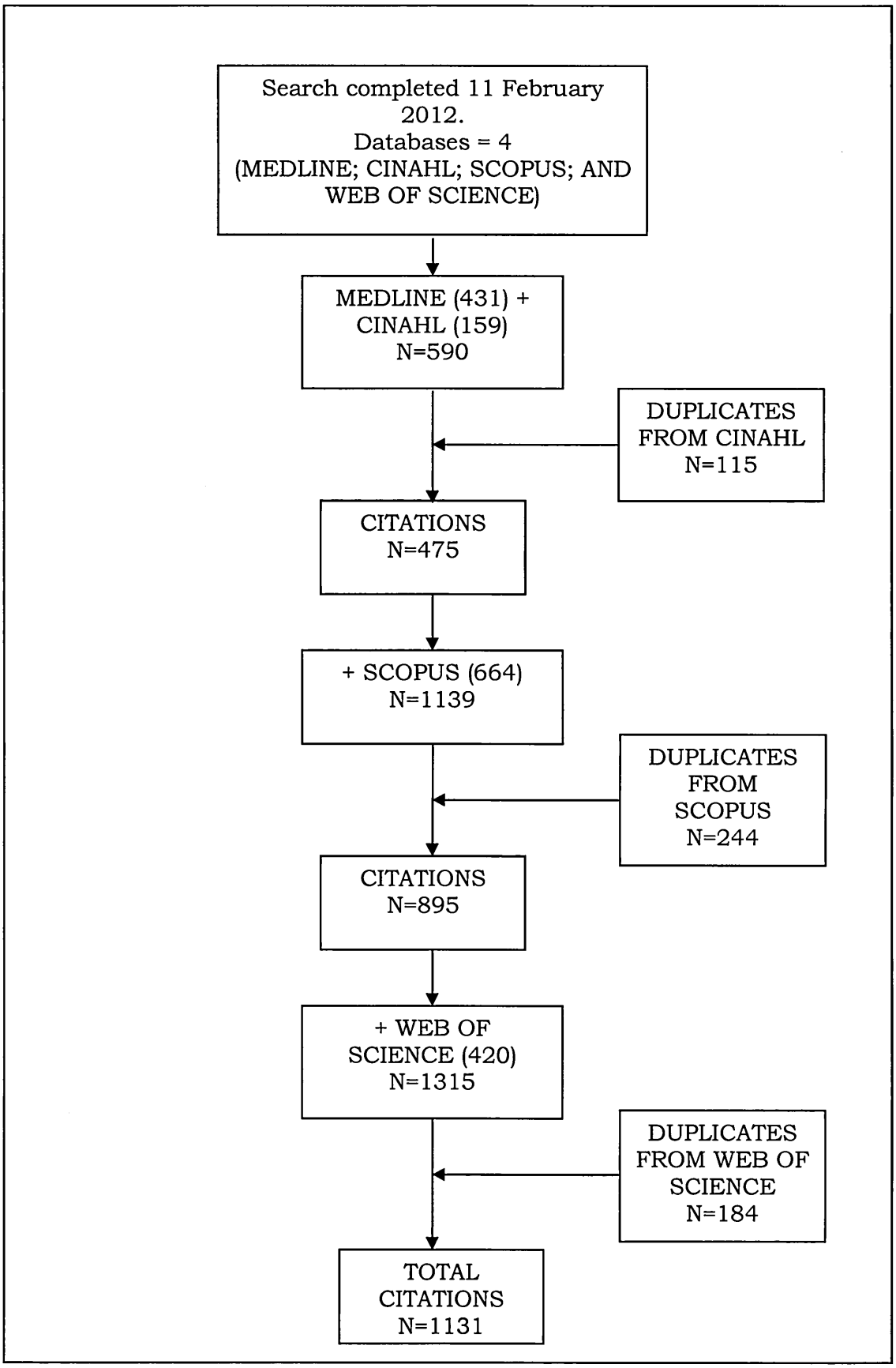


Figure 3.4 Flowchart representing process for identifying papers

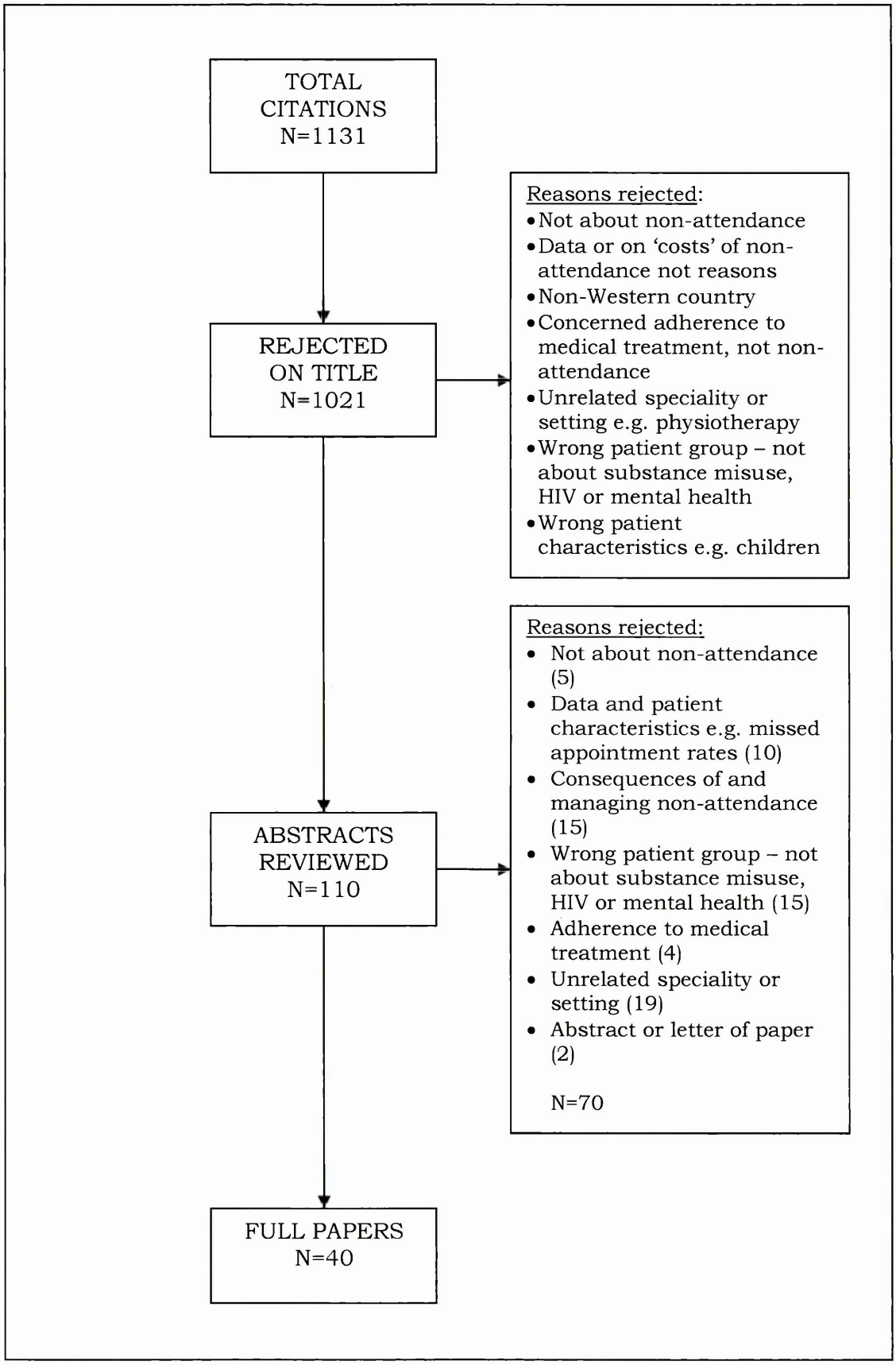


Figure 3.5 Flowchart for checking key papers found and additional papers identified

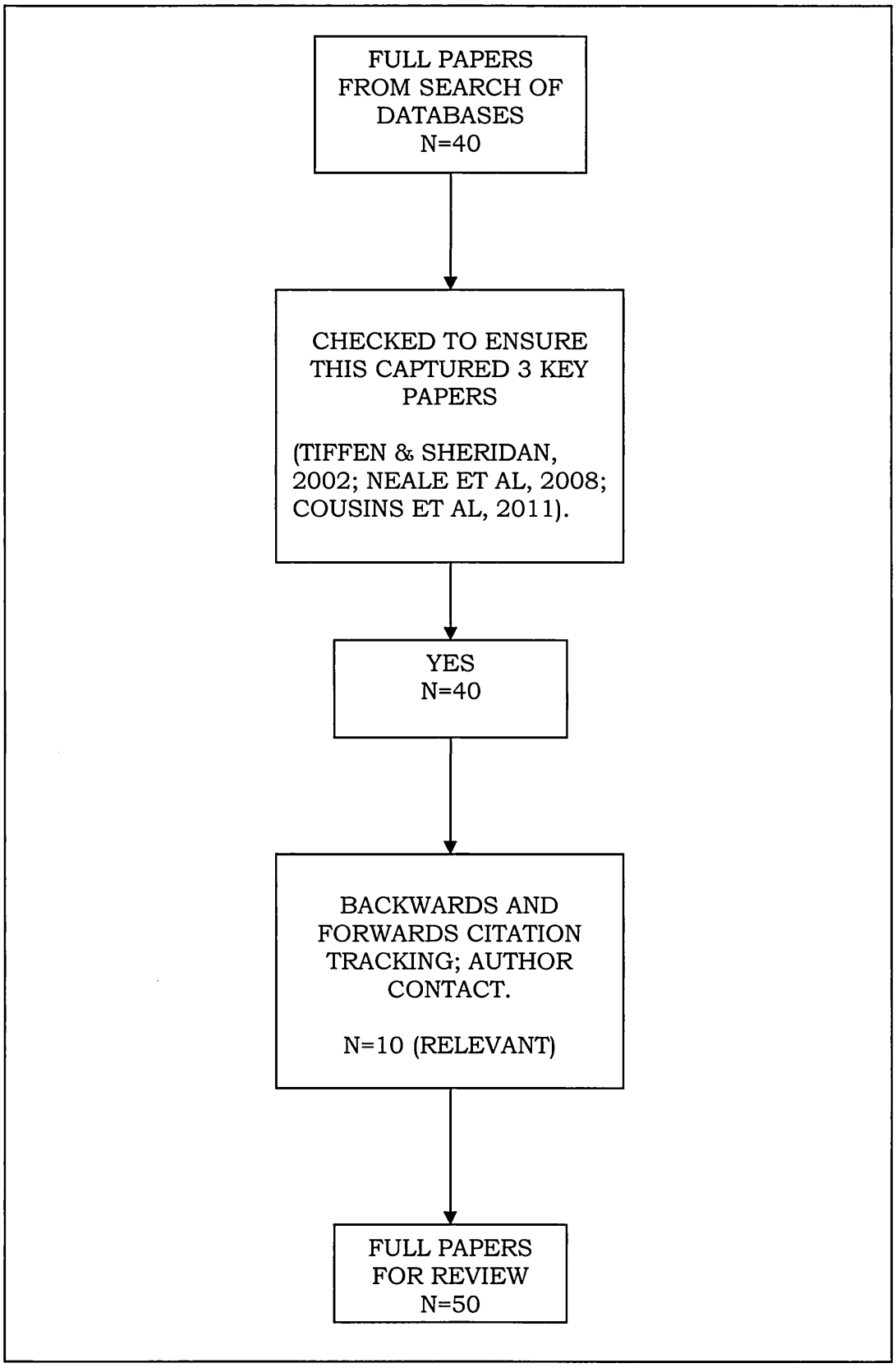
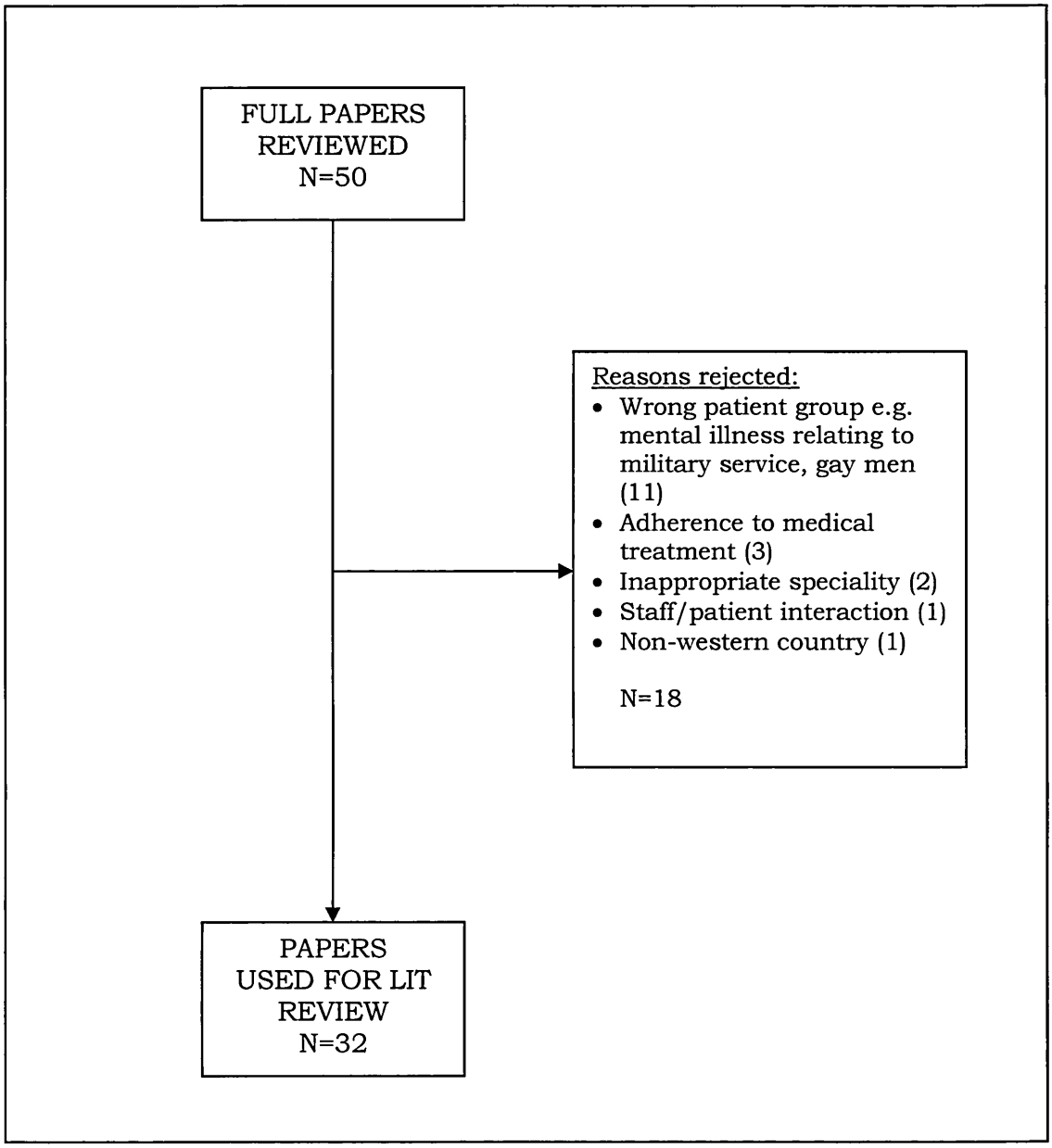


Figure 3.6 Flowchart identifying check of search completeness plus citation tracking



3.2.6 Data extraction

Each paper was critically appraised in the following areas:

- The type e.g. empirical, conceptual or grey literature
- UK or non-UK
- Hepatitis C or other related group
- Outreach or other setting

- Sample size
- The reasons for non-attendance
- Limitations
- Methods, and how a future project might be undertaken
- What, if any, strategies had improved attendance.

The extraction tool can be found in the appendices (see Appendix 8).

3.3 Findings and synthesis

Due to the lack of empirical literature on the reasons for non-attendance in hepatitis C and drug users, it was necessary to consider evidence drawn from other groups which share similar characteristics and challenges in keeping appointments. Therefore, as stated above, this realist review included reasons for non-attendance from psychiatry, counselling, alcohol misuse, HIV and sexual health (with some papers from outside the UK). The theories that have been uncovered are put into five categories:

- Organisation of appointments
- Patient motivation or ambivalence
- Other commitments or demands
- Experience with services or professionals
- Patient characteristics

3.3.1 Organisation of appointments

Studies have suggested that a long wait for appointments is a reason for not keeping them (Carpenter et al, 1981; Hyslop and Kershaw, 1981; O'Neill and Kerr, 1991; Morton, 1995; Peeters and Bayer, 1999; Snape et al, 2003; Booth and Bennett, 2004; Hills, 2009). The importance of a long wait for an appointment was such that individuals referred to a community mental health centre added spontaneous comments to the survey (Peeters and Bayer, 1999). Further, some of the study participants missed their appointment because they had been able to get an earlier appointment at another service. For some people referred for counselling or to a mental health service they had waited so long for an appointment that their circumstances had changed or resolved such that they no longer required

the service (Carpenter et al, 1981; O'Neil and Kerr, 1990; Peeters and Bayer, 1999; Snape et al, 2003). Also, it was suggested that people may have pushed their distress into the background and could not face it re-emerging when a counselling appointment was finally offered (Snape et al, 2003). Conversely, at a time of distress people lacked the ability to respond to the offer of an appointment. It is suggested that the longer wait for an appointment may be good as it filters out unnecessary referrals and people who are poorly motivated to attend (Farid and Alapont, 1993). However, non-attendees at a psychiatric day hospital clinic reported that despite some improvement 'they were still ill enough to need some help' (O'Neill and Kerr, 1991).

Lefforge et al (2007) recommend that initial appointments occur as soon as possible. In substance misuse this needs to be the same day or within one week. Some clients who missed appointments with a short-term psychotherapy group had wanted an immediate appointment (Morton, 1995). However, two studies looking at non-attendance by psychiatric patients (Farid and Alapont, 1993; Killaspy et al, 2000) and another exploring non-engagement in drug and alcohol treatment (Coulson et al, 2009) found no difference for the length of wait for an appointment. In a future study it would be important to identify or define the length of wait for an appointment and the nature of the problem. For example, clients with less acute problems might be more able to tolerate waiting a couple of weeks compared to someone in crisis.

The time of the appointment is reported to be a factor in non-attendance. In a Canadian mental health unit patients were 3.6 times more likely to show up if their first appointment was scheduled in the afternoon (Weinerman et al, 2003). An incidental finding for 'follow-up no-show' at a forensic psychiatric outpatient clinic in the Netherlands was 'overslept' (Feitsma et al, 2012). It seems unlikely the findings of studies abroad can be generalised to the UK because, first, it has a different model of health care provision and, second, reasons for non-attendance are likely to be culturally

specific. Nevertheless, a qualitative paper about improving access to services for IDUs in West Yorkshire, England recommended not giving morning appointments to people because they will be experiencing opiate withdrawal and will be preoccupied with either obtaining illegal drugs or a substitution drug treatment script (Neale et al, 2007). This explanation seems to provide some insight into what is meant by ongoing drug use and a so-called 'chaotic lifestyle'. Also, stimulant injectors trying to reduce or stop using have felt too tired to attend (Neale et al, 2008).

A survey of missed appointments within psychiatric specialities across the UK found that there were significantly fewer missed appointments on Fridays (Mitchell and Selmes, 2007).

The lack of an appointment at a time chosen by the patient has been given as a reason for non-attendance (Snape et al, 2003; Hills, 2009). Patients at risk of hepatitis C infection reported the convenience (and location, see 3.3.4 'Experience with services or professionals') of services as a factor affecting attendance at screening (and hepatitis B immunisation) sessions (Agarwal et al, 2011), with attendance being more likely to occur if linked to regular drug treatment service appointments.

Hills (2009) suggests that patients miss appointments because they do not understand how the appointment system works – believing it to be flexible, subject to negotiation, with staff seeing patients without keeping to appointment times. This needs to be set against the finding that some IDUs reported that strict times operated by some pharmacies (despite being open to other customers for longer) to collect substitute medication was problematic for those who were working, had a long distance to travel, were unwell or had other commitments elsewhere e.g. housing, criminal justice or social welfare services (Neale et al, 2007). This finding suggests that non-attendance is complex in this setting with drug users facing many challenges in keeping appointments.

Snape et al (2003) reports that some counselling patients do not attend because they: did not know what to expect from the service; tried to cancel an appointment but failed; and did not receive an appointment letter. The former was also experienced by clients who missed an appointment with a hepatitis C clinic (Tiffen and Sheridan, 2002). The latter was reported by clients with mental health problems (Morton, 1995; Feitsma et al, 2012). For some patients with alcohol problems the card with confirmation of the appointment arrived after the date to be seen (Hyslop and Kershaw, 1981). Clerical error was given as a reason for missed new appointments by psychiatric patients (Killaspy et al, 2000; Feitsma et al, 2012).

3.3.2 Patient motivation or ambivalence

Cousins et al (2011) found no differences between IDUs with hepatitis C that did or did not attend a hospital clinic in the North of England in respect of duration of diagnosis, confidence about knowledge of hepatitis C, expected discrimination from staff, expectations of the first appointment and difficulties with transport. This suggests that there must be another independent factor that influences attendance (Cousins et al, 2011). For example, the degree of importance that patients place on their hepatitis C, which is likely to be higher in IDUs who do attend than those that miss their appointment. Another paper about hepatitis C and non-attendance reports drug users do not prioritise the infection (Australian Injecting and Illicit Drug Users League [AIVL], 2010). However, the degree of importance is relative because there might be other competing demands on individuals' time which take priority, such as keeping an appointment with a probation officer to avoid prison. Imprisonment has also been linked to missed appointments in the settings of HIV, mental health and drug use (Pieper and DiNardo, 1998; Peeters and Bayer, 1999; Morrison et al, 2011).

The asymptomatic nature of hepatitis C has been given as a reason by some experts to explain a high rate of non-attendance by people with the infection referred to a gastroenterologist working in New York, USA (Martin, 2005). In contrast, patients with other gastrointestinal conditions may be more

motivated to attend because they were experiencing symptoms such as diarrhoea, abdominal pain or difficulty with swallowing. On the other hand, some individuals with HIV may not attend services because they are not unwell (Morrison et al, 2011).

Buetow (2007) suggests (although without directly referring to empirical evidence) that patients may miss appointments to take control and protect themselves from information about a disease that is serious, chronic and stigmatising. Patients wish to remain individuals and not simply be known as belonging to a marginalised group. The author argues that people make a rational choice to miss appointments largely to protect themselves from services they consider threatening to their personal identity. Thus, if the risk of having a health problem is considered small the person does not attend. Also, individuals may function better without addressing health issues e.g. smoking relieves stress, or they may be concerned about the present rather than future or potential harms. For example, according to some hepatitis C nurses, patients may feel there is no urgency to see a hospital specialist because the infection is described as a 'slowly progressive disease' (with liver disease in the absence of other aggravating factors developing over many years) (NHS Greater Glasgow and Clyde, 2012).

According to the literature, mental health and substance misuse patients (including those with leg ulcers) do not attend because they are not bothered or lack motivation (Pieper and DiNardo, 1998; Peeters and Bayer, 1999; Killaspy et al, 2000; Coulson et al, 2009; Darker et al, 2012; Feitsma et al, 2012). Further evaluation of the respondents from a community mental health centre, who were not motivated to attend despite persistent problems, found the majority did not seek any other help after their 'no-show' (Peeters and Bayer, 1999). The authors state that lack of motivation is a feature of the study population, who fail to engage in active help-seeking behaviour. These explanations for missed appointments appear to be inadequate and do not address the complex underlying mechanisms and influences that

could be at play. Thus, motivation and not being bothered appeared to be important theories to test in this study.

Hyslop and Kershaw (1981) found that patients with alcohol problems missed appointments because they changed their minds; disagreed that their problems were due to alcohol; and did not agree to the referral. The latter is a common reason for non-attendance in the setting of mental health. Killaspy et al (2000) found that 17% of psychiatric patients were unhappy with referral to hospital out-patient clinics.

3.3.3 Other commitments or demands

Ongoing drug and alcohol use has been given as a reason by patients and staff for missed appointments in hepatitis C (Agarwal et al, 2011; NHS Greater Glasgow and Clyde, 2012). Further, according to some nurses, patients who drink alcohol excessively may not turn up because they know this to be a barrier to starting treatment (and that they will be asked by the staff to reduce and/or stop drinking in the first instance) (NHS Greater Glasgow and Clyde, 2012). Some drug users felt unable to keep appointments because they were anxious about experiencing withdrawal symptoms if kept waiting by hospital staff (Neale et al, 2008).

The impact of individuals' drug use in explaining non-attendance has been identified. Of those who missed their appointments, more participants identified their substance use as having a negative impact on their mood, coping and social ability (Coulson et al, 2009). It has been found that those who use a wider variety of recreational and illicit drugs are less likely to attend needle exchange services and drop out of drug treatment early (Frischer and Elliott, 1993; Coulson et al, 2009). Also, non-attendees of needle exchange services are more likely to engage in unsafe practices such as the infrequent use of condoms with casual partners and more frequent injecting drug use with (and exchange of) used equipment (Frischer and Elliott, 1993). A commonly cited reason for drug and alcohol clients not keeping appointments is 'being busy' (Coulson et al, 2009). In the setting of

HIV, Morrison et al (2011) suggest alcohol misuse can lead to 'chaotic lifestyles' and difficulties with keeping appointments. However, these authors give insufficient information on what activity is making people 'busy' or too 'chaotic' to attend. As such, this was an area also worth further exploration in this study.

Another widespread explanation for non-attendance relates to work commitments, including not taking time off, because this would be unpaid time (Carrion et al, 1993; Morton, 1995; Gariti et al, 2008; Coulson et al, 2009; Hills, 2009; Swarbrick et al, 2010; Feitsma et al, 2012). Some people worked in jobs where employers were not flexible and were questioning when it came to attending medical appointments or being ill (Morrison et al, 2012). In addition, some individuals 'disappeared' into work to distract themselves from their HIV status. These findings need to be set against the report of a high rate of unemployment among psychiatric outpatients who gave other commitments taking priority as a reason for missed appointments (Killaspy et al, 2000).

Other commitments for patients with mental health problems, HIV and venous ulcers included: childcare responsibilities; attending a funeral; taking care of others and having a social service appointment (Morton, 1995; Pieper and DiNardo, 1998; Morrison et al, 2011; Feitsma et al, 2012). Also, there was a fear amongst some women with HIV that where services know their status this might influence decisions made about child welfare (Morrison et al, 2011). In a Genito-Urinary Medicine [GUM] (Sexual Health) clinic, as well as childcare issues and carer responsibilities, academic study had been given as a reason for missed appointments (Swarbrick et al, 2010). For patients referred to a smoking cessation program, keeping family obligations negatively impacted on attendance (Gariti et al, 2008). It is worth noting that although these areas (GUM and smoking cessation) might have some relevance to hepatitis C outreach clinics (which is why they were included in this review) there are nonetheless likely to be systematic differences.

Unplanned or unexpected events have been given as reasons for missed appointments (Gariti et al, 2008), for example, patients with alcohol problems being taken into police custody (Hyslop and Kershaw, 1981). Also being in prison including the sudden imprisonment of a spouse has been cited as a reason for non-attendance (Peeters and Bayer, 1999; Morrison et al, 2011). In addition to jail, some patients with venous ulcers reported being in hospital and harsh weather as reasons for missing appointments (Pieper and DiNardo, 1998). For a relatively small number of clients referred for small group psychotherapy it was 'not the right time' to attend because they had suffered bereavement (and were getting support elsewhere) (Morton, 1995). For drug and alcohol clients, being out of area at the time of the appointment and being evicted or moving house were given as reasons for non-attendance (Pieper and DiNardo, 1998; Coulson et al, 2009).

3.3.4 Experience with services or professionals

A possible lack of effective communication by the doctor about the reason for referral may be a factor for non-attendance in hepatitis C (Martin, 2005).

In a UK psychiatric outpatient clinic the quality of the referral letter significantly differentiated those who attended appointments and those who did not (Farid and Alapont, 1993). For individuals who did not attend, the letter (mainly written by General Practitioners [GP's]) was of lower quality, and did not contain an adequate history or a specific description of the patients' problems. The authors hypothesise that: non-attendees may have been inappropriately referred; some GPs may not be aware of other helping services available; inappropriate referrals to psychiatry may be depriving patients of the help they require; and the GPs may be depriving other patients of the opportunity to see a psychiatrist at the earliest appointment. As has been noted (see 3.3.1 'Organisation of appointments') the longer wait for an appointment appears to be correlated with non-attendance. On the other hand, patients who missed an appointment appeared to give vague or evasive reasons for seeking help (Carpenter et al, 1981).

For referrals, 'no-show' at a community mental health centre in the Netherlands was higher among those referred by other services rather than the GP or self-referral (Peeters and Bayer, 1999). The authors suggest that: the participants were already in contact with other services and may have been less motivated to start a new or additional treatment; and the referral process by non-GP services might be experienced in a different way e.g. a single discussion with a worker that leads to advice to seek care at the mental health centre may be perceived as less obligatory than the same advice from the GP with whom patients usually have a long-standing and personal relationship. The impact of the GP consultation, i.e. peoples' problems being taken seriously, appeared to be positively correlated with uptake of counselling appointments (Snape et al, 2003).

In a UK paper examining missed psychiatric appointments by a referring agency, the rate of initial and subsequent non-attendance was highest following self-referral and referrals from the police or probation service and lowest for referrals from community psychiatric nurses and social services (Mitchell and Selmes, 2007). In the USA more psychiatric patients referred from a medical clinic or local physician kept the appointment than those referred by friends or relatives, an emergency room, another psychiatric facility, or self (Carpenter et al, 1981). Clients referred for small group psychotherapy were less likely to turn up if referred from probation or a social worker (Morton, 1995). Although these findings are slightly ambiguous they may signify an important dimension in the relationship with the referrer and whether individuals are likely to attend appointments. The probation service and some social workers (for example those working in child protection) represent authority and the law, whilst psychiatric nurses and local doctors are viewed as caring and helping professionals. The latter may be more knowledgeable about what other health services provide; who works in them; and may be more experienced and skilled in dealing with peoples' anxieties about referral. It has been shown that specifying a particular consultant psychiatrist on the referral was a significant factor in the patient attending a clinic at a day hospital (O'Neill and Kerr, 1991).

Qualitative feedback from clients with hepatitis C who missed an appointment with a hospital clinic in the North of England revealed they: feared visiting the clinic; had mental images of advanced disease and death; and were apprehensive about medical terminology, specifically terms around 'liver biopsy' (Tiffen and Sheridan, 2002). The authors conclude that a lack of information meant that clients were not able to make informed decisions about their care. For example, elsewhere, a lack of information and understanding about the need for confirmatory testing (to establish ongoing chronic infection) and the value of regular monitoring can result in people developing complacency about disease progression, adopting lifestyle measures to minimise harm to the liver and disengaging with health services (AIVL, 2010). Thus, a lack of information might also explain why some people with hepatitis C may report or are perceived by others to be 'not bothered' or 'lack motivation' to attend.

In a more recent evaluation of a hepatitis C outreach service nurses suggested that patients missed appointments because they had concerns or were misinformed about the condition: such as the necessity of having a liver biopsy; it being a death sentence; and the treatment being ineffective (NHS Greater Glasgow and Clyde, 2012). By contrast, for one hospital clinic in the North of England confidence about knowledge of hepatitis C was not a factor for non-attendance (Cousins et al, 2011). HIV literature showed that some people believe they are going to die and think there is no point attending (Morrison et al, 2011). In the UK it stopped being routine for patients to undergo liver biopsy to assess the need for treatment after 2006 (although this change in practice may not have reached most of those infected). Over the years developments in treatment have made it much more effective (NICE, 2006; NICE, 2012a; NICE, 2012b). Thus, the reasons for non-attendance in hepatitis C are likely to change over time as service provision changes (as well as other contextual factors such as welfare and drug misuse policy). This was an important consideration in taking a realist approach in this study. This is because a realist approach is better suited

to investigation in open systems where factors affecting outcome change over time (Pawson and Tilley, 1997).

Within the evaluation of a hepatitis C outreach service the nurses also suggested that patients did not attend because they feared finding out they had serious liver disease (NHS Greater Glasgow and Clyde, 2012). Further, patients may consider it better not to know the condition of their liver, particularly if they are asymptomatic (a common feature of infection). The latter was also given as a reason for non-attendance and is described under 3.3.5 'Patient characteristics'.

Some IDU's stated they had missed outpatient appointments because they were afraid of being diagnosed with a serious health problem such as hepatitis or HIV/AIDS (Neale et al, 2008; AIVL, 2010). In the setting of HIV people may be in shock and denial following a positive test result (Morrison et al, 2011). Some people may move away to be anonymous elsewhere and avoid engaging with services. For those who struggle to come to terms with their diagnosis, attending can be a constant reminder of their infection (Morrison et al, 2011). In addition, drug users may be tested too early e.g. having just started on a drug treatment script or feel coerced into being tested for fear of delays in getting onto a drug substitution script and before they are ready to engage with hepatitis C services (AIVL, 2010; NHS Greater Glasgow and Clyde, 2012). Some drug users wanted to know their status but declined further care and treatment (NHS Greater Glasgow and Clyde, 2012). However, it is not clear the reasons why these patients did not want further care and treatment. This review of the literature offered some possible explanations which were explored in this study.

In two papers about missed appointments with mental health services non-attendees reported fears and anxieties about the appointment (O'Neill and Kerr, 1991, Morton, 1995). They described being uncertain about the treatment available; felt uncomfortable discussing treatment; were afraid of

treatment and participating in a small psychotherapy group; were worried that their symptoms might worsen; and wanted more information.

Continuity of care, clinical competence and differences in clinical style have been suggested as the key reasons for differences in non-attendance rates between staff groups working in mental health (McIvor et al, 2004). The non-attendance rate for the clinical psychologist was lower than the rates for medical staff. This may be partly explained because psychologists are more likely to emphasise principles of therapeutic alliance, collaboration and education in their work. For medical staff, the non-attendance rate increased progressively between consultant psychiatrists, specialist registrars and senior house officers. Like the psychologist, consultant psychiatrists saw most of their patients over long periods, which facilitated the development of a good rapport and a positive, uninterrupted therapeutic relationship. This is possibly akin to the take up of GP referrals described earlier where the patient has a long-term relationship with their doctor (Peeters and Bayer, 1999). On the other hand, non-consultant medical staff move departments every six or twelve months, leading to interruption of clinical care. This change in medical staff might negatively impact on patients' willingness to keep their appointment. In addition, patients may feel they are being given a better service by seeing a more senior member of staff.

Nurses working in hepatitis C reported that some patients may miss appointments because they fear being judged by other people (NHS Greater Glasgow and Clyde, 2012). If there are visible signs of recent injecting drug use people may not attend for testing or ongoing monitoring for fear of this being discovered (AIVL, 2010). Some patients may have had bad experiences of hospitals in the past and perceive there to be a risk of 'being treated like a junkie' (NHS Greater Glasgow and Clyde, 2012). For example, disclosure of injecting drug use causes concern for people about the possible negative impact on their ongoing care including restrictions on other medications (AIVL, 2010).

Other marginalised patients feel stigmatised and report this as reasons for missed appointments. A group of female street-based prostitutes reported difficulty attending the GP surgery or the sexual health clinic because they felt or were fearful of being judged by the staff (Jeal and Salisbury, 2004). They also had difficulty waiting with other patients because they were or might be stared at. Due to stigma and discrimination people with HIV may not keep appointments because the staff are 'unfriendly' (Morrison et al, 2011). The respectful and non-judgemental attitudes of outreach sexual health clinic staff were highlighted as strengths by young people (Hayter, 2005). The other two areas were: the importance of confidentiality; and having someone to talk to with. Similarly drug users felt that professionals would help to reduce some of the stigma, shame and embarrassment they experience when approaching agencies by being less judgemental, more welcoming, more understanding of their problems, and more encouraging of their progress (Neale et al, 2007). Snape et al (2003) add that for employed persons the stigma associated with undergoing counselling or experiencing mental health problems is a barrier when explaining to an employer why it is necessary to take time off work.

In the setting of hepatitis C concerns about confidentiality and being seen by other people was given as a reason by nurses for non-attendance (NHS Greater Glasgow and Clyde, 2012). This was also a concern for HIV patients who may not attend services for fear of being seen by others they know (Morrison et al, 2011).

Travelling to city centre locations was a problem for young people attending sexual health services (Hayter, 2005). For people with HIV living in rural or island communities in Scotland travelling to services particularly if using public transport can be a challenge (Morrison et al, 2011). A reason for not attending a smoking cessation program was location of the facility (Gariti et al, 2008). Also, patients referred to an alcohol clinic were more likely to attend if they travelled a very short distance (Booth and Bennett, 2004). However, for patients referred to a psychiatric clinic distance from home

address was not correlated with missed appointments (Carpenter et al, 1981; O'Neill and Kerr, 1991). But psychiatric patients who missed appointments were found to live significantly nearer the hospital psychiatric outpatient clinic (Farid and Alapont, 1993). On reflection, this may be a social class difference as the hospital is situated in the inner-city. For others a lack of or inadequate transportation has been given as factors to explain non-attendance (Carrion et al, 1993; Pieper and DiNardo, 1998; Peeters and Bayer, 1999; Neale et al, 2008; Coulson et al, 2009; Feitsma et al, 2012). An example, the bus being late was reported by some patients (predominantly with a history of drug use) with venous leg ulcers (Pieper and DiNardo, 1998). Finally, it has been noted that attendees of an Alcoholism Referral clinic often had a car (Hyslop and Kershaw, 1981), whilst having personal transport has been seen to make it more likely that drug users attend appointments (Neale et al, 2007).

The financial costs incurred travelling to services has been cited as a reason for missed appointments in hepatitis C and related groups (often associated with unemployment but also includes employed people on low incomes) (Pieper and DiNardo, 1998; Booth and Bennett, 2004; Gariti et al, 2008; AIVL, 2010; Morrison et al, 2011; Feitsma et al, 2012; NHS Greater Glasgow and Clyde, 2012). This factor should be seen in the context of the welfare reforms and getting people back to work (Morrison et al, 2011). For HIV patients a fear of disclosure of status can result in people not following up extra benefit or housing entitlement (Morrison et al, 2011). Nurses suggest that for hepatitis C patients the cost of travel is particularly a problem when appointments do not coincide with the patients' benefit payments (NHS Greater Glasgow and Clyde, 2012). Although travel costs can be reimbursed this is dependent on staff informing people or individuals asking (Morrison et al, 2011).

Loss of momentum and delays between stages of the care has been suggested by nurses working in hepatitis C as a reason for missed appointments (NHS Greater Glasgow and Clyde, 2012).

3.3.5 Patient characteristics

Patients with hepatitis C indicated 'social issues' as a reason for non-attendance (NHS Greater Glasgow and Clyde, 2012). "The audit findings suggest that the majority of chronic positive non-attendees have needs and issues that take precedence over those associated with hepatitis C" (NHS Greater Glasgow and Clyde, 2012 p12). However, there appeared to be a lack of detail about the wider socioeconomic and environmental issues that caused hepatitis C not to be a priority for those infected and was an area investigated in this study.

In the literature on related groups, non-attendees (compared to those who keep appointments) are younger, male and of lower social class (Hyslop and Kershaw, 1981; O'Neill and Kerr, 1991; Farid and Alapont, 1993; Booth and Bennett, 2004; Coodin et al, 2004; Gariti et al, 2008; Coulson et al, 2009). Younger age i.e. aged 18-24 years old but not gender or socioeconomic status was a significant factor for missed appointments at psychiatric outpatients (Carpenter et al, 1981). For patients referred to an alcohol clinic the duration of the problem is considered a confounding factor with age i.e. younger patients are less likely to attend because they have not experienced difficulties for as long as their older counterparts (Booth and Bennett, 2004). However, in the setting of hepatitis C the duration of diagnosis was not a factor for non-attendance (Cousins et al, 2011).

People who miss appointments are more likely to be unmarried and living with parents rather than with a partner or children of their own (Hyslop and Kershaw 1981; Frischer and Elliott, 1993; Coulson et al, 2009). This needs to be set against a report that childcare issues (see 3.3.3 'Other commitments or demands') are factors for non-attendance (Morton, 1995; Swarbrick et al, 2010; Feitsma et al, 2012). For IDUs, not having anyone to accompany them to hospital outpatients to offer moral support (or provide a lift) was associated with non-attendance (Neale et al, 2008). 'Selfless' individuals may wish to protect other people from the burden of their ill-health (Buetow, 2007). Also, they may believe that scarce resources should

be allocated to patients with greater needs. For example, patients who acquired hepatitis C from drug use may feel that they are not entitled to care (NHS Greater Glasgow and Clyde, 2012).

Fewer years in formal education has been given as a characteristic of substance misuse patients who miss appointments (Frischer and Elliott, 1993; Coulson et al, 2009). Also, in the setting of HIV literacy difficulties make it difficult to understand the information required to access and to engage with services (Morrison et al, 2011).

The employed are more likely to attend appointments than the unemployed (Gariti et al, 2008; Coulson et al, 2009; Swarbrick et al, 2010). But as described under 3.3.3 'Other commitments or demands' people may miss appointments because they have difficulty getting time off work. Thus, there are contradictions in evidence regarding employment positively correlating with keeping appointments. Similarly, in an evaluation of attendance and non-attendance at a needle exchange clinic, housing, employment and prison experience were not found to be of influence (Frischer and Elliott, 1993). On the other hand, this needs to be considered against the findings that imprisonment and moving house contribute to non-attendance (Morton, 1995; Pieper and DiNardo, 1998; Coulson et al, 2009; Peeters and Bayer, 1999).

Both mental and physical co-morbidity are associated with missed appointments in hepatitis C (Agarwal et al, 2011; NHS Greater Glasgow and Clyde, 2012). The former supports the strategy taken in this realist review of exploring reasons for non-attendance within psychiatry. Being too unwell (physically and mentally) has been given as a reason for missed appointments by other related groups (Hyslop and Kershaw 1981; Pieper and DiNardo, 1998; Killaspy et al, 2000; Morrison et al, 2011; Feitsma et al, 2012). For example, patients with venous leg ulcers reported being 'in too much pain', feeling 'too sick' and 'stressed' to turn up (Pieper and DiNardo, 1998). Also, drug and alcohol problems can result in psychoses which make

clinic attendance difficult (Morrison et al, 2011). This needs to be set against the finding that for people whose long wait for an appointment meant that they felt better and no longer needed to attend (see 3.3.1 'Organisation of appointments') (Carpenter et al, 1981; O'Neil and Kerr, 1990; Peeters and Bayer, 1999; Snape et al, 2003). Although some patients not waiting too long for an appointment also felt better and did not attend (Pieper and DiNardo, 1998).

However, physical ill-health (and putting oneself at risk of infection) has also been identified as a motivating factor for attendance for hepatitis C testing (Agarwal et al, 2011). Having been at risk of infection from hepatitis C may well be a motivating factor to attend for testing but this needs to be seen in the context of other factors that may conspire against attending e.g. fear of disclosing recent injecting drug use, fear of a positive result and difficulty getting a blood sample. A relatively common finding for not turning up to an appointment relating to hepatitis C is patients having poor veins (AIVL, 2010; Agarwal et al, 2011). The mechanisms appear to be two-fold with staff having difficulty obtaining blood samples and a fear of the procedure triggering drug misuse. Thus, the reasons for non-attendance are likely to be numerous and complex and probably best investigated by a realist project similar to the one undertaken here.

Forgetting is a common reason given for not keeping appointments across hepatitis C (sometimes despite reminders) and related groups (Carrion et al, 1993; Sparr et al, 1993; Pieper and DiNardo, 1998; Killaspy et al, 2000; Neale et al, 2008; Coulson et al, 2009; Swarbrick et al, 2010; Agarwal et al, 2011; Feitsma et al, 2012; NHS Greater Glasgow and Clyde, 2012). There is insufficient information about why people forget to attend, even if services provide reminders. This was an area that required exploration in this study.

Also, patients may misread or lose their appointment cards (Hyslop and Kershaw, 1981). And, non-attendees are more likely not to have kept appointments in the past (Farid and Alapont, 1993).

3.4 Discussion: Theories about non-attendance at the hepatitis C outreach clinic

Despite missed appointments being a problem in hepatitis C clinics this literature search found little direct empirical evidence showing why this is. This suggested that the question being asked in this research study was legitimate. However, more evidence and potential theories had emerged from papers on reasons for missed appointments in other related groups which were useful in the study.

This discussion will critically consider which theories and ideas had most relevance for testing in the case of non-attendance at drug service hepatitis C outreach clinics. These are clustered under the headings used in the previous synthesis of findings. The theories generated from the literature review are summarised in tabular form (see Table 3.1). Each of the theories is then considered in relation to practice.

Table 3.1 Summary of the theories about non-attendance

1.	**Appointment**
1.1	Longer wait for an appointment
1.2	Morning appointment
1.3	Appointment time not chosen by the patient
1.4	Appointment time flexible or strict
1.5	Did not know what to expect from the outreach clinic
1.6	Patient unable to cancel the appointment
1.7	Did not get an appointment letter
1.8	Clerical error
2.	**Motivation or ambivalence**
2.1	Not a priority, not bothered or motivated to attend
2.2	No urgency to address hepatitis C because asymptomatic and 'slowly progressive disease'
2.3	Patient changed their mind or disagreed with referral
3.	**Other commitments or demands**
3.1	Ongoing drug and alcohol use
3.2	'Disappear' into work or unable to take time off
3.3	Other commitments take priority
3.4	Unplanned or unexpected events
4.	**Experience with services or professionals**
4.1	Lack of information or clarity about the reason for referral to the outreach clinic
4.2	Absence of long-term therapeutic relationship with referrer and outreach clinic nurse
4.3	Tested for the infection too soon or coerced and feared finding out have hepatitis C
4.4	Feared visiting the clinic and being reminded of the infection or finding out have advanced liver disease
4.5	Patients misinformed or lack of knowledge about hepatitis C
4.6	Fear of being judged by the outreach nurse and others
4.7	Worried about confidentiality and being seen by other patients
4.8	Outreach clinic located in or near the city centre

Table 3.1 Summary of the theories about non-attendance (continued)

4.	**Experience with services or professionals (continued)**
4.9	Lack of own or adequate transport
4.10	High cost of travel and may not get money reimbursed
4.11	Faced by too many appointments or steps to progress onto treatment
5.	**Patient characteristics**
5.1	Younger age, male and lower social class
5.2	Fewer years in formal education or literacy problems
5.3	Unmarried, living with parents and nobody to accompany to the clinic
5.4	Patient feels not deserving of medical care
5.5	Other co-morbidity and feeling unwell
5.6	Poor veins
5.7	Forgot the appointment
5.8	Lost or misread the appointment card

3.4.1 Appointment

The two outreach clinics run by the researcher are held fortnightly, and some patients have been asked to return for results in two weeks. Thus, the wait for an appointment could be a reason for non-attendance. The outreach clinics also ran at different times of the day. It was considered appropriate to undertake the study at both to assess for any differences in non-attendance which could be explained by the time of day of appointments. The outreach clinics also offered a limited choice of appointment times to clients which may be a factor for non-attendance. Although the outreach clinics used an appointment system the times were relatively flexible and clients were not turned away if they arrived late. It was anticipated that strict or flexible appointments was not a factor for non-attendance in the study. It is not clear what clients are told about the outreach clinic appointment or what to expect. Thus, the amount or quality of information given at the point of making an appointment was considered to be of relevance in this study. Clients may not have a phone or any credit

on one so being unable to cancel an appointment was a theory worth testing. Clients typically make an appointment with the outreach clinic whilst attending the drug service. The appointment may be written down by the individual or a member of staff using a standard appointment card. It is not routine for appointment letters to be sent in the post. For these reasons it seemed unlikely that not getting the appointment letter or 'clerical error' would be factors for non-attendance in this study.

3.4.2 Patient motivation or ambivalence

The infection not being a priority and people not being bothered or lacking motivation to keep appointments appear to be very poor explanations which lack any depth of understanding. Without identifying the underlying mechanisms and contextual factors for these behaviours there is a risk that people will be blamed for missing appointments and almost permits services to avoid making changes to improve attendance. For this reason these terms warranted further investigation and with probing this study may uncover the 'real' reasons for non-attendance. It is highly probable that patients referred to the hepatitis C outreach clinic have no symptoms of the infection and some may have been told it progresses into liver disease over many years. Thus, the theory of non-attendance relating to these factors was relevant. Also, it seems plausible that people may not keep an appointment because they changed their mind or disagreed with the referral.

3.4.3 Other commitments or demands

Although in drug treatment some clients referred to the hepatitis C outreach clinic may be using illicit drugs and/or drinking alcohol excessively. This theory of ongoing substance misuse appeared to be an area worthy of investigation in the study. Whether they are former or current drug users the clients of the drug service are unlikely to be in employment. However, some patients attending the drug treatment clinic may be stable on a substitution script and be in work. It was anticipated that the study would uncover any reasons for non-attendance in relation to both employment and

unemployment. People referred to the outreach clinic may have to look after children or elderly parents. Thus, other commitments taking priority over keeping an appointment appeared worth researching. Also, clients of the drug clinic may be at increased risk of losing their home, being arrested, suffer relationship breakdown and have friends or partners die. Therefore, unplanned or unexpected events were a theory relevant to the study.

3.4.4 Experience with services or professionals

It is not clear what information is given to clients about the reasons for referral to the outreach clinic and whether this is understood by them. This theory was considered to be of relevance to the study. It seemed unlikely that the absence of a long-term relationship with the referrer and outreach clinic nurse was a factor for non-attendance in the study because the clinical team was relatively stable with minimal turnover of staff. Clients may be referred to the outreach clinic with hepatitis C or for screening for the infection. Thus, not wanting to be reminded of having hepatitis C and the fear of finding out about advanced liver disease was worth asking the participants. Also, factors relating to testing and diagnosis were applicable to the study. The ambiguity of whether non-attendance was due to misinformation or a lack of knowledge about hepatitis C suggested that it was an area worth researching to try and clarify the issue(s). The outreach clinics are located in drug services and clients may not be concerned about being judged by people or worried about confidentiality in this setting. However, on reflection the Nurse Consultant was an external member of staff from the hospital and may be unfamiliar to clients. Over time the Nurse Consultant running the outreach clinic may become known as the 'hepatitis C nurse'. Clients of the drug service are likely to know each other from their past lifestyle and through regular visits for drug treatment. This combination of factors suggested that issues relating to stigma and confidentiality were important to explore in the study.

One of the two hepatitis outreach clinics is located further way from the city centre than the other. Thus, not only was the location of the two clinics an

area worth investigating but a comparison of the findings between the two might have provided additional evidence. It was unlikely the clients had a car and therefore relied on public transport to get to appointments. Therefore, lack of own or inadequate transport was a theory that seemed relevant to test in the study. The patients of the outreach clinic are likely to be unemployed and receiving benefits or in low paid jobs. The outreach clinic provided reimbursement of travel expenses but it was possible that not all patients received this. Thus the high cost of travel and reimbursement were likely to be factors worth investigating in the study. The two hepatitis C outreach clinics were set up to increase rates of diagnosis and improve engagement with the hospital service. However, clients may not attend because they perceive the outreach clinic appointment and/or the stages of care at the hospital as too many. This appeared to be a relevant theory for testing in the study.

3.4.5 Patient characteristics

The characteristics of the clients referred to the hepatitis C outreach clinic included: males; younger age; lower social class; fewer years in formal education; literacy problems; unmarried; living with parents and not having anyone to accompany them to the clinic. Therefore, these were all factors considered relevant for the study. It was anticipated that using a realist approach may also uncover the deeper mechanisms and contextual factors that underpin some of these characteristics. Some clients may feel that they are not entitled to care (and treatment) because the infection was self-inflicted from drug use and/or because they might still be using drugs or drinking alcohol excessively. Although this theory seemed slightly less relevant (compared to others) it was considered worth investigating in the study. It is likely that some clients referred to the hepatitis C outreach clinic will have mental and physical co-morbidity, and feel unwell. This theory was deemed relevant to the study with underlying mechanisms sought using a realist approach. Due to a history of injecting drug use some clients will have poor veins and this seemed to be an appropriate theory to test. A common reason for missing appointments in all groups is forgetting

and warranted exploration in this study. Finally, clients referred to the outreach clinic may be given an appointment card and could have lost or misread it. Therefore, this theory seemed relevant to the study.

3.5 New literature

In keeping with a realist methodology the researcher purposely searched for new literature.

Since completing the study, two papers about non-attendance and hepatitis C have been published (Astell-Burt et al, 2012; Butt et al, 2013). It is important to note that neither study was investigating non-attendance in outreach clinics. Also, both studies were situated outside England with different health care systems and cultures; as such, comparisons with this study must be made cautiously. Clearly the Scottish paper (Astell-Burt et al, 2012) reporting the findings of a quantitative study is likely to have the clearest similarity to the context of this present study.

The Scottish researchers found that the mean travel time of 20 minutes to a specialist centre was not a factor for non-attendance but other factors were identified (compared to attendees) (Astell-Burt et al, 2012). These other factors included: living in more deprived areas; younger age; male gender; current or past injecting drug use; excess alcohol consumption (more than 21 units of alcohol per week); and higher body mass index (BMI).

The other paper was a qualitative study carried out in Canada across five provinces which examined the patient, provider and institutional factors for non-attendance in hepatitis C throughout the disease course i.e. from primary to specialist care (Butt et al, 2013). The authors found that the perspectives of patients and providers were congruent. They identified six common themes (with some overlapping) to explain non-attendance. However, the definition of non-attendance included patients who delayed or deferred care (not just those who missed an appointment).

The factors for non-attendance within the *'self-protection'* theme were a consequence of perceiving to be judged or treated differently by others following disclosure of hepatitis C. This resulted in deferring testing to keep the diagnosis a secret from others, concerns about confidentiality e.g. sitting in a waiting room and people knowing what they were attending for, and not feeling worthy of care. Within the *'determining the benefits of attendance'* theme were reasons relating to weighing up the benefits of attending. For example, not feeling unwell, believing going to die from hepatitis C anyway, concerns about the side-effects of treatment and believing the cure rates to be low (and waiting for more effective treatment to become available). For the *'competing priorities'* theme factors for non-attendance concerned patients having multiple and sometimes conflicting priorities in their lives. These included: work commitments; looking after others; ongoing drug use; 'unstable' income and living conditions; multiple hospital appointments due to other physical co-morbidity; and forgetting an appointment due to memory loss from advanced liver disease.

The fourth theme was *'knowledge gaps'* which affected both patients and providers. For example, believing there was no treatment or not knowing that it was curative; having to abstain from drugs and alcohol to be eligible for treatment; and feeling overwhelmed by the complexity of information about hepatitis C. Within the *'access to services'* theme were 'system' factors which meant the service was difficult to access or inaccessible. For example, patients might be in poverty and the cost of travel was a problem, a long time spent in waiting rooms, long wait times for an appointment and too many appointments before starting treatment. The last theme also operated at a 'system' level and involved *'restrictive policies'* which impacted on patients' ability to engage with care. This included the demands of adhering to a substitution drug treatment script, limited times to be able to phone for an appointment, obtaining a doctors referral and needing to demonstrate evidence of having liver disease. The implications of these two studies will be revisited in Chapter 6 'Discussion'.

3.6 Conclusion

The absence of empirical evidence on the reasons why patients with hepatitis C do not attend appointments with an outreach clinic suggested the study needed to be done. A review of the literature on the reasons for non-attendance with hospital hepatitis C clinics found evidence to be fairly limited and, therefore, the search for evidence was extended to other related groups. This approach resulted in sufficient evidence being found to enable the construction of several theories about non-attendance at hepatitis C outreach clinics (set out in this chapter under different sub-headings). The literature also provided learning regarding ways to improve attendance and of the methods that might have been appropriate and work in practice in areas similar to the proposed study. These additional outcomes are deferred to subsequent chapters.

Chapter 4: Client Interviews

4.1 Introduction

This chapter describes how the interview data was collected and analysed. It also includes a description of the ethical considerations. A brief explanation of the underpinning theory for the study and the thematic framework developed from the findings is provided. Lastly the findings of the interviews are presented. Thus, this chapter begins with a description of the method, including details about the setting, sample, data collection, data analysis, and ethical issues. It then sets out the findings.

4.2 Method

4.2.1 Setting

The telephone interview participants were recruited from two drug treatment clinics in a city in the north of England. 'Service 1' was a GP led treatment clinic for clients with straightforward opiate addiction and was located outside the city centre. In contrast, 'service 2' was run by consultant psychiatrists, treated clients with complex needs including underlying mental health problems and was situated closer to the city centre. These two treatment services were able to provide a range of participants in terms of age, demographics, drug history, co-morbidity and distance to travel. The two hepatitis C outreach clinics were run fortnightly on different days and times.

4.2.2 Sample

Sampling method

Clients with a written or verbal diagnosis of hepatitis C (including past or current infection), or clients seeking testing because they had put themselves at risk were invited to take part. The sample needed to reflect the socio-economic, demographic and co-morbid variations within the population of interest. It needed to have the capacity to capture accounts of their experience and to be able to test emerging theories about reasons for missed appointments. Purposive sampling meant an adequate range of

relevant characteristics were included. This included age, length of drug use, hepatitis C diagnosis, home, and family and employment circumstance (see Table 4.1 'Sample characteristics').

Client exclusion criteria included:

- Clients who had not missed at least one appointment with the hepatitis C outreach clinic before April 2011;
- Clients, who cancelled an appointment, re-booked and attended;
- Clients who were not able to or did not want to give informed consent to participate; and
- Clients who were not able to speak English.

Clients with a history of non-attendance but who subsequently attended and clients who were still not attending were invited to participate. Clients that missed an appointment with the hepatitis outreach clinic during the study were also invited to participate.

Sample size

It was difficult to predict precisely the number of clients required to take part. It was anticipated that a total sample of approximately 30 would be sufficient. This would allow within and cross-case-orientated analysis reflecting variations within the sample (Sandelowski, 1995) and would take into account the realist approach taken (Baker and Edwards, 2012). The final interview sample totalled 28 participants. At this point no new themes, topics or concerns were emerging from the data. Saturation was deemed to have been reached and data collection was stopped (Wallace, 2005).

Sample characteristics

Some straightforward demographic information was collected for all participants. In addition, details regarding social circumstances, drug use and hepatitis C status were disclosed by some of the participants. This information is aggregated in Table 4.1 below. The denominator in each case indicates the number who replied to the question.

Table 4.1 Sample characteristics

Characteristics	**No. of Participants**
Demographic	
Male	23/28 (82%)
Female	5/28 (18%)
Age range	22 – 63 years (median 39 years)
Had partner	7/9 (78%)
No partner	2/9 (22%)
Had children	12
Lived with others	10/14 (72%)
Lived in hostel	2/14 (14%)
Lived alone	2/14 (14%)
Working	4/17 (24%)
On benefits	13/17 (76%)
Drug use	
Within last few months	2/14 (14%)
Not recent	12/14 (86%)
Hepatitis C status	
Chronic infection	21/26 (81%)
Past infection	3/26 (12%)
Not sure	2/26 (7%)

Identification and recruitment of participants

The interview participants were identified from electronic data kept by the drug service and previous clinic lists routinely kept by the outreach clinic. As part of the researcher's professional role he was legally entitled to view this data as he was part of the clients' care team.

At a routine appointment, at the end of their consultation, the staff of the drug treatment service offered clients with a history of not turning up for the outreach clinic an information leaflet (see Appendix 9). They invited the

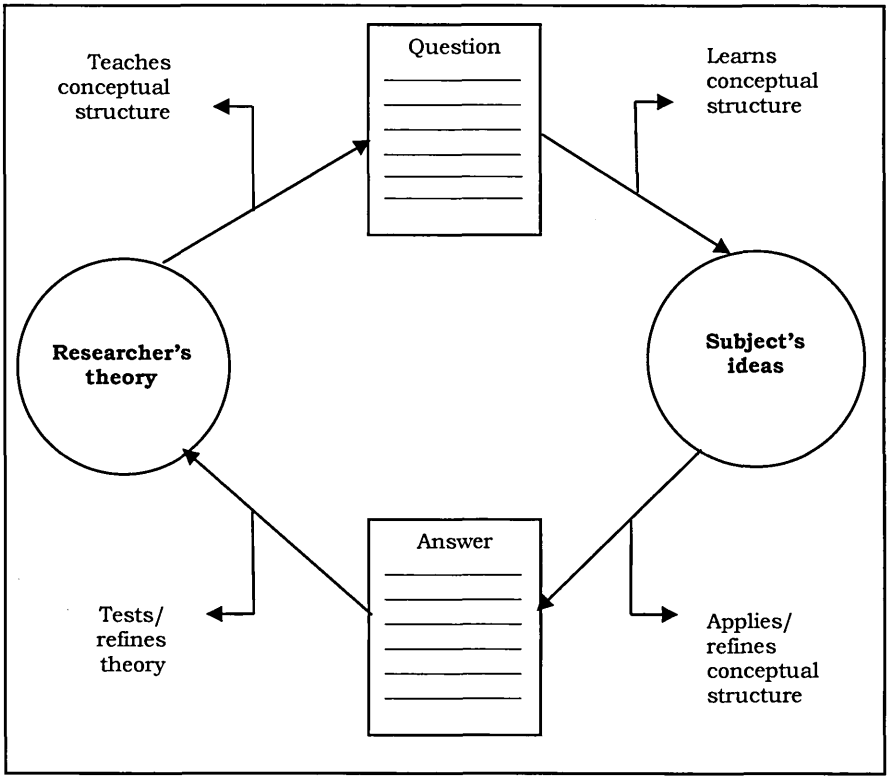
client to participate and gave a brief explanation of the study. This enabled any clients with a low level of literacy to talk to a member of staff about the research. Clients who were interested in participating and who agreed to speak with the researcher were asked to complete and sign a contact details sheet giving a preferred (and alternative if they had one) telephone number (see Appendix 10). The completed sheets were put in an envelope, securely sealed and placed in the researcher's work pigeon-hole to collect. If a client did not have a phone number then a face-to-face interview was offered. In these circumstances the client was asked to provide a contact address so that an interview could be arranged; in the event, no-one requested this option. A record of those who declined to participate was kept so that they were not asked again at a later date.

4.2.3 Data collection

A realist (theory-led) approach to interviewing was taken (Pawson, 1996). The flow of information within a theory-led interview (and common to all interviews) is captured in Figure 4.1. However, for the theory-led approach there are some subtle differences in interviewing style (Pawson, 1996; Pawson and Tilley, 1997). Thus, as depicted in Figure 4.1 in the 'northern' or top part of the interviewing cycle, the realist interviewer adopts an active and explicit role in 'teaching' the interviewees the overall conceptual structure of the study. This is done to assist the interviewee to make sense of the overall purpose of the study and to give some context to why the questions are being asked. Within a realist interview, the interviewer pays particular attention to explanatory descriptions, to narratives that may be connected to particular themes, and to participants' asking questions when seeking clarification about their responses. Also, the realist interviewer needs to be sensitive to the potential difficulties the interviewees might have in understanding the themes or categories that the interviewer was testing. For example, in this study the interviewer was mindful of the importance of needing to explain to the participants the information being sought, namely the underlying reasons (including the wider contextual factors) for missed appointments with the outreach clinic. Also, the interviewer was aware of

the possibility of needing to explain the nature of some themes by giving examples of what other participants had said as well as more conventional prompts.

Figure 4.1 Basic structure of the realist interview (Pawson and Tilley, 1997 page 165 with permission; see Appendix 11)



A further step of the realist interview represented on the 'southern' or bottom section of the interview cycle (see Figure 4.1) is the opportunity for the interviewees to describe their own thoughts about what led to a particular action or behaviour. The key point is that interviewees are able to describe their thoughts within the contextual framework of the study and gives them the chance to amend the interviewer's theory. Thus, during this phase of the interview the interviewees are able to agree or disagree with ideas contained within the interviewer's questions and to refine their conceptual basis. It is at this point in the realist interview that mutually shared knowledge is achieved (Pawson, 1996). For example, in this study

the participants gave explanations or theories for ongoing drug and alcohol use which challenged the term 'chaotic lifestyle'.

In summary, by leading with theory, the realist interviews undertaken in this study comprised of two features:

- The teacher-learner function; and
- The conceptual refinement process.

The former is depicted in the northern half of the interview cycle, and the latter describes the return route to the south. There was a greater or lesser emphasis on each of these two features in the interviews depending on the state of the development of the theory about missed appointments.

In the interviews, the participants were invited to give their own reasons for non-attendance and also to suggest reasons for the non-attendance of others. This was an interview strategy designed to facilitate response where, for example, a participant was reluctant to own up to particular reasons. As such, the analysis did not focus on any difference between the two types of question. As it was, there seemed little difference between answers to the two types anyway. Thus, throughout this study no distinction will be made between reasons given for non-attendance by participants themselves or for others.

The interviews were undertaken by telephone rather than face-to-face. There were several reasons for this:

- The nature of the research topic meant participants may not turn up for an interview.
- Drug users may live in parts of the city which might be considered unsafe to visit for face-to-face interviews (Marcus and Crane, 1986).
- The cost of undertaking telephone interviews, in terms of time, effort and money, is lower than face-to-face interviews (Denscombe, 2003).
- The relative anonymity of telephone interviews, lack of face-to-face contact and the establishment of confidentiality may enable

participants to talk honestly and openly about their experiences (Carr and Worth, 2001).

- Most of the clients, like most of the general population, were regular users of mobile and land-line phones and so familiar and comfortable with them.

The telephone interviews were conducted at a time convenient to the participant. With consent, the interviews were taped and downloaded onto a password protected computer. The dictaphone was kept in a locked filing cabinet in the researcher's office when not in use. An interview schedule was devised from the related literature, expert opinion of clinicians and clinical expertise of the researcher (see Appendix 12). For participants with a history of non-attendance but who subsequently attended, they were asked what helped them to attend. Before the interview the study was explained, questions invited from the participants, and informed consent obtained.

The interviews were transcribed verbatim by a medical secretary covered by a confidentiality agreement. The researcher subsequently read each transcript alongside the relevant tape for accuracy.

4.2.4 Data analysis

The 'framework method' was used to analyse the client interviews (Ritchie et al, 2003). There were several features of this method that meant it was a helpful way of analysing the data in this study:

- It is a pragmatic approach to qualitative data analysis that has emerged from policy research (like Pawson's 'realist evaluation'). Thus, it was an analytic approach that appeared to be both closely aligned with investigating non-attendance with health services and with the methodology of the study, namely realism.
- It is explicit and transparent which allows the analysis to be viewed and assessed by others for its 'objectivity' (Donovan and Sanders, 2005).

- The systematic process of coding, developing and applying an analytical framework, charting and sorting the material into key issues and themes was easy to follow, even with a large data set (such as the one in this study) (Gale et al, 2013).
- Although the general approach is inductive, it allows for the inclusion of *a priori* as well as emergent concepts to be used in coding of the data (Lacey and Luff, 2007). Thus, the data (theories) from the literature review ('realist synthesis') and other sources were used in helping to devise the initial analytical framework. In this way, the 'framework method' sits easily in a theory-led approach.
- As well as being a practical means of reducing the data, summarising the data during 'charting' allowed the supervisors of the study to "engage with the data and offer their perspectives during the analysis process without necessarily needing to read all the transcripts or be involved in the more technical parts of analysis" (Gale et al, 2013). Critical discussion regarding the analysis and emerging findings took place during regular supervision meetings.
- Charting also ensured that close attention was paid to describing the data using the participants' words and accounts in the first instance, before moving onto interpretation.
- The interpretation of the data (last stage of the framework) lends itself to explanation of phenomena (such as missed appointments), particularly if the data are rich enough (Gale et al, 2013).

In summary, the 'framework method' of analysis of the qualitative data complemented the realist methodology of the study and facilitated the development of the study outputs including explanations for missed appointments and policy recommendations for improving attendance.

4.2.5 Ethical issues

The study was given ethical approval by the South Yorkshire NHS Research Ethics Committee on 1 March 2012. There were several ethical issues related to the interviews. These ethical concerns were:

- Recruitment
- Remuneration
- Confidentiality
- Consent
- Conflict of interest
- Risks, burden and benefits

Recruitment

Clients eligible for the study were invited to take part (see 4.2.2 'Sample - *Sampling method*'). They were invited to participate during a routine drug clinic appointment rather than have the inconvenience of making a special journey. The drug clinic was an environment where the staff and surroundings were familiar to the participants so they may have felt more relaxed to share any possible concerns about taking part. It was important that clients were invited to participate at the end of their drug clinic appointment to prevent them feeling coerced into taking part because of possible fears about not getting a repeat script or other form of help if they declined the study.

Remuneration

The interview participants were offered a high street voucher for the sum of five pounds. Other researchers (Jeal and Salisbury, 2004; Neale et al, 2008) believe that remuneration of participants' time is appropriate, and is one of the surest ways to obtain a satisfactory response in circumstances where participants might be hard-to-reach for the purposes of doing research or to retain their participation. The study was investigating the reasons for non-attendance with an outreach clinic and there was a risk that these factors might also contribute to non-participation in the study. Remuneration made clear that the participants were offering the researcher a service rather than being asked to 'turn up' for something. It showed that the researcher was grateful and changed the dynamic of the relationship even though the amount involved was small.

Confidentiality

The interview participants were made aware of how they were afforded confidentiality both verbally and in the information leaflet (see Appendix 9). The researcher explained to the participants that should something of concern relating to their health, such as an unmet need, and/or their safety arise, such as thoughts of suicide, then it may have been necessary to share this with other health professionals, including their GP. Also, if a participant disclosed any information about a criminal act through which a third party had been or might be seriously harmed, the police may be informed. These situations (were they to have occurred) would have been discussed with the participants at the time and their consent for sharing the information would have been sought where possible. The researcher was aware of the need to adhere to his professional Code of Conduct (Nursing and Midwifery Council [NMC], 2008) and arranged to consult with his supervisors to discuss what to do and/or inform them of any action taken. It was usual for personal information concerning the interview participants to be kept confidential except under circumstances outlined above.

The study operated in accordance with the Data Protection Act (Her Majesty's Government, 1998). The researcher ensured that any data (including from the questionnaires) that was released or published was in a form that did not allow the participants or services to be identified. The recordings of the interviews were deleted after they had been transcribed. The interview transcripts were stored on a password-protected computer. They will have all links to the participants removed at the end of the study and will then be kept by the researcher for as long as they might be useful in future research. The only persons who had access to the data were the researcher and a designated medical secretary (who transcribed the interviews and was familiar with the principles of confidentiality in their day-to-day work).

Data collected on the participants is only presented in aggregated form, thereby minimising the possibility of clients being identified (see 4.2.2 'Sample – *Sample characteristics*').

Consent

The study information leaflet (see Appendix 9) was offered to potential interview participants and they were given an opportunity to ask questions and discuss the study with staff from the drug service (and again with the researcher before the interview). The participants were informed:

- What the research was about;
- Who was undertaking it;
- Why it was being undertaken; and
- How the findings would be shared and used.

The researcher asked participants for their permission to access their drug clinic notes to obtain background information that was not asked within a time-limited telephone interview. They were also advised how far they would be afforded confidentiality (see *'Confidentiality'*). They were able to decline the use of a dictaphone to record the interview at their preference. The participants were made aware of their right to refuse to take part whenever they wished, without having to give a reason.

If a client was under the influence of drugs and/or alcohol or mentally ill and their judgement was impaired they were not invited to participate in the study (or be interviewed).

If a client agreed to take part and be interviewed they completed and signed a contact details sheet (see Appendix 10) with a preferred (and alternative if they had one) telephone number which was given to the researcher in his work pigeon-hole. He then contacted the clients by phone. Consent was re-taken (see Appendix 13) and recorded by the researcher before the telephone interview commenced; thus it was verbal consent over the phone rather than signed. None of the participants declined the use of the dictaphone.

Conflict of interest

The researcher was aware of a potential conflict of interest in researching whilst also being a health professional and running the hepatitis C outreach clinic. The researcher considered employing the services of an independent person to undertake the interviews, but this would have added to the cost of the study both in terms of time and money. In addition, the researcher had knowledge, skills and experience in non-attendance and engaging marginalised groups such as running a telephone reminder service which were well utilised.

The researcher minimised the conflict of interest of his two roles in a number of ways. Whilst running the hepatitis C outreach clinic the researcher avoided inviting a patient to participate in the study and did not conduct interviews in this setting. As a researcher, whilst undertaking the interviews he avoided personal clinical discussions with the participants other than giving factual information about hepatitis C if asked. He advised the participants to make an appointment with the hepatitis C outreach clinic or arranged referral to the hospital clinic where indicated. The researcher reflected upon the interviews to help identify and address any conflict of interest. This reflection was supported through discussion with his academic supervisors and via the researcher's reflective diary (see Chapter 2 'Methodology and Method' 2.7.3 'Reflexivity').

Risks, burden and benefits

Some of the issues raised by the study may have brought up unhappy memories or experiences for the clients: of a past or current lifestyle; contact with health and social services; and/or raise anxieties about living with hepatitis C. The researcher was familiar with these issues and would be able to direct interview participants to sources of ongoing advice and support within his own team or via external agencies.

In contrast, the interview participants had the opportunity to describe past events and experiences related to missing appointments that they may not

have shared before. It may also have prompted them to seek further care of their hepatitis C i.e. to make an appointment with the clinic (either at the hospital or outreach). The researcher anticipated the findings of the study would contribute to local and national policy agendas of engaging marginalised groups into care and treatment. Thus, the study might have been of practical benefit by recommending ways of improving attendance in the setting of hepatitis C.

In summary, the study raised several ethical issues relating to recruitment, remuneration, confidentially, consent, conflict of interest, and risks, burdens and benefits. Several accepted procedures and strategies were put in place to address these ethical concerns.

4.3 Findings

The findings of the client interviews are presented here in two parts; the 'prima-facie' reasons and 'mechanisms' for non-attendance respectively. They are presented using a thematic framework (see Figure 4.2). The framework was developed from themes drawn from the analysis. For the full thematic schema see Table 4.2. The thematic framework is underpinned by the methodological and the theoretical basis for the study.

4.3.1 Realism and the thematic framework

In realist terms, what Pawson calls the 'outcome' and what Bhaskar calls the 'experience' is the non-attendance plus the immediate or 'prima-facie' reasons given for this by the various people who experience it, particularly the clinic staff and the clients themselves (Collier, 1994; Pawson, 2013). However, the realist considers there to be processes that have resulted in this outcome. Pawson calls these 'contexts' and 'mechanisms', Bhaskar calls them 'events' and 'mechanisms'. The differences between these approaches are not of importance here. In the thematic framework, Pawson's terminology is used.

Figure 4.2 Thematic framework – reasons for non-attendance at drug service hepatitis C outreach clinics

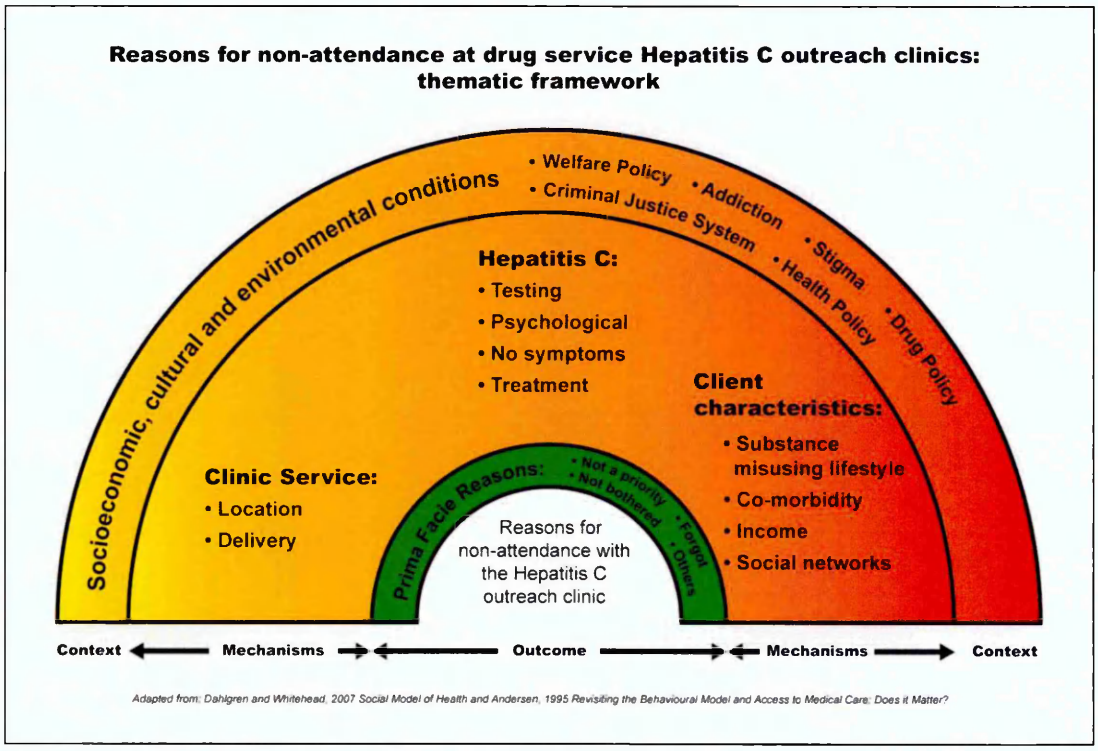


Table 4.2 Full thematic schema – Non-attendance at drug service hepatitis C outreach clinics

'Prima-facie' reasons	Client Characteristics	Hepatitis C	Clinic Service
• Not a priority [19] • Forgot (18) • Not Bothered [9] • Others > Poor motivation [4] > Felt ill [3] > Weather [2] > No reason [1]	• Substance misusing lifestyle > Priority [14] - Withdrawal [7] > Busy [13] > Multiple appointments [7] > Money [6] > High [5] > Psychosocial [3] > Homeless [3] > Crime [3] > Avoid town [1] > Start life [1] • Co-morbidity > Physical - Bad/sore legs [7] - Short illness [2] - Long illness [2] > Psychological - Agoraphobia [5]	• Testing > Poor veins [5] > Scared of result [4] > Naturally cleared [4] • Psychological > Denial [6] > 'Bad' news [3] • Symptoms > None [6] > Low category [1] • Treatment > Beliefs - Side-effects [5] - Going to die [4] - Effectiveness [3] - Not available [2]	• Location > Difficult journey - Distance [8] - Rely on lift [4] - No transport [2] - No bus stop [1] - Bus [1] > Relationship with clients [5] > Not hospital [2] > Confidentiality [1] • Delivery > Re-imbursement [5] > Appointment - Not morning [5] - Waiting [4] - Different appointment [3] - No card/letter [3] - Lost paper [1] - Wrong date [1]

	- Depression [3] - Mental illness [2] - Bad day [1] • Income > Cost of travel [12] > Phone [4] > Work [4] > Other priorities [1] • Social networks > Children [6] > Busy [5] > Non-disclosure [3]	> Barriers - Liver biopsy [2] - Alcohol [2] - Many appointments [1]	- "Counselling" [1] - Drug clinic nurse [1] > Relationship with staff [4] > Entrance [2]

4.3.2 Theoretical framework

The theoretical underpinning provides the backdrop to the study and informs the epistemological approach. As described in Chapter 3 (section 3.2.3) the theoretical framework for the study combines elements of two theories:

- The social model of health (Dahlgren and Whitehead, 1993); and
- A model of access to medical care (Anderson, 1995).

To explain the complexity of the reasons for non-attendance at hepatitis C outreach clinics this study conceptualises the themes drawn from the analysis as a rainbow. The rainbow depicts layers of influencing factors or mechanisms for non-attendance (see Figure 4.2). These reflect the layers of social determinants that Dahlgren and Whitehead (1993) propose influence health. Some of the themes within the thematic framework (and sub-themes within the full schematic schema see Table 4.2) were drawn from Andersen's (1995) model of access to medical care. For example, the themes 'income' and 'social networks', and the sub-theme 'beliefs' (from 'health beliefs') have been used. The thematic framework is now briefly summarised.

4.3.3 The thematic framework

At the core of the thematic framework is the phenomenon non-attendance (the 'outcome'). This is the appointment(s) the client missed with the hepatitis C outreach clinic. The first layer of themes refers to *'prima-facie'* reasons for non-attendance. These are the factors that have the most immediate influence on non-attendance and are likely to be given as an instant explanation for missed appointments by clients. They are relatively easily explained and understood by people. The *'prima-facie'* reasons include: *'not a priority'; 'forgot'; 'not bothered';* and *'others'*. The second layer of reasons that influence non-attendance can be thought of as the 'causes of the causes' or mechanisms. These are often hidden, and in the interviews an attempt was made to uncover these. It is a feature of the 'realist evaluation' approach used here that we are seeking depth of causation

(Pawson and Tilley, 1997). This second layer of mechanisms includes the themes *'client characteristics', 'hepatitis C'* and *'clinic service'*. The outer layer, 'context', is comprised of the socioeconomic, cultural and environmental conditions, which in turn influence the mechanisms below it. These contextual factors include: drug, welfare and health policy; addiction; the criminal justice system and stigma.

The findings of this study revealed many reasons for non-attendance at the outreach clinic which interact and play out in different people in different ways. The thematic framework emphasises the interactions across the layers and also between themes within the layers. For example, initial (*'prima-facie'*) reasons given for non-attendance might be *'not bothered'* and/or *'not a priority'*. During the interview mechanisms for these *'prima-facie'* reasons were identified from themes within the layer above. The participant might explain they are not unwell and the treatment will not cure the infection (see the theme *'hepatitis C'* and its sub-themes *'no symptoms'* and *'treatment'*). Further, the participant reports that they live out of the city and it is two buses to get to the clinic (see the theme *'clinic service'* and the sub-theme *'location'*). Not only is it expensive to get the bus but their benefit has been reduced and the participant does not always get their travel expenses reimbursed (see the themes *'client characteristics'* and *'clinic service'*). Recent welfare reform (Her Majesty's Government, 2012) to get people off benefits and into work has meant the participant now receives a lower amount of benefit (see the outer context layer and 'welfare policy'). The blurring of the colours across all themes and layers within the thematic framework represents a windscreen wiper effect with participants' experiences and reasons for non-attendance not only being numerous and varied, but also merging into and affecting each other, and possibly changing over time.

In keeping with the framework the *'prima-facie'* reasons which are closest to non-attendance are presented first (see 4.3.4). The influencing reasons or mechanisms from the layer above under the themes *'client characteristics', 'hepatitis C'* and *'clinic service'* then follows (see 4.3.5).

For each section of findings a small case study will be presented at the beginning of each sub-theme to illustrate the complexity of non-attendance. This is followed by the most commonly reported factor for missed appointments with an illustrative example. The less commonly cited reasons are presented in tabular form also with quotes from the participants.

4.3.4 Prima-facie reasons for non-attendance

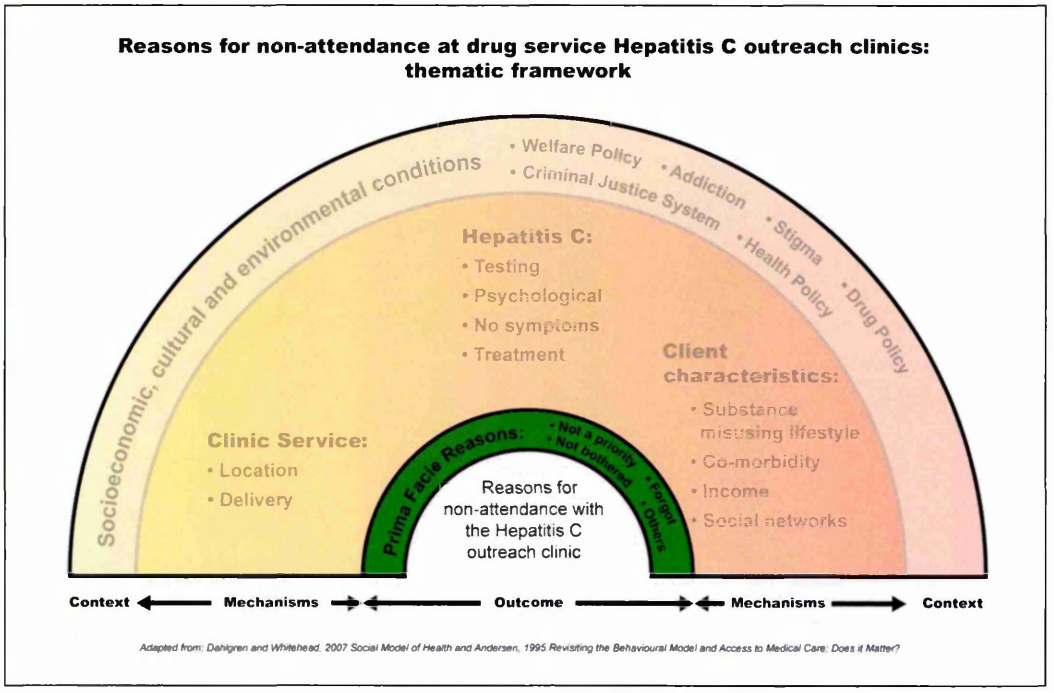
Prima-facie reasons (see Figure 4.3) for non-attendance given by participants were fairly immediate causes, such as forgetting. On the face of it these were simple explanations given by the participants. Also, they are often heard and adopted without question by services as reasons for missed appointments. However, non-attendance in this setting is more complicated with the surface *'prima-facie'* reasons being heavily influenced by underlying causative factors. Further, the latter are interrelated with clients giving other reasons for non-attendance.

In the interviews, adopting a 'realist evaluation' approach, the attempt was made to uncover underlying 'causes of the causes' or mechanisms (influencing reasons). It is these that are set out in section 4.3.5 'Mechanisms for non-attendance' under the other main theme headings drawn from the layer above.

The immediate 'prima-facie' reasons for non-attendance include:

- *Not a priority*
- *Forgot*
- *Not bothered*
- *Others*

Figure 4.3 Thematic framework – 'Prima facie' reasons for non-attendance



'Not a priority'

19 participants (almost 70%) suggested attending the hepatitis C outreach clinic was *'not a priority'* because other things were more important.

Case study 1 – 'Not a priority' and other reasons for non-attendance

Ian said a reason for non-attendance with the outreach clinic was *"getting their first hit before they worry about seeing you"*. He had been advised that an underlying physical problem needed investigating before he could be offered treatment for his hepatitis C. He attended several hospital appointments but it was taking longer than he expected and he stopped going. Although Ian understood his hepatitis C was *"not life threatening"* he was worried and made an appointment with the outreach clinic, which he did not keep. The bus fare to the clinic had been spent on more important everyday items and he was not confident about getting his travel expenses back. Ian gave other reasons for not attending the clinic. The clinic was a *"fair distance"* from home and he had no transport of his own or anyone to take him. Also, the outreach clinic was run on a different day to the one he attends for his methadone script which would have meant attending two appointments.

The priority to 'score' drugs was reported by the majority of the participants (n=13) as a factor for not turning up.

"People who are still using anyway I mean find it very difficult to be able to commit to anything and they don't know if they're going to be sick they're going to be alright .... They seem to put the score, well they do, I did, scoring before other things ...". (Lindsay)

Thus, *'not a priority'* appears to be largely influenced by the theme *'client characteristics' – 'substance misusing lifestyle'.*

The participants gave other factors for *'not a priority'* to attend and these are summarised in the table below.

Table 4.3 Less common reasons influencing 'not a priority' and non-attendance

Description	Quote
Other appointments were perceived to be more important to attend.	*"... it were just before or just after or around the same time at job centre or work programme then it's sort of quite hard because not only is it your benefits but it's your housing your housing benefits ... so you sort of have to prioritise one thing and then come back to the other". (George)*
Being homeless and having other priorities.	*"Obviously not having no blankets or anything like that so ... you are cold and ... you just want to warm up ...". (Michael)*
Come off drugs and had lots of things to arrange which were more important e.g. get a house.	*"... get your other priorities sorted out first ... because when you come off drugs you've got so much to sort out ... so much to catch up on ... I have had to get a house". (Andrea)*
Advised to get physical health problem sorted out first before got treatment for hepatitis C. Therefore was	*"... I can remember you saying to me that ... until you get sorted this out with your chest ... I were thinking well is there any point in me really going if I have to get that sorted out first". (Ian)*

ambivalent about whether to attend.	
Needed money to support family and did not want to take time off work.	*"... I have a little boy now ... and getting money in for him to put bread on table for him so trying to help out as much as I can". (Michael)*
On benefits and a priority to spend bus fare on everyday items rather than go to the clinic. Also not confident that would get travel expenses reimbursed.	*"... if you haven't got a lot of money and it comes to a choice in buying some tobacco or going to your clinic [appointment] and if you don't feel confident in getting their bus fare back ... they might say whoa don't go there because with the money we could get some tobacco or it could be anything do you know what I mean". (Ian)*
Needed to look after children.	*"Some might have kids and they haven't got anyone to look after them". (Malcolm)*
Busy with other or more important things to do.	*"... I had to move house, we had a death in the family and everything was really upside down. Trying to get rent sorted out for the new place trying to get a bond; everything was really hectic". (Kevin)*
Either thought or told the infection had gone. Did not think it was important to attend.	*"... some people I have talked to who said it [hepatitis C] might go itself". (Andrew)*
Did not feel unwell so not a priority to attend.	*"... it's not affecting me at minute ... less a priority". (Jordan)*
Believed going to die prematurely from hepatitis C.	*"People just think it is the end of the line what's the point in going when I might be dead in six or seven years". (Edward)*
Believed treatment did not clear the infection so no point in going to the appointment.	*"But when you get rid of it haven't you still got your hepatitis, it's just that no one can catch it, they have they still got their antibodies ...". (Joyce)*

The table above illustrates multiple factors meant it was *'not a priority'* to attend. These factors linked to other themes including *'client characteristics'* – *'social networks'* and *'hepatitis C'* – *'testing'* and *'treatment'*.

'Forgot'

18 participants (64%) suggested that forgetting was a reason for non-attendance with the hepatitis C outreach clinic. When invited for an opinion about telephone reminders as a strategy for improving attendance, four of these participants indicated that forgetfulness was a problem for them. Although they did not give this as a reason for non-attendance with the outreach clinic they are included in the 18 participants reported under this theme.

Case study 2 – 'Forgot' and other reasons for non-attendance

Bradley missed an appointment with the outreach clinic because he did not think it was important to attend and it *"slipped his mind"*. The appointment was for a blood test to confirm he had cleared his hepatitis C. He added that the weather was a factor for non-attendance because it was *"really bad snow"*. The snow made it more difficult to walk to the clinic. He suffered with 'bad' legs caused by his past drug use which swelled up and gave him *"loads of jip"* when it was cold. Bradley suffered from poor venous access and the cold made it more difficult to get a blood sample. He also suggested being kept waiting was a reason for not turning up.

For the 18 participants who *'forgot'* an appointment, the most frequently cited reason was having *"lots of appointments"* to remember and attend (n=7). The participants said it was difficult to keep a track of their appointments which may be *"scattered a lot"* and at different times on the same day.

"... I had three [appointments] in a week, and then if there's one at ten, one's at nine. You try and keep a mental note of when your appointments are and when you are due to go in on a certain day. I think because I had that many sometimes because like I actually rely on mental information that sometimes one slips my mind every now and again". (Joseph)

These other appointments were with a range of agencies including the drug service, mental health, probation, the job centre, the benefits office and

post-natal clinic. Thus, *'forgot'* appears to be influenced by the theme *'client characteristics' – 'substance misusing lifestyle'.*

Less common factors influenced *'forgot'* to attend (see Table 4.4).

Table 4.4 Less common reasons influencing 'forgot' appointment

Description	Quote
Forgot appointment because using drugs.	*"I think 90% of people who are at that clinic are still on gear and I think they forget". (Graham)*
Being homeless and having other priorities.	*"Obviously not having no blankets or anything like that so ... you are cold and ... you just want to warm up and I think basically forgetting really". (Michael)*
Busy at work so forgot.	*"... obviously you do forget anyhow if you're busy at work as well ...". (Michael)*
Had a lot to do such as childcare.	*"... I've got two kids and I've got to pick them up Monday, Tuesday, [and] Wednesday. ... me mind's all over sometimes I do forget things ... plus you know other bits and bobs, decorating ...". (William)*
Told cleared infection and so was not important to attend for repeat test.	*"I thought that I had been cleared of it and it slipped my mind, it wasn't as important then". (Bradley)*
Preferred afternoon appointments because up late and needed time to get ready.	*"... if I have been up late at night before and I forget last minute rushing about if I have got it set and I know say it is 2, 3, 4 o'clock I can get it in my head to get myself there on time". (Edward)*
Uncertain whether got a letter or appointment was written down.	*"I think this time round, I mean I may have had it written down or had a letter sent out but I wasn't aware until [name of specialist nurse] said that I had missed an appointment to see you. ... I may have had a letter or may have had it written down or somewhere but if I had I had totally forgot about it". (George)*

The table above shows how multiple factors influenced remembering to attend. These factors linked to other themes including *'client characteristics' – 'income'* and *'social networks'* and *'clinic service' – 'delivery'* and *'appointment'.*

'Not bothered'

Nine participants (just over 30%) gave *'not bothered'* as a reason for non-attendance with the hepatitis C outreach clinic.

Case study 3 – 'Not bothered' and other reasons for non-attendance

Joyce missed an appointment with the outreach clinic but not because she *"could not be bothered to go"*. She drank a lot and got *"a bit panicky"* if she has not had a drink before meeting a worker for the first time. Joyce thought the appointment was with one of the drug service nurses that had little knowledge of hepatitis C. When she was informed that the appointment was with a specialist nurse from the hospital (whom she had met before), she gave other reasons for non-attendance. Joyce had 'contact' with her daughter (who lived with a relative) during the week which made it difficult to attend. She said that there were workers at the drug clinic who were *"disrespectful"* towards her and not very helpful. Joyce spoke about other people not going near her because of the stigma of hepatitis C. She stated the infection can cause *"damage"* and *"kill you"*. Although she knew about treatment for hepatitis C Joyce did not understand that it might be curative.

Five participants reported an underlying factor for *'not bothered'* was using drugs and alcohol. Two participants suggested that using drugs was a priority over addressing hepatitis C, and one suggested being *"too busy"* taking drugs to attend.

"... just probably through lifestyle they live, if it's [hepatitis C] probably not so much of a big issue for them. It depends what their drug use is like ..., they might not be too bothered that they have got it and just it is like burying their head in the sand if you like". (Edward)

The two participants who drank alcohol to excess including Joyce (see case study three above) gave different explanations for non-attendance. The other participant, a dependent drinker said he might be drinking with other people at a location *"far away"* from the clinic and think it is okay to miss the appointment because another one can be made.

"... you know I'm pretty far away and I'm having a drink I can make another appointment so I get pissed go with the moment". (David)

These examples illustrate that *'not bothered'* was influenced by multiple factors. These factors link to other themes including: the *'prima-facie'* reason *'not a priority'*; *'client characteristics'* – *'substance misusing lifestyle'* and *'co-morbidity'*; *'hepatitis C'* – *'psychological'* and *'denial'*; and *'clinic service'* – *'delivery'* and *'location'*.

Less common factors for *'not bothered'* reported by the participants are summarised in the Table 4.5.

Table 4.5 Less common reasons influencing 'not bothered' and non-attendance

Description	Quote
Had bad or sore legs and relied on getting a lift. Not bothered to attend as meant going on a different appointment and in the morning.	*"Well I couldn't get there, simple as that. I usually get a lift there and my legs are so sore so I just couldn't be bothered going really. ... I usually go on a Monday because a couple are still working Mondays and I usually go with them ... I can get there after well two o'clock or something like that". (John)*
Busy with more important events to attend.	*"... if they've got something on that's more important then they are going to go to what's more important aren't they. ... funerals ...". (Liam)*
Denied that had hepatitis C and did not want to be reminded of it.	*"... I put [hepatitis C] at the back of my mind just to forget it, I've got hepatitis C, and obviously I don't want to go back to me depression mode again". (Michael)*
Not bothered about attending because did not feel unwell.	*"I suppose it depends as well if they are bothered about [it] if everything is alright ...". (Howard)*
Did not know that treatment may cure hepatitis C and believed going to die prematurely.	*"... like when I first heard about it I thought that is it, you get it, you can't get rid of it, you are going to die and there is no point even going for treatment ...". (Edward)*

As depicted in Table 4.5 there were numerous factors that influenced *'not bothered'* to attend. These factors linked to other themes including: *'clinic service'* – *'location'* and *'delivery'*; and *'hepatitis C'* – *'treatment'*.

Others

Other less frequently reported *'prima-facie'* reasons were given for non-attendance with the hepatitis C outreach clinic. These were:

- *Poor motivation*
- *Felt ill*
- *Weather*
- *Unable to give reason*

Four participants explained that non-attendance was because they found it hard to motivate themselves. For example, it was difficult to get up and get dressed. All four participants described some form of underlying psychological co-morbidity (see *'client characteristics': 'co-morbidity'* – *'psychological'*) as influencing their *'poor motivation'*.

Three participants reported being physically unwell as a reason for not attending the outreach clinic (see *'client characteristics': 'co-morbidity'* – *'physical'*). The impact of the *'weather'* was mentioned by two participants with an example given in case study two (see under *'forgot'*).

Although these other factors were less frequently reported they may need to be investigated if further research in this area is undertaken.

Summary

All participants gave at least one *'prima-facie'* reason for non-attendance with the hepatitis C outreach clinic (see Table 4.6). 18 participants (64%) gave more than one *'prima-facie'* reason.

Table 4.6 Summary of participants who gave 'prima-facie' reasons for non-attendance

Participant	'Prima-facie' reasons			
	'Not a priority'	'Forgot'	'Not bothered'	'Others'
John	√	√	√	
Peter		√		√
Deborah				√
Bradley	√	√		√
Howard			√	
Simon		√		√
Oliver				√
Joseph	√	√		
Edward	√	√	√	
George	√	√		
Michael	√	√	√	
Jordan	√			
Andrew	√	√		
David	√	√	√	
Graham		√	√	
James				√
Ian	√			
Liam	√	√	√	√
Kevin	√			
Lindsay	√			
Andrea	√	√		√
Joyce	√		√	
Malcolm	√	√		√
Anne		√		
William	√	√		
Terry	√			
Robin	√	√		
Neil		√	√	
	19	18	9	9

These were reasons closest to non-attendance that may have been given relatively quickly, and were easily explained and understood by others.

Many other factors were identified which influenced these *'prima-facie'* reasons.

The *'prima-facie'* reasons for non-attendance in order of frequency were:

- *'Not a priority'* to attend largely because of the need to score drugs.
- *'Forgot'* to attend mainly because of having multiple appointments with other agencies to remember and keep.
- *'Not bothered'* to attend due to drug and alcohol use.

The factors that largely influenced the *'prima-facie'* reasons for non-attendance were linked to the theme *'client characteristics'* and *'substance misusing lifestyle'*. However, other less common influencing factors from the other two themes *'hepatitis C'* and *'clinic service'* were also identified.

Thus, the findings show that reasons for non-attendance with the hepatitis C outreach clinic are more complex with deeper underlying causative factors linked to other themes. In addition, as described in the small case studies participants gave other reasons for non-attendance.

In keeping with the thematic framework the themes from within the layer comprising *'client characteristics'*, *'hepatitis C'* and *'clinic service'* now follows.

4.3.5 Mechanisms for non-attendance

This section builds on the study findings in section 4.3.4 'Prima-facie reasons for non-attendance'. The influencing reasons for non-attendance given by the participants may be considered as the 'causes of the causes'. These were the mechanisms that not only caused the *'prima-facie'* reasons but they also interacted with one another. An attempt to uncover these mechanisms in the interviews was made adopting a 'realist evaluation' approach.

This section comprises of three sections of findings:

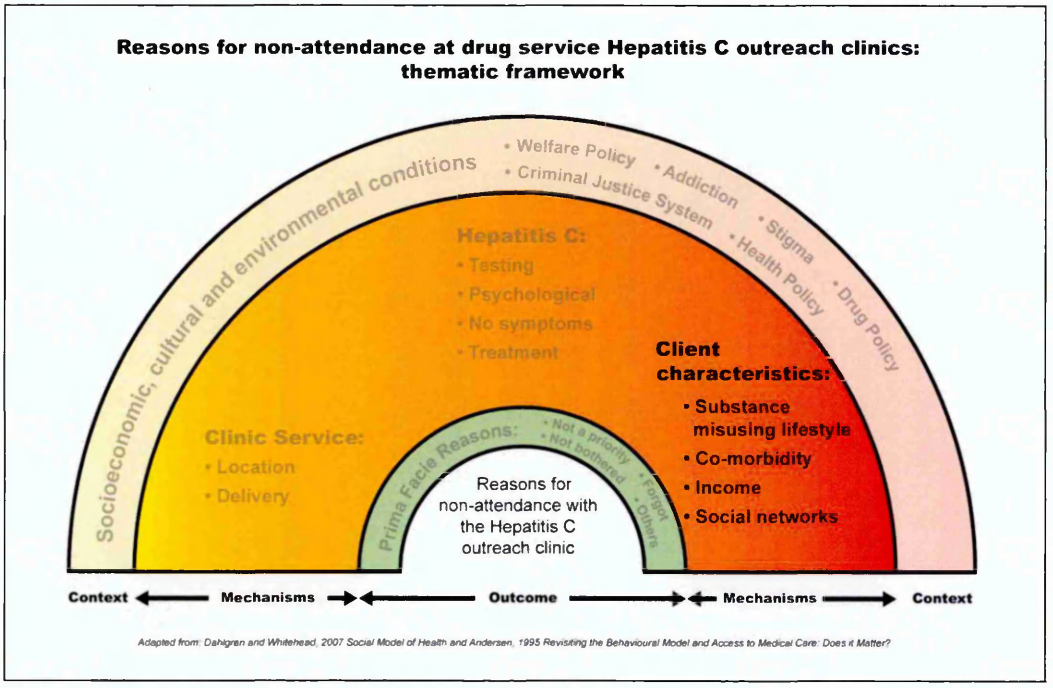
- *Client characteristics*
- *Hepatitis C*
- *Clinic service*

Client characteristics

The first theme is *'client characteristics'*, it comprises of factors that influence non-attendance and relate to the clients (see Figure 4.4). They are:

- *Substance misusing lifestyle*
- *Co-morbidity*
- *Income*
- *Social networks*

Figure 4.4 Thematic framework – reasons for non-attendance – 'Client characteristics'



Substance misusing lifestyle

25 of the participants (almost 90%) reported that lifestyle issues linked to substance misuse (predominantly drug use), contributed to non-attendance with the hepatitis C outreach clinic.

Case study 4 – 'Substance misusing lifestyle' and other reasons for non-attendance

Robin said he missed one appointment with the outreach clinic because he *"got incarcerated"*. Also, he suggested that when you're using drugs *"it takes over your life"* and rather than go to your appointment there was more important things to do like obtain drugs and 'score'. When he was using drugs Robin would sell or 'pawn' his phone and he would be unable to receive text appointment reminders. Robin thinks he missed a second appointment with the outreach clinic because he was scared that a blood test would be returned as positive. Since his last test he had relapsed into drug use and shared a spoon. If he had hepatitis C Robin said he would feel *"ashamed"* and would not want anybody to know. He believed the infection was untreatable and could not be cured. Robin did not like going to the drug clinic because he might bump into previous drug using acquaintances. He also said that the drug clinic was far away and that the bus fare was expensive.

The small case study about Robin above not only illustrates the many reasons for missed appointments but it also shows that factors can change and are not fixed. For example, he moved in (relapsed) and out of using drugs. Therefore, on some occasions drug use may not be a factor for non-attendance.

14 of the participants (almost 60%) reported using drugs and alcohol (n=3) was a *'priority'* over attending appointments. This was also the main factor influencing the prima-facie reason *'not a priority'*. It was a *'priority'* to use drugs or alcohol to avoid suffering the effects of withdrawal (n=7). The participants described not being able to go for an appointment until they felt well beforehand. For example a participant who stated he was an alcoholic said:

"... I need time to get a drink to sort myself out because I'm ill if I don't have that". (David)

Further, prior to scoring drugs, the participants may have had every intention to attend the appointment afterward but, scoring had taken longer than they planned.

"... I used to miss appointments because I were dependent on drugs ... I might planned it to obtain drugs before my appointment time with drug dealers and it never goes to plan so that's why I used to be late ..." . (Joseph)

Also, 13 participants (just over 50%) talked about being *'busy'* was a reason for non-attendance with the outreach clinic. They described being *'busy'* dealing, obtaining and using drugs or alcohol, and getting the money to buy drugs. The participants described having to steal or resort to prostitution to fund a drug habit because their benefits may have run out or not arrived. It was suggested that stealing was a *"full-time job"* and that a drug using lifestyle,

"... is just a mad circle, you have no time to yourself, you just go twenty-four hours". (Bradley)

Less common factors for missed appointments linked to a *'substance misusing lifestyle'* are summarised in the Table 4.7.

Table 4.7 Less common reasons for 'substance misusing lifestyle' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Multiple appointments (7)	Many appointments to remember and go to. Had to prioritise which to attend or may have forgotten the appointment with outreach clinic.	*"And I have missed appointments with you where I just forgot but if I had a reminder then I would have. Like now I have to keep a diary of all my appointments if not it just goes out of me head". (Andrew)*

Money; and *Income - Phone* (6)	Spent money on drugs and did not have bus fare or credit on phone. Also pawned phone to buy drugs.	*"It's quite hard for people when they don't have credit and when they have the money they have spent it on drugs so I think it would be quite hard for them to phone up and make that appointment". (Michael)*
High; and *Hepatitis C: Psychological – Denial* (5)	The effects of drugs contributed to denial of having hepatitis C and/or forgot to attend.	*"I think that's sort of one of the reasons that people probably just being off their heads, not really accepting what's going off or just forgetting about it because they're still using stuff". (Simon)*
Homeless (3)	Other priorities like keeping warm and getting food from another area. Being disorganised and having a low self-esteem.	*"If they're living rough it might be hard for them to make appointments. They might think what's the point; look at the state of me living on the streets". (James)*
Crime (3)	Wanted by the police and kept a low profile. Also, having to appear in court or being in prison.	*"... not wanting to be seen out and about, so finding it hard to get from A to B full stop ... for instance you could have a warrant out for your arrest or somebody could be looking for you". (George)*
Start life (1)	Come off drugs and had lots of things to sort out or catch up on e.g. get a house.	*"... get your other priorities sorted out first ... because when you come off drugs you've got so much to sort out ... so much to catch up on ... I have had to get a house". (Andrea)*
Avoid town and *Clinic Service: Location – Difficult journey – Rely on lift* (1)	Avoided going into town to prevent 'scoring' with previous drug using acquaintances and relied on a lift from family.	*"... I don't really trust myself to go down there on my own just yet because I sort of go past places and see places where I used to use ... I sometimes bump into people actually, so ... I am having to get lifts down there with my family ...". (Simon)*

This table demonstrates the reasons for non-attendance linked to a *'substance misusing lifestyle'* covered a multitude of factors with other sub-themes identified. Also, some of these factors were linked to other themes including *'hepatitis C' – 'psychological'* and *'clinic service' – 'location'*.

Co-morbidity

This theme consists of what the participants said about additional *'physical'* and *'psychological'* health problems, which contributed to non-attendance with the outreach clinic. It was difficult to identify what caused the co-morbidity, and whether it predated or was a consequence of a substance misusing lifestyle. This information will be given where possible. The frequency and range of illness given by the participants is summarised in the Table 4.8.

Table 4.8 Range and frequency of 'co-morbidity' that contributed to non-attendance

Participant	**Co-morbidity**						
	Physical			*Psychological*			
	Bad/sore legs	*Short illness*	*Long illness*	*Agora-phobia*	*Depression*	*Mental illness*	*Bad day*
John	√						
Peter		√		√			
Bradley	√						
Simon					√		
Oliver						√	
Edward	√					√	
George							√
David	√						
James	√				√		
Ian			√				
Liam		√					
Andrea			√	√			
Joyce				√			
Malcolm				√			
Anne				√			
William	√						
Terry	√				√		
	7	2	2	5	3	2	1

17 of the participants (60%) reported a health problem that contributed to non-attendance with the outreach clinic. 11 participants gave *'physical'* and *'psychological co-morbidity'* respectively as a reason for non-attendance. Five participants reported dual co-morbidity.

Case study 5 – 'Co-morbidity' and other reasons for non-attendance

Edward served in the 'forces' and developed both physical and mental health problems. Due to the training he underwent he had problems with his knees which needed several operations. He also said he was a 'paranoid schizophrenic'. Edward could only walk certain distances and there was no bus stop outside the clinic. Due to his underlying co-morbidity Edward was reliant on getting a lift or a taxi. However, the clinic did not reimburse the full cost of his travel expenses. Other reasons Edward gave for non-attendance included the appointment was not written down on a card. However, even it had been written down he would have *"struggled to get there financially"* if the appointment was not on his pay day. Edward also found it hard to keep morning appointments if he was up late the night before. When he was first diagnosed with hepatitis C he did not know there was curative treatment and did not think there was *"any point in going"* to an appointment. Also, due to the stigma the infection carried an appointment may have been missed to avoid being reminded of it. In addition, Edward suggested that using drugs may have been more important than keeping an appointment.

Physical co-morbidity

Seven of the participants (just over 60%) with *'physical co-morbidity'* reported having *'bad'* or *'sore legs'* was a reason for not turning up. For at least three of the participants this was a consequence of drug use, and caused poor circulation, pain, abscesses and swelling probably due to previous deep vein thrombi (blood clots). For example:

"... bad circulation with injecting over the years". (John)

"... had an operation on one [leg] because of an abscess which it gives me loads of jip that, especially when it is cold, it kills, and I have had deep vein thrombosis as well and my legs swell up really bad". (Bradley)

For six participants with *'bad'* or *'sore legs'* they expressed difficulty with walking.

"... sometimes I haven't got the bus fare to get there and back and I don't feel like walking there and back because I've got bad legs as it is to be honest". (James)

All seven participants with *'bad'* or *'sore legs'* gave additional related reasons for non-attendance. These are summarised in Table 4.9.

Table 4.9 'Bad' or 'sore legs' and related reasons for non-attendance

Participant	Client Characteristics: Co-morbidity – Physical - Bad/sore legs	Prima-facie reasons – Not a priority	Prima-facie reasons – Forgot	Prima-facie reasons – Not bothered	Prima-facie reasons – Others (Poor motivation)	Prima-facie reasons – Others (Weather)	Client Characteristics: Co-morbidity – Psychological – Depression	Client Characteristics: Income - Cost of travel	Hepatitis C: Testing – Poor veins	Hepatitis C: Testing – Naturally cleared
John	√			√					√	
Bradley	√	√	√			√			√	√
Edward	√							√		
David	√									
James	√				√		√	√		
William	√								√	
Terry	√						√	√		
	7	1	1	1	1	1	2	3	3	1

Participant	Client Characteristics: Co-morbidity – Physical - Bad/sore legs	Clinic Service: Location – Difficult journey - Distance	Clinic Service: Location – Difficult journey – Rely on lift	Clinic Service: Location – Difficult journey - No transport	Clinic Service: Location – Difficult journey - No bus stop	Clinic Service: Delivery - Reimbursement	Clinic Service: Delivery – Appointment – Not morning	Clinic Service: Delivery – Appointment – Different appointment	Total
John	√	√	√				√	√	6
Bradley	√					√			6
Edward	√		√		√	√	√		5
David	√			√					1
James	√					√			4
William	√								1
Terry	√		√				√		4
	7	1	3	1	1	3	3	1	27

A further 16 factors alongside *'bad'* or *'sore legs'* were reported by the participants. Thus non-attendance is complex in this setting with multiple factors influencing not turning up. The most commonly reported (n=3 respectively) *'cost of travel'*, *'poor veins'*, *'rely on a lift'*, difficulty with *'reimbursement'* and not being able to keep a morning appointment (*'not morning'*) were linked to the themes *'client characteristics'* – *'income'*, *'hepatitis C'* – *'testing'*, and *'clinic service'* – *'location'* and *'delivery'*.

Less common factors for *'physical co-morbidity'* and missed appointments are summarised in Table 4.10.

Table 4.10 Less common reasons for 'physical co-morbidity' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Short illness (2)	Relatively short period of feeling unwell. Forgot the appointment or to notify the clinic of absence due to illness.	*"... I was badly, I was in bed then. I thought I had an appointment with somebody else and I let them know I was badly but I forgot to let you know because I forgot about your appointment. ... I had a chest infection if I remember rightly". (Peter)*
Long illness (2)	Long period of illness which needed to be resolved first but worried about hepatitis C. Also unable to get to the clinic due to poor health.	*"Basically it were a fact that I'd seen you in the [name of hospital] and I can remember you saying to me that until you had got this sorted out with your chest ... I were thinking well like is there any point in me really going if I have to get that sorted out first". (Ian)*

The table above shows the reasons for non-attendance linked to *'physical co-morbidity'* were different across the participants with other sub-themes identified.

Psychological co-morbidity

Five of the participants (45%) with *'psychological co-morbidity'* indicated that suffering from *'agoraphobia'* was a reason for non-attendance. The participants described a fear of leaving the house and meeting people (including workers they did not know), having panic attacks and staying in their own area to avoid the city and *"crowds"*.

"Agoraphobia and scared to go out of the house that would be a good reason for not wanting to go". (Oliver)

"I don't go out a lot. I mean I go out every day but it's only in my area. I don't go to town. I am not right good with crowds ... I am not right good you know I get I feel closed in ... I don't like being in big areas you know like when I go to town I don't like it, I feel everybody's rushing at me I start to panic. I don't like being in that kind of place for too long so I tend to you know stay local you know where I know my area". (Andrea)

Two participants had a drink problem and used alcohol to help overcome their fears. Also, another participant suggested that his fear of leaving the house and not wanting to talk to anybody can change depending on his state of mind. This suggests on some days he may feel well enough psychologically to keep an appointment. These examples illustrate the complexity of non-attendance with reasons played out in different ways and changing over time.

In Table 4.11 less common factors relating to *'psychological co-morbidity'* and missed appointments are given.

Table 4.11 Less common reasons for 'psychological co-morbidity' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Depression (3)	Participant suffered from low mood. Not motivated to get up and to do things or to face people.	*"... I suffer from depression that is another point whereas it's very hard for me to deal with people unfortunately. I am okay on phones and stuff, you know it's not a problem but at the moment I'm very unwell with it and I feel all for doing things now [but] when it comes to actually meeting the people and talking to them then it's a different ball game". (Terry)*
Mental illness; and *Clinic Service: Delivery – Not morning* (2)	Suffered from a mental health problem. Prescribed medication that caused excessive tiredness and resulted in not being awake until the afternoon.	*"... Olanzapine ... and then Diazepam ... It knocks me out for twelve hours so if I don't go to bed until twelve I won't wake up until twelve in the afternoon and so if I have an appointment in the morning I won't make it ... If it is an afternoon appointment I should be able to make it". (Oliver)*
Bad day (1)	Did not feel like attending because was not having a good day.	*"... you don't feel like it, you are not having a good day". (George)*

The table depicts the reasons for non-attendance due to *'psychological co-morbidity'* was experienced differently for the participants with other sub-themes identified. Also, one of these sub-themes was linked to *'clinic service' – 'delivery'.*

Income

This theme describes what the participants said about being on a low income and non-attendance with the outreach clinic. Many of the participants disclosed receiving benefits with some having payments reduced as a consequence of government welfare reforms aimed at getting

people into work. Two of the participants were having money deducted from their benefit to pay off arrears.

Case study 6 – 'Income' and other reasons for non-attendance

Simon missed an appointment with the outreach clinic because of the cost of getting there. He had been taken off his usual benefits following the recent welfare reforms to get people into work and was receiving less money. It was not *"easy to get work when you have been to prison and you are an ex-drug user"*. Simon lived *"quite out of the way"* and had to catch two buses to the clinic. Sometimes Simon got *"a bit down"* and *"a bit depressed"*, and found it *"hard to motivate"* himself. In addition, he was keen to avoid town and not *"bump into"* his past drug using acquaintances because he did not trust himself not to score. He relied on his family to take him to appointments to make sure he got there. Simon suggested other reasons for non-attendance was using drugs and drinking alcohol. For example, being *"off your head"* and forgetting or putting hepatitis C to the back of one's mind and *"not accepting what is happening"*.

12 of the participants (just over 40%) said the high *'cost of travel'* contributed to non-attendance.

"Not having enough money to get to catch the bus there. If they haven't got enough money then maybe they might not be able to come from where they live. If they come from [part of the city] and you have to come all the way down to the [name of hospital] it's a long way without having any money in your pocket isn't it?" (Oliver)

One participant said if the appointment was not on the day he got his benefit paid (which he arranged to collect his substitution drug treatment script) he would *"struggle to get there"*.

10 of the participants (just over 80%) gave other reasons alongside the high *'cost of travel'* for not turning up to an appointment (see Table 4.12).

Table 4.12 'Cost of travel' and related reasons for non-attendance (continued overleaf)

Participant	Client Characteristics: Income – Cost of travel	Prima-facie reasons – Not bothered	Prima-facie reasons – Others (Poor motivation)	Client Characteristics: Substance misusing lifestyle – Money	Client Characteristics: Co-morbidity - Physical – Bad or sore legs	Client Characteristics: Income – Other priorities	Hepatitis C: Testing – Poor veins	Hepatitis C: Testing – Scared of result	Hepatitis C: No symptoms
Deborah	√						√		√
Howard	√	√					√		√
Simon	√		√						
Edward	√				√				
James	√		√		√				
Ian	√					√			
Andrea	√								
Terry	√				√				
Robin	√							√	
Neil	√			√					
	10	1	2	1	3	1	2	1	2

Table 4.12 'Cost of travel' and related reasons for non-attendance (continued)

Participant	Client Characteristics: Income – Cost of travel	Hepatitis C: Treatment – Barriers - Liver biopsy	Clinic Service: Location – Difficult journey - Distance	Clinic Service: Location – Difficult journey - No transport	Clinic Service: Location – Relationship with clients	Clinic Service: Delivery - Reimbursement	Clinic Service: Delivery – Appointment - Different appointment	Clinic Service: Delivery – Appointment - Waiting	Total
Deborah	√	√							3
Howard	√		√					√	5
Simon	√		√						2
Edward	√					√			2
James	√					√			3
Ian	√		√	√		√		√	5
Andrea	√		√		√	√	√		4
Terry	√		√						2
Robin	√		√		√		√		4
Neil	√								1
	10	1	6	1	2	4	2	2	31

The participants gave a further 15 factors for not turning up alongside the *'cost of travel'*. The most commonly reported factors (n=6 and n=4 respectively) *'long distance'* to the clinic and difficulty with *'reimbursement'* were linked to the themes *'clinic service'* – *'location'* and *'delivery'*.

Four participants in paid work gave different reasons for non-attendance. These and other less common factors for missed appointments linked to *'income'* are given in Table 4.13.

Table 4.13 Less common reasons for 'income' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Phone; and *Substance misusing lifestyle - Money* (4)	Sold phone to get money for drugs. Did not have money to put credit on phone. Therefore was unable to ring the clinic to say was running late or unable to attend. Also, could not receive appointment reminders.	*"You've got to think about the people that what's got no money and can't do it. Obviously them people that's got no credit on their phone, they can't really ring in do you know what I mean? It's quite hard for people when they don't have credit and it's obviously when they have the money they have spent it on drugs or whatever they do so I think it would be quite hard for them to phone up and make that appointment". (Michael)*
Work; and *Hepatitis C: No symptoms* (4)	Unable to ask for or take time off work because embarrassed to tell employer about hepatitis C, would lose money, and did not feel unwell. Worked out of the city and difficult to get to an appointment. Also, busy with work and may have forgotten the appointment.	*"... it was when I was working the reason why I couldn't keep me appointment because of my employer. It just weren't something that I was going to tell him about that I've got hepatitis. I didn't want to go and ask him about going to the hospital because it was hepatitis and I was embarrassed about it. Embarrassing for him that's why I missed it you know". (Andrew)*
Other priorities; and *Clinic Service: Delivery*	Did not have much money and had to make a choice about	*"... if you have not got a lot of money and it comes to a choice in buying some tobacco or going to your clinic*

– *Reimbursement* (1)	buying something or getting to the clinic. Also, was not confident about getting travel expenses back.	*[appointment] and if you don't feel confident in getting their bus fare back. … they might say whoa don't go there because with money we could get some tobacco or it could be anything do you know what I mean". (Ian)*

As shown by the table, *'income'* and its contribution to missed appointments consisted of additional factors with other sub-themes identified. Also, each of these factors was linked to other themes including *'substance misusing lifestyle'* – *'money'*, *'hepatitis C* – *'no symptoms'* and *'clinic service'* – *'delivery'*.

Social networks

Participants described the ways in which interactions with family or friends and the local community contributed to missed appointments.

Case study 7 – 'Social networks' and other reasons for non-attendance

William explained he missed an appointment with the hepatitis C outreach clinic because he had to pick up one of his two children from school. Also, he was busy decorating his partner's house. Sometimes he forgot things, especially important things. He also had a bad leg that gave him pain and he was unable to walk for more than twenty minutes before it started *"going dead"*. He added that using drugs and being 'high' was a reason for not tuning up to an appointment. Also, drug users would be too busy to keep an appointment *"making their own bits of money"*, dealing or scoring.

Six participants (just over 20%) indicated that having *'children'* was a reason for non-attendance with the outreach clinic due to competing demands. The participants explained that: there might not be anyone else to look after them; they need picking up from school or contact with their child arranged through social services was during the week and not at the weekend.

"Some might have kids and they haven't got anyone to look after them". (Malcolm)

Two male participants who took their parenting roles seriously said work to provide for their child was a priority over keeping an appointment. Also, being busy looking after their child and forgetting to check the calendar (on which they kept a record their multiple appointments) meant they did not attend.

"Sometimes I might get not kind of preoccupied you know just wrapped up in caring for my son and just being a dad really. Because I have had a lot of appointments in between like jobs, looking for work before I actually got into work and my script and just various other appointments. Sometimes I genuinely used to get them muddled up. ... I might have like you know sometimes you wake up and look at your calendar and maybe on the day I just forgot to do that". (Joseph)

Thus, not only was this theme played out in different ways in different people but some factors were linked to other themes including *'client characteristics'* – *'substance misusing lifestyle'* and *'income'* and the *'prima-facie'* reason *'forgot'*.

Less common factors for *'social networks'* contributing to missed appointments are given in Table 4.14.

Table 4.14 Less common reasons for *'social networks'* and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Busy (5)	Unable to attend because social events or other activities occurred.	*"I was more or less homeless, I had to move house, we had a death in the family and everything was really upside down. Trying to get rent sorted out for the new place trying to get a bond; everything was really hectic in [month]". (Kevin)*
Non-disclosure (3)	Avoided talking about hepatitis C with other people because felt dirty. Did not tell partner about hepatitis C because would have to explain where going.	*"I suppose if they have got a partner and then they get a card saying they have got to go for [an appointment] to do with hep C they might not have told their partner so then they have got that added thing of where you going, what is the appointment for, why are you going. Do you know what I mean? So they probably want to keep it covered up as well". (Edward)*

As shown by the table above the reasons for non-attendance linked to *'social networks'* were experienced differently by the participants with other sub-themes identified.

Summary

The key factors for missed appointments relating to clients in order of frequency were:

- A *'substance misusing lifestyle'* and needing to score drugs (or drink alcohol) being a *'priority'* over attending appointments, partly to avoid the effects of *'withdrawal'*. Also, being *'busy'* dealing, obtaining and using drugs or alcohol, and getting the money to buy drugs.

- Both *'physical'* and *'psychological co-morbidity'*. The participants described suffering with *'bad'* or *'sore legs'* (in some cases a consequence of drug use) and had difficulty walking. Other factors

linked to *'bad'* or *'sore legs'* included the *'cost of travel'*, *'poor veins'* and difficulty getting a blood sample, having to *'rely on a lift'*, difficulty with *'reimbursement'* of travel expenses and not being able to make a morning appointment (*'not morning'*). Some participants suffered from *'agoraphobia'* and described a fear of leaving the house or meeting people.

- Being in receipt of benefits (reduced in some cases following recent welfare reforms) resulting in a low *'income'* and the high *'cost of travel'*. Other factors linked to the *'cost of travel'* included *'distance'* to the clinic and difficulty with *'reimbursement'* of travel expenses.

- Participating in a *'social network'* and caring for *'children'*.

For each of the above factors less common themes were also identified. Thus, reasons for non-attendance with the hepatitis C outreach are complex with themes played out in different ways in different people and with these linked to other themes.

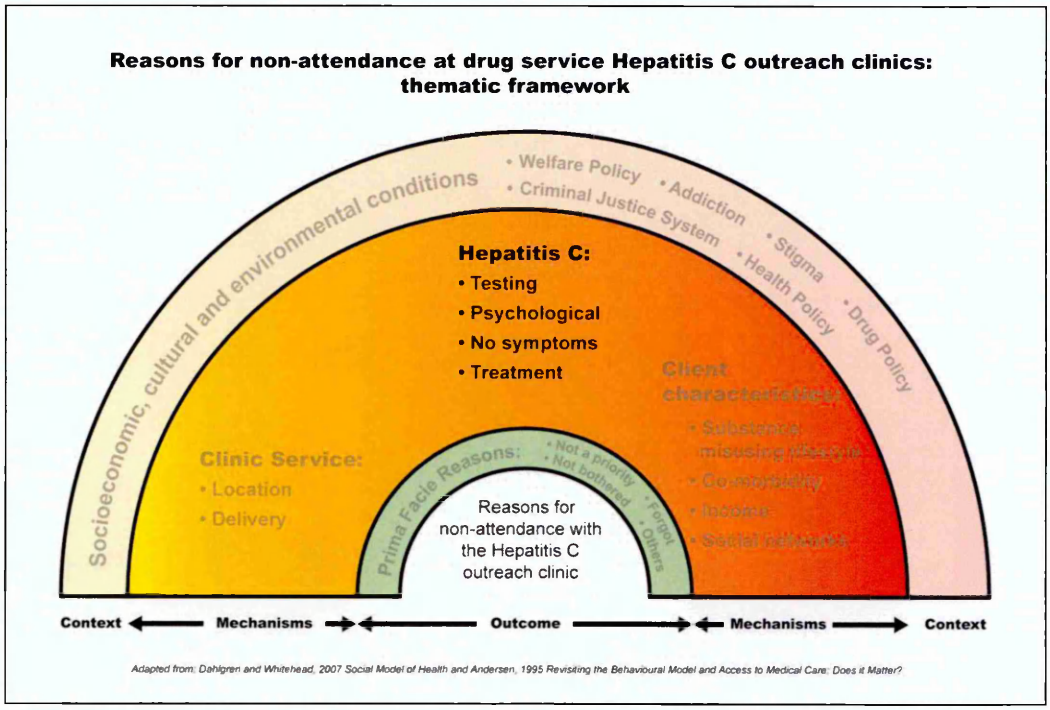
The interviews also uncovered factors for non-attendance relating to *'hepatitis C'* and these now follow.

Hepatitis C

The second theme *'hepatitis C'* comprises of factors that influence non-attendance and relate to the infection itself (see Figure 4.5). These factors are:

- *Testing*
- *Psychological*
- *No symptoms*
- *Treatment*

Figure 4.5 Thematic framework – reasons for non-attendance – Hepatitis C



Testing

The participants described some aspects of testing for hepatitis C that led to missed appointments with the outreach clinic.

Case study 8 – 'Testing' and other reasons for non-attendance

Howard had a positive mouth swab for hepatitis C but he needed a blood test to see if the infection was present or whether he had cleared it. Howard explained that staff had tried in the past with *"big needles"* but were unsuccessful. He suggested that there was *"no point in going"* to the outreach clinic because the hepatitis nurse was not going to get blood out of him and he did not attend. Howard also described not wanting to get tested for fear of testing positive. Other reasons he gave for not attending was the outreach clinic being held on a different day to the one for his drug substitution treatment script. This meant attending two appointments in one week. It was a long distance to the clinic and involved getting two buses. Also the cost of travel was expensive. In addition, he reported not being *"bothered"* about an appointment if there was no signs of infection and *"everything was alright"*.

Five participants (almost 20%) suggested a reason for not attending was because they had *'poor veins'* (resulting from drug use) and a blood test was needed to confirm the presence of hepatitis C. From past experience it was hard to get any blood. The participants described several attempts by staff to get blood (often unsuccessfully) because they did not listen to the client about where best to locate a vein and may have tried using needles that were too big.

"..... we hate it, absolutely hate it. It takes ages to get any kind of blood out even a dribble and when you tell somebody where to go they'll be going oh no, no, no like they know best but you end up coming out looking like that thing off .... with cotton wool balls all over us where we've been speared a million times". (Deborah)

They described a dislike of the procedure and took steps to minimise harm to themselves either by limiting the number of attempts they would allow staff and by refusing to attend.

In Table 4.15 less common factors relating to *'testing'* and not turning up are summarised.

Table 4.15 Less common reasons for 'testing' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Scared of result; and *Treatment – Beliefs – Going to die* and *Effectiveness* (4)	Fearful and would be ashamed of testing positive for hepatitis C. Scared because believed the infection was not curable, that it resulted in premature death.	*"And I think the other one [missed appointment] was I were a bit scared of the results because I'd been obviously I'd not been sharing needles but I'd been sharing the spoons and things so I were a little bit scared and apprehensive of what the results going to be ...". (Robin)*
Naturally cleared (4)	Either think themselves or had been told that cleared the infection and did not attend for testing to establish or confirm this. Thought it was not important to attend.	*"I've heard people say to me oh it can go you know what I mean go on its own or whatever and that's why they might not come ...". (Andrew)*

The participants gave different accounts of how *'testing'* contributed to non-attendance with other sub-themes given. Also, one of these factors was linked to the theme *'hepatitis C' – 'treatment'*.

Psychological

In contrast to *'psychological co-morbidity'* (see under *'client characteristics'*) which comprised of factors related to participants' underlying mental well-being this theme describes what the participants said about the emotional impact of having hepatitis C and its contribution to missed appointments.

Case study 9 – 'Psychological' and other reasons for non-attendance

At the time of his hepatitis C diagnosis Neil did not think the infection was curable. He thought it would make him *"really poorly"* and he thought his *"life was going to change"*. Later, Neil had treatment in a different city but did not complete the course largely because he became depressed (a recognised side-effect). He was living on his own at the time and away from his family. Neil missed an appointment with the outreach clinic because he was scared of receiving 'bad' news. He was afraid of being told something else was wrong or that the hepatitis C was *"worse than what it was"*. Sometimes he put the infection to the *"back of his mind and forgot about it"*. He had also used drugs and this was a priority rather than keeping an appointment. Also, the money spent on drugs meant not having any for bus fare.

Six participants (just over 20%) suggested that *'denial'* of having hepatitis C was a reason for missing an appointment. The participants talked about trying to pretend or forget about having the infection. They did not want to be reminded of it because: they were scared of other people knowing they were infected; believed the treatment was not curative and were scared of the side-effects; and wanted to avoid suffering from low mood and being suicidal again.

"... I am not saying that it's not important because it is important but I put it at the back of my mind just to forget it, and I've got hepatitis C, and obviously I don't want to go back to me depression mode again ...". (Michael)

This example illustrates how other factors influenced *'denial'*. These factors link to other themes within *'client characteristics'* – *'co-morbidity'* and *'treatment'* – *'beliefs'*.

Three participants suggested being scared of receiving *'bad news'* was a reason for non-attendance. For example, being told that that the infection had got worse or that something new had been found. One of the participants also suffered from *'agoraphobia'* and found it harder to be given

'bad news' whilst experiencing this. He was unable to explain what *'bad news'* would entail but he believed the infection would shorten his life. This is a further example of a theme being influenced by other factors. Also, the participant's account suggests that that on some days he may be psychologically well enough to receive *'bad news'* and that this would not be a factor for non-attendance.

No symptoms

The participants talked about the physical effects of the infection and how this contributed to missed appointments with the hepatitis C outreach clinic.

Case study 10 – 'No symptoms' and other reasons for non-attendance

Jordan missed an appointment with the outreach clinic because he was working. He had taken a lot of time off work in the past. Jordan did not want to risk losing his job over *"something that wasn't affecting him at the minute"*. It was not a priority and he would go to the clinic when he *"started seeing symptoms"*. He was diagnosed with the infection whilst an inpatient in hospital but started using drugs and *"it just went to the back of his mind"*. Jordan said he might also have missed an appointment because he had to score drugs which probably took longer than he planned. He offered that non-attendance might be due to not getting on with a drugs worker from the clinic. Jordan also suggested missing the appointment because of not wanting to *"face up to it"* and pretending not to have hepatitis C. He explained being scared of the infection because people will find out and by the side-effects of treatment.

Six participants (just over 20%) reported that the asymptomatic nature of hepatitis C was a factor for not turning up. They suggested that the absence of symptoms (*'no symptoms'*) made them *"think twice"* about going for a test or keeping an appointment for further assessment and treatment of their infection. One participant said it was okay to delay attending for treatment until becoming *"sick"*.

".... basically if you didn't feel ill already or it wasn't affecting your life in any way it were better to carry on and sort of leave it alone which is exactly what I have done". (Deborah)

Another participant explained that they did not want to attend for a liver biopsy or treatment because this would have made them ill. One participant did not want to risk losing his job since he was not unwell. He added it would only be a priority to attend if he were to get *"symptoms"*. The same participant suggested that telephone or text reminders would be less effective in hepatitis C compared to drug use because unlike the latter (due to symptoms of withdrawal) treatment will not make people feel better.

These findings show how other factors influenced the asymptomatic presentation of hepatitis C and non-attendance. These factors link to other themes *'client characteristics' – 'income'* and *'hepatitis C' – 'treatment'*.

One participant reported some clients may not have turned up to the outreach clinic if they thought their hepatitis C was not at a severe level or in a bad condition (*'low category'*).

"... if it's not really severe it's quite low that would probably stop them from [attending]. They would probably think oh I am okay or I can leave it a bit longer ...". (David)

Treatment

This theme includes factors given by the participants relating to *'treatment'* for hepatitis C and how they contributed to non-attendance. Only two of the study participants reported having had treatment (with one having stopped prematurely because of the recognised side-effect depression). Thus, the accounts given by the participants are based on what they heard from other people i.e. non-specialists. Two of the participants indicated having had information about treatment from a specialist although for one this was

almost ten years ago. The other participants had spoken with people they knew had treatment and received information this way.

Case study 11 – 'Treatment' and other reasons for non-attendance

Deborah was unable to remember the reason(s) for missing an appointment with the outreach clinic. However, she later recounted that she had been too frightened to have a liver biopsy to see if treatment was necessary. She was also *"scared to death"* about treatment (which she described as *"chemo"*) because she had been told *"you could lose your hair"* and *"you feel really sick"*. Deborah did not feel unwell and did not want any intervention that caused pain or adversely affected her wellbeing. She thought if the infection was not *"affecting your life in any way"* it was okay to carry on and leave it alone. Deborah gave other reasons for missing an appointment. It was hard to get blood because her veins were *"messed up"* from using drugs. The procedure takes a long time because workers ignore her advice about where best to locate a vein and afterwards she is covered in cotton wool balls. Her benefits had been reduced following recent government welfare reform to get people into work. Deborah said she did not have the money to get the bus to the clinic because it was expensive. Although she had her travel expenses reimbursed at the drug clinic she did not for some of her other appointments.

Five participants (just under 20%) suggested that the *'side-effects'* of treatment were a factor for missed appointments. The participants were put off attending because: they heard the treatment made people ill; that it caused prolonged tiredness; and hair loss (and they were not unwell before). Two participants described the treatment as *"chemotherapy"* whilst another suggested it was like drug withdrawal.

"Another thing that put me off a bit as well is like treatment you know people saying to me it makes you really ill and things like that". (Andrew)

This finding illustrates how another factor influenced the *'side-effects'* of treatment and non-attendance. This factor of not being unwell before treatment is linked to the preceding theme *'hepatitis C' – 'no symptoms'*.

Not only were the participants scared of the *'side-effects'* but one participant explained the prospect of being ill for a year was also scary (the usual course of treatment being either twenty-four or forty-eight weeks).

"... also I mean the idea you know you're going to be sick for a year or something you know is frightening. You know the idea that you're going to have to take this one appointment is one thing and then you're going to have to start a course of treatment that is going to keep you sick for a year is something that people find excuses to not attend". (Lindsay)

Less common factors relating to *'treatment'* and non-attendance are given in Table 4.16.

Table 4.16 Less common reasons relating to 'treatment' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Beliefs - Going to die; and *Effectiveness*; and *Psychological – Bad news* (4)	No point attending because thought going to die prematurely. Did not want to be given bad news. Believed the treatment did not cure the infection.	*"... I really don't know the outcome. I know it will kill me eventually but I had to find that out myself nobody ever told me that. ... Well from what I have read on the internet and that, eventually it will kill me ... because I have got a really bad chest and got other things up with me". (Peter)*
Beliefs - Effectiveness; and *Going to die* (3)	Did not think treatment cured the infection and going to die. Also, although treatment curative it was not guaranteed to work for all.	*"I think there's a lot of missed appointments like when I first heard about it I thought that is it, you get it, you can't get rid of it, you are going to die and there is no point even going for treatment ...". (Edward)*
Beliefs - Not available [2]	Not aware that there was treatment for hepatitis C so not point in attending.	*"I didn't think you could treat hepatitis C. I didn't think I thought it wasn't treatable. ... I thought it was a disease that you can't get rid of once you've got it". (Robin)*

Barriers - Liver biopsy; and *No symptoms* (2)	Scared of having a liver biopsy (to assess if treatment was needed) and did not want to become unwell or suffer pain. Did not feel ill beforehand.	*"If I know that they're going to cut a piece off me I think oh my god I am not going. I also ... not feeling ill because I feel fine I do think what is the point, don't sort of mess with it. It's like having a tooth that you know is bad but it doesn't hurt you. Then if you go to the dentist and they poke it might start hurting". (Deborah)*
Barriers – Alcohol (2)	Drinking alcohol to excess and would not be offered treatment so no point in attending.	*"It's basically because I've been drinking. I thought you know I'm not going to waste NHS money and time when you know as I said it's a really expensive treatment and I don't want to waste their time if I'm drinking". (Kevin)*
Barriers - Many appointments (1)	Expected to attend too many appointments before getting onto treatment.	*"... the amount of appointments prior to getting prescribed. It's like me I have been engaged with you for nearly one year now and I haven't actually started treatment and that can be a bit off putting for some people". (Joseph)*

The table shows that *'treatment'* and its contribution to non-attendance was played out in different ways amongst the participants with other sub-themes identified. Also, some of these factors were linked to each other and separate themes such as being given *'bad news'* and *'no symptoms'*.

Summary

The key reasons for non-attendance relating to hepatitis C in order of frequency were:

- The *'psychological'* impact of having hepatitis C leading to *'denial'*. For example, some of the participants put it to the back of their mind and did not want to be reminded of the infection. Related to *'denial'* was a belief that the treatment was not curative, being scared of the side-effects and wanting to avoid becoming depressed.

- There was *'no symptoms'* with hepatitis C. Participants did not perceive clinic attendances for tests e.g. a liver biopsy or treatment (that will result in illness) to be a priority to attend because they did not feel unwell. Going to an appointment or having treatment could be delayed until symptoms developed. Linked to *'no symptoms'* was did not want to take time off work for fear of losing a job.

- Participants being put off by the *'side-effects'* of *'treatment'*. Some of the participants described treatment as *"chemotherapy"* because they heard it caused tiredness and hair loss. Also, the duration of treatment was *"frightening"* because it can take up to one year. A factor related to *'side-effects'* was not feeling unwell beforehand.

- *'Testing'* to establish if the infection was present. Due to past drug use and some participants having *'poor veins'* it often took workers several attempts to get blood (sometimes without success) and participants disliked the process.

For each of the factors above less common themes were also identified. Thus, reasons for non-attendance with the hepatitis C outreach clinic are complex with themes played out differently amongst the participants and with these linked to other themes. In addition, in the small case studies participants also gave further reasons for non-attendance.

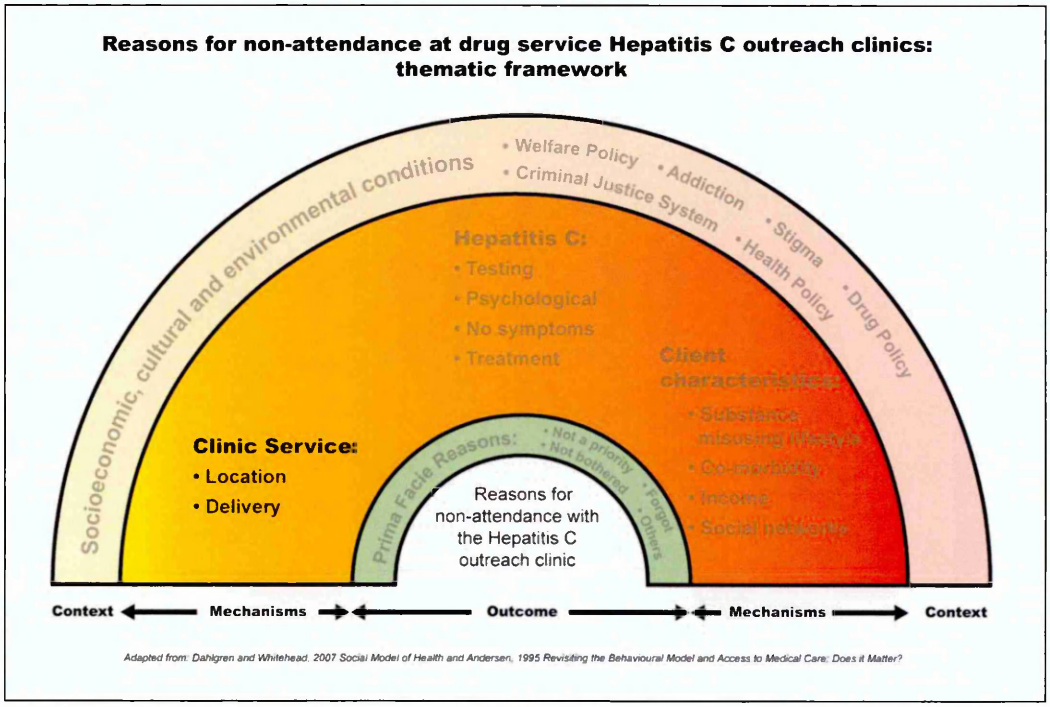
The interviews also uncovered factors for non-attendance relating to the *'clinic service'* and these now follow.

Clinic Service

The third and last theme *'clinic service'* comprises of factors for missed appointments the participants gave about where and how the clinic operated (see Figure 4.6). They are:

- *Location*
- *Delivery*

Figure 4.6 Thematic framework – reasons for non-attendance – Clinic service



Location

The *'location'* of the outreach clinic was described by the participants as a factor for non-attendance in several ways. The clinics were located in two drug misuse services in the city.

Case study 12 – 'Location' of the clinic and other reasons for non-attendance

After hearing that one of her partner's friends had died of hepatitis C Andrea panicked and rushed to get an outreach clinic appointment but did not keep it. She was physically unwell and had an eighteen-month-old son who needed her attention. Andrea had been to the doctors on four occasions but still did not know why she was having back and stomach pain. She was unable to *"walk down the road without being out of breath"*. It was two buses to get to the clinic and with her poor health it would have been *"embarrassing because I am only forty-one"*. The bus fare was expensive particularly as she was having money deducted from her benefit to pay off arrears. In the past Andrea had difficulty with getting her travel expenses reimbursed. She also suffered from agoraphobia and tended to *"stay local"* because she was not *"right good with crowds"*. She disliked going to the drug clinic in case she bumped into female clients she used to work with as a prostitute to fund her drug habit. Being busy using drugs was another reason for missed appointments. Andrea did not think the drug clinic was a suitable environment to take her young son. At one of the drug clinics she sometimes had to wait an hour- and-a-half before being seen. Andrea had lots of appointments and had to prioritise which ones to keep.

Eight participants (almost 30%) suggested that the long *'distance'* to travel to the clinic was a factor for missed appointments. They reported that getting to the clinic involved getting two buses which can be troublesome.

"You see its two buses for me to get to yours from mine. You know what I mean because I can't walk any distance at all ...". (Andrea)

"Yes, but living out here you have to change buses and all that carry on". (John)

All eight participants gave additional reasons for missed appointments related to the long *'distance'* to the clinic. These are summarised in Table 4.17.

Table 4.17 Long 'distance' to the clinic and other related reasons for non-attendance (continued overleaf)

Participant	Clinic Service: Location – Difficult journey - Distance	Prima-facie reasons: – Not bothered	Prima-facie reasons: Others (Poor Motivation)	Client Characteristics: Substance misusing lifestyle - Busy	Client Characteristics: Co-morbidity: Physical – Sore/Bad legs	Client Characteristics: Co-morbidity: Physical – Long illness	Client Characteristics: Co-morbidity: Psychological – Agoraphobia	Client Characteristics: Co-morbidity: Psychological – Depression	Client Characteristics: Income - Cost of travel
John	√	√			√				
Howard	√	√							√
Simon	√		√					√	√
David	√			√					
Ian	√					√			√
Andrea	√					√	√		√
Terry	√								√
Robin	√								√
	8	2	1	1	1	2	1	1	6

Participant	Clinic Service: Location – Difficult journey - Distance	Client Characteristics: Income – Other priorities	Client Characteristics: Social networks - Children	Hepatitis C: Testing – Poor veins	Hepatitis C: Testing – Scared of result	Hepatitis C: No symptoms	Clinic Service: Location – Difficult journey – Rely on lift	Clinic Service: Location – Difficult journey – No transport	Clinic Service: Location – Relationship with clients
John	√			√			√		
Howard	√			√		√			
Simon	√								
David	√								
Ian	√	√						√	
Andrea	√		√						√
Terry	√								
Robin	√				√				√
	8	1	1	2	1	1	1	1	2

Table 4.17 Long *'distance'* to the clinic and other related reasons for non-attendance (continued)

Participant	Clinic Service: Location – Difficult journey - Distance	Clinic Service: Delivery – Reimbursement	Clinic Service: Delivery - Appointment – Not morning	Clinic Service: Delivery – Appointment – Different appointment	Clinic Service: Delivery – Appointment – Waiting	Total
John	√		√	√		6
Howard	√			√		5
Simon	√					3
David	√					1
Ian	√	√		√		6
Andrea	√	√			√	7
Terry	√					1
Robin	√				√	4
	8	2	1	3	2	33

The participants gave a further 20 themes for non-attendance alongside the long *'distance'* to the clinic. The most commonly reported factors (n=6 and n=3 respectively) *'cost of travel'* and being expected to attend on a *'different appointment'* to the one for a substitution drug treatment script were linked to the themes *'client characteristics'* – *'income'* and *'clinic service'* – *'delivery'*.

Less common factors relating to *'location'* of the clinic and missed appointments are summarised in Table 4.18.

Table 4.18 Less common factors for 'location' of the clinic and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Rely on lift; *No bus stop*; and *Client Characteristics: Substance misusing lifestyle – Avoid town* and *Co-morbidity – Physical - Bad* or *sore legs* [4]	Relied on getting a lift to the clinic due to bad legs and difficulty walking. Also to make sure did not go into town to score with past drug using acquaintances. There was no bus stop outside the clinic	*"Obviously because of my illnesses I have to rely on someone to take me physically in a car ... rely on other transport and things. ... I can only walk certain distances". (Edward)*
No transport; Distance; and *Client Characteristics: Co-morbidity – Physical – Bad* or *sore legs* (2)	Did not have own transport and lived fair distance from the clinic. Also, no bus went from home to the clinic. This meant having to walk but had bad legs.	*"... but also it means then where I live and also having like a lack of funds, like me I haven't got a lot of money because I am out of working for the first time and also like I haven't got no transport. All them things just like added to the situation". (Ian)*
No bus stop; Rely on lift; and *Client Characteristics: Co-morbidity – Physical – Bad* or *sore legs* (1)	No bus stop outside the drug clinic which made it troublesome because of health problems including difficulty with walking.	*"... it would be better if a bus stopped outside because of me health issues". (Edward)*

Bus (1)	Inconvenience of having to get a bus.	*"... they don't want to mess about getting on a bus. It would be easier if somebody came and picked them up or supported them on their way there". (Joseph)*
Relationship with clients; and *Client Characteristics: Social networks – Children* (5)	May have problems or issues with other clients and preferred to avoid them. Reminded of past drug using lifestyle. Also, some clients still using drugs and may have been tempted to score drugs with them. Not suitable environment for little boy.	*"Only trouble with [name of drug clinic] is that I kind of bump into people that I don't really want to bump into. It brings up memories and I'm easily led as well ... so that's why I'd rather go to [area of the city] where there's like probably one person waiting before you and then you get seen and then you leave and you are not bumping into loads of people. ... What obviously like are still using ....". (Robin)*
Not hospital; and *Hepatitis C: Testing – Poor veins* (2)	If appointment at the hospital take it more seriously and easier to explain to other people. Also, only at the hospital that was able to get a blood sample.	*"It feels less serious going to the clinic than it does going to the [name of hospital]. And if you've got a hospital appointment you may take it more seriously even though it's for your clinic. ... if your mum says come up for your tea on Wednesday or whatever and you've got an appointment you don't want to say I'm going to me hep C clinic, or I'd better go to my methadone clinic, you don't want people to know. That's another good thing about having appointments in the hospital". (Lindsay)*
Confidentiality (1)	Other clients knew the outreach clinic nurse and did not want them to know that had hepatitis C.	*"I didn't really want to see you at the [name of drug clinic]. I'd rather do it in private. It's I know people in [name of drug clinic]. I don't really want them knowing what you are if you understand what I mean. I don't want people knowing that I've got it". (James)*

The table above shows the reasons for non-attendance linked to the *'location'* of the clinic comprised of many factors with other sub-themes identified. Also, most of these factors were linked to other themes including:

'client characteristics' – *'substance misusing lifestyle'; 'co-morbidity'* and *'social networks';* and *'hepatitis C'* – *'testing'.*

Delivery

The participants also talked about the *'delivery'* of the outreach clinic contributing to missed appointments which were hosted within two drug treatment services. Thus, the reasons for non-attendance given by the participants are largely factors relating to way the drug clinic delivered its service. Where this was not the case, but because of the outreach clinic will be distinguished.

Case study 13 – 'Delivery' of the clinic and other reasons for non-attendance

James said a reason for non-attendance was he did not always have the bus fare to attend. He did not feel like walking to the clinic because of having *"bad legs"*. As well as being on benefits he is paying off arrears from unpaid bills. When he attended the drug service they did not always reimburse his travel expenses. The letter from the benefits office was out of date. James did not have a current letter because he did like waiting in a long queue. Other reasons he gave for non-attendance were finding it *"hard to get motivated"*. He was a *"little bit depressed"* because of a lack of a *"real good quality of life"*. He had been evicted from his flat and was living in a hostel. James felt he should be doing *"normal"* things such as *"car, job, marriage, kids"*. He had been homeless and thought *"... what's the point [attending], look at the state of me living on the streets ...."* James suggested being afraid to turn up at the outreach clinic because of the possibility of being given bad news about the infection. Also, the need to 'score' drugs before the appointment to avoid the effects of withdrawing but this takes longer than planned.

Five participants (almost 20%) reported that not getting travel costs reimbursed was a factor for non-attendance. Four of the participants advised having been declined *'reimbursement'* because they did not have the correct letter from the benefit office which had to be within date. Further,

one of the participants described having to wait in a long queue to obtain a letter.

"... when I get there I ask for bus fare back and they can't give it to me because I haven't got a letter from the social. ... they've already seen a letter from the social and nothing has changed since then. ... It is a bit of a pain because I have to go to the social, wait in a queue sometimes its right long, massive, wait for a letter and then go to [name of drug clinic]. It's a bit of a headache to be honest". (James)

The fifth participant also with *'bad'* or *'sore legs'* and only able to walk a short distance, had to *'rely on a lift'* and reported not getting full *'reimbursement'* for petrol or the taxi fare.

"I can only walk certain distances. ... No I have to give them petrol and stuff and I know if you claim for petrol they hardly give you anything. They only give you sort of ninety pence or one pound and eighty pence if you get a taxi. They don't give you the full amount". (Edward)

All five participants gave additional reasons for missed appointments related to *'reimbursement'* of travel costs. These are summarised in Table 4.19.

Table 4.19 Reasons for non-attendance alongside 'reimbursement' (continued overleaf)

Participant	Clinic Service: Delivery – Reimbursement	Prima-facie reasons – Not a priority	Prima-facie reasons – Forgot	Prima-facie reasons – Others (Poor motivation)	Prima-facie reasons – Others (Weather)	Client Characteristics: - Co-morbidity - Physical – Bad or sore legs	Client Characteristics: Co-morbidity – Physical – Long illness	Client characteristics: Co-morbidity: Psychological – Agoraphobia	Client Characteristics: Co-morbidity – Psychological – Depression
Bradley	√	√	√		√	√			
Edward	√					√			
James	√			√		√			√
Ian	√						√		
Andrea	√						√	√	
	5	1	1	1	1	3	2	1	1

Participant	Clinic Service: Delivery – Reimbursement	Client Characteristics: Income – Cost of travel	Client Characteristics: Income – Other priorities	Client Characteristics: Social networks - Children	Hepatitis C: Testing – Poor veins	Hepatitis C: Testing – Naturally cleared	Clinic Service: Location – Difficult journey – Distance	Clinic Service: Location – Difficult journey - Rely on lift
Bradley	√				√	√		
Edward	√	√						√
James	√	√						
Ian	√	√	√				√	
Andrea	√	√		√			√	
	5	4	1	1	1	1	2	1

Table 4.19 Reasons for non-attendance alongside 'reimbursement' (continued)

Participant	Clinic Service: Delivery – Reimbursement	Clinic Service: Location – Difficult journey - No transport	Clinic Service: Location – No bus stop	Clinic Service: Location – Relationship with clients	Clinic Service: Delivery – Different appointment	Clinic Service: Delivery – Waiting	Total
Bradley	√						6
Edward	√		√				4
James	√						4
Ian	√	√			√		6
Andrea	√			√		√	7
	5	1	1	1	1	1	27

The table shows a further 20 factors for non-attendance were given by the participants alongside *'reimbursement'*. The most commonly reported factors (n=4 and n=3 respectively) *'cost of travel'* and *'bad'* or *'sore legs'* were linked to the theme *'client characteristics'* – *'income'* and *'co-morbidity'*. Thus, non-attendance is complex in this setting with multiple factors influencing missed appointments.

Five participants (almost 20%) also reported that being given a morning appointment was a reason for non-attendance (*'not morning'*). This was because they got up late and lacked motivation to get up and get dressed. One participant needed time to drink alcohol before going out to relieve his *"agitation"*.

"... one is time, depending on what time it is. I can't remember and yes forgetfulness. ... Well usually a case of the night before if I've been up quite late and the appointment is say nine, ten, [or] eleven. Even though it's not that far away I find it hard to motivate myself to get up and dressed, and also I've got a slight drink problem which means that I need a little bit of drink before I go out". (Malcolm)

For two participants the difficulty of a morning appointment was compounded by other factors. These included *"unforeseen problems"* such as the weather, and living a long *'distance'* from the clinic and having to *'rely on a lift'*. For the latter participant the outreach clinic was a *'different appointment'* to the one to collect a substitution drug treatment script. This example illustrates how other factors alongside being given a morning appointment contributed to not turning up. These factors linked to other themes within *'client characteristics'* – *'co-morbidity'*, and *'clinic service'* – *'location'* and *'delivery'* (see Table 4.20).

Less common factors for clinic service *'delivery'* and missed appointments are summarised in Table 4.20.

Table 4.20 Less common reasons for clinic service 'delivery' and non-attendance

Theme **(Frequency)**	**Description**	**Quote**
Waiting (4)	Put off attending because thought may be kept waiting to be seen.	*"Sometimes you can be waiting a bit long but that goes with the territory anyway. I know they are busy down [there]. ... I think its just people's attitude to waiting in general. ... It could be people think oh I have got to go down there and I will be waiting ages ...". (Bradley)*
Different appointment; Not morning; and *Location – Difficult journey –Distance; Rely on lift*; and *Client Characteristics: Co-morbidity – Physical – Bad* or *sore legs* and *Income – Cost of travel* (3)	Having to attend a different appointment to the one for a methadone script. Lived a long way, had bad or sore legs and relied on getting a lift so not bothered to attend. Also, expected to attend in the morning. There was the additional cost of travel.	*"Well like say if someone has got to come more for their methadone. Having more appointments might not help them do you know what I mean. But say if they're trying to see you but they can't see you and they can't see the methadone bloke at the same time which has happened before because it's happened to me and my partner when I can't see you both at the same time. What are the chances of me going down there and seeing you both on a different day; they're going to be reduced aren't they?" (Ian)*
No card/letter (3)	Not aware of the appointment because it was not written on a card or letter.	*"... I'm pretty sure I wasn't aware that I'd got an appointment. The only appointment card that I'd got was for [date]. It wasn't that I didn't attend it was I was totally unaware of it". (Kevin)*
Lost paper (1)	Had the appointment written down on a piece of paper but lost it.	*"... when they give [the appointment] to me they write it down for me on a piece of paper. I take it home and I get a few more letters and I end up losing it. It gets put under something and then I have not been able to find it". (Oliver)*
Wrong date (1)	Wrong date on appointment card so attended on a different day when	*"Yeah right the one in March was for the [day of the clinic] but they had put the date down and when I came in on the date it were [different day] so I*

	the outreach clinic was not running.	*come in on [different day] instead of [clinic day]. ... They had put the wrong date on the card". (Graham)*
"Counselling" (1)	Did not know what the outreach clinic offered. Thought it was like a support group.	*"I thought that the [name of drug clinic] thing I always thought it was more a counselling group rather than a medical group. ... they don't want to go to go to another NA [Narcotics Anonymous] type situation where people sit around you know worried about this and don't want to do this if it's another NA sort of situation that's perhaps not beneficial just to keep it to themselves". (Lindsay)*
Drug clinic nurse; and *Client Characteristics: Co-morbidity – Psychological - Agoraphobia* (1)	Thought appointment was with a drug clinic nurse who had little knowledge about hepatitis C rather than with a hospital specialist nurse who had met before.	*"I thought it was just going to be with one of the nurses or something. I didn't realise it was you. They didn't say it was you. ... they've told me before that it is you what works around there but they didn't tell me that it would be you I would be seeing. ... Because you know what you're on about and like nurses, do you know I don't mean this in a nasty way to them but they just know stuff about like being on methadone and dealing with that sort of stuff like". (Joyce)*
Relationship with staff (4)	Did not like way treated by staff in drug service and may negatively impact on whether to attend an appointment.	*"I don't like going down there. I feel like a lot of people or workers don't like me down there. I don't know why. It's just how I feel. ... Just because they said stop crying it's not this and that and the other. And I just feel a little bit helpless when I go down there". (Anne)*
Entrance (2)	The entrance is clearly visible to others and clients drinking alcohol outside.	*"I don't like walking into clinics when everybody knows where it is. It used to be open at the back door". (Lindsay)*

The table shows the reasons for non-attendance related to clinic service *'delivery'* were numerous with other sub-themes identified. Also, two of these factors were linked to other themes including: *'client characteristics'* – *'co-morbidity'* and *'income'*; and *'clinic service'* – *'location'*.

Summary

The key factors for non-attendance relating to the clinic service in order of frequency were:

- The *'location'* of the clinic, with the *'distance'* causing it to be a *'difficult journey'*. This meant the inconvenience for some participants of getting two buses. Other factors related to *'distance'* included the *'cost of travel'* and being asked to attend on a *'different appointment'* to the one for a substitution drug treatment script.

- The *'delivery'* of the clinic and the difficulty with *'reimbursement'* of travel expenses and being asked to attend a morning appointment (*'not morning'*). Without a current letter from the benefits office travel expenses were not given. A morning appointment was not convenient because of getting up late and not being motivated to get up and get dressed. Other factors related to *'reimbursement'* included the *'cost of travel'* and having *'bad'* or *'sore legs'*.

For each of the above factors less common themes were also identified. Thus, reasons for non-attendance with the hepatitis C outreach clinic are complex with themes played out in different ways in different people and with these linked to other themes. In addition, as described in the small case studies participants gave other reasons for non-attendance.

Chapter 5: National Staff Survey

5.1 Introduction

This chapter describes how the survey data was collected and analysed. It also includes a description of the ethical considerations before the findings are presented. Thus, this chapter begins with a description of the method, including details about the sample, data collection, data analysis, and ethical issues. It then sets out the findings.

5.2 Method

5.2.1 Sample

Sampling method

Health professionals running hepatitis C outreach clinics in drug treatment centres in England were invited to participate. The outreach clinics that were not located in a drug service were excluded e.g. GP surgery, health centre and prison.

Sample size

The total number of hepatitis C outreach clinics in drug treatment centres in England was unknown although 18 outreach clinics in drug and alcohol services were identified in a publication by the All Parliamentary Hepatology Group (2010). This figure was not comprehensive and did not include all outreach clinics in drug treatment services throughout England. Therefore, for this study 142 Drug and Alcohol Action Teams (DAATs) were contacted about the survey. Out of 65 (46%) respondents, 41 confirmed they ran a hepatitis C outreach clinic within a drug misuse clinic and so were eligible to complete the survey. These 41 services formed 29% of the original 142 DAATs.

Identification and recruitment of participants

Health professionals running hepatitis C outreach clinics were identified via an e-mail sent to the commissioner/manager of each of the drug services in England. The e-mail gave a brief explanation of the study and included a

hyperlink to the quantitative survey. The commissioner/manager was asked to forward the e-mail onto staff in their area that ran a hepatitis C outreach clinic. A polite reminder e-mail was sent to the commissioner/manager a couple of weeks later.

5.2.2 Data collection

A National electronic survey (see Appendix 14) was sent to health professionals throughout England using Survey Monkey®.
It aimed to:

- Identify models of hepatitis C outreach clinics within drug services, including data on the number of patients seen, frequency of the clinic, and the number of and level of staff employed.
- Find out if and to what extent, these outreach clinics experience problems with non-attendance.
- See whether themes explaining non-attendance from the client interviews ran through the experiences of health professionals providing outreach clinics.
- Find out if and what measures have been undertaken, whether any evaluation of these has been conducted and their evidence of success in reducing non-attendance.

Some outreach clinics may have been run in 'drug services' that did not provide substitution treatment but offered other interventions e.g. counselling, needle exchange. Thus, the survey also asked the type of drug service the outreach clinic was located in and the interventions it offered.

5.2.3 Data analysis

The data from the electronic questionnaire was analysed to provide descriptive statistics such as the number of clients seen, the type and number of staff employed and the services provided. The analysis looked to see whether the reasons for non-attendance given by health professionals matched those given by clients. The similarities and differences were noted.

5.2.4 Ethical issues

There were three ethical issues related to the survey. These ethical concerns were:

- Confidentiality
- Consent
- Risks, burden and benefits

Confidentiality

Data collected from the questionnaires sent to health professionals was only used to gather details about the delivery of clinical services, and their experiences of and reasons for patients missing appointments. The questionnaire did not ask for specific information about patients.

Consent

The electronic questionnaire to health professionals started with 'participant information', outlining who was undertaking the research, the purpose of the project, how the data would be kept and used, and details of who to contact for further information. Completion of the questionnaire was viewed as a sign of consent to be included in the survey.

Risks, burden and benefits

Health professionals running hepatitis C outreach clinics throughout England may have felt that they did not have time to complete the survey and perceived it as burdensome on an existing heavy workload. The introduction to the survey outlined: how long it took to complete (the survey was short and was easy to complete); that participants could save their responses and return to it later; and it emphasised that the research was of national interest and that their experience and views were invaluable.

Health professionals may have perceived a risk in completing a survey; such as submitting sensitive data about their service and expressing their views to a researcher. Participants were given a choice as to the amount of detail they provided about who they were and where in the country they worked.

The introductory participant information explained how and where the data were kept, and included a statement about confidentiality (see *'Confidentiality'*).

Benefits of the study to health professionals was contributing to original research, and that it may stimulate discussion (and increase networking) about ways to improve attendance and the delivery of services.

5.3 Findings

The findings of the survey are presented in four sections:

- Models of hepatitis C outreach clinics;
- The prevalence of non-attendance in outreach clinics;
- Reasons for non-attendance highlighting the areas of agreement and disagreement between clients and staff; and
- Measures taken by staff to reduce non-attendance including their effectiveness.

5.3.1 Models of hepatitis C outreach clinics

This study was investigating non-attendance in drug service hepatitis C outreach clinics. A drug clinic can vary in what it provides to clients and may or may not have complemented the services offered by the outreach clinic. Thus, it was necessary to briefly identify what the drug clinic provided.

Host drug clinic

35 out of the 41 (85%) respondents indicated which services the drug clinic provided for clients. As well as a number of drug misuse interventions including substitution drug treatment and key working, 35 out of 35 (100%) of drug clinics offered blood-borne virus (BBV) testing (including for hepatitis C) and 34 out of 35 (97%) provided hepatitis B immunisation. 2/35 (6%) drug clinics offered treatment for hepatitis C and 1/35 (3%) drug clinics provided referral for treatment and support. A summary of the services offered by the drug clinics is provided in Table 5.1.

Table 5.1 Summary of services offered by the drug clinics (who answered the question n=35)

Services	**No. of responses**
Blood-borne virus testing	35/35 (100%)
Hepatitis B immunisation	34/35 (97%)
Key working	31/35 (89%)
Substitution treatment e.g. methadone	27/35 (77%)
Needle exchange	25/35 (71%)
Counselling	22/35 (63%)
Other: Specialist review for patients with alcohol related harm/liver disease; Referral and support for treatment if positive; Hepatitis C treatment (2); HIV screening; Electrocardiogram [ECG] (test for measuring the electrical activity of the heart) screening (2); Structured day programme; Alternative therapies; Chronic disease management; Low intensity support; Structured psychosocial groups; Leg ulcer management; Pregnancy testing; Treatment for chest infections, soft tissue infections, HIV and Hepatitis B; Screening for sexually transmitted infection (STI) (and treatment), diabetes (and monitoring), and Tuberculosis (TB).	9/35 (26%)

Hepatitis C outreach clinics

Findings about the models of hepatitis C outreach clinics throughout the country are presented under three headings:

- Services offered
- Frequency of the clinic
- Delivery

Services offered

31/41 (76%) respondents gave information about what the hepatitis C outreach clinic offered to clients. Most of the clinics provided testing supported with information, referral for hepatitis C treatment and hepatitis B immunisation. 11/31 (35%) of these clinics provided hepatitis C treatment. For a summary of services offered to clients by the hepatitis C outreach clinics see Table 5.2.

Table 5.2 Summary of services offered by hepatitis C outreach clinics (who answered the question n=31)

Services	**No. of responses**
Post-test discussion and information	30/31 (97%)
Pre-test discussion and information	28/31 (90%)
Blood-borne virus testing	28/31 (90%)
Hepatitis B immunisation	25/31 (81%)
Referral to hospital for treatment	25/31 (81%)
Hepatitis C treatment	11/31 (36%)
Other: Referrals for clients with hepatitis B; Chronic disease management; Pre-treatment work up; Hepatitis C support group; Assistance to access hospital treatment; Ongoing support for clients on hospital treatment; Integrated care pathway with acute hospital for blood testing during treatment.	9/31 (29%)

Frequency of clinic

29/41 (71%) respondents indicated the frequency of the outreach clinic. 15/29 (52%) of these clinics were weekly with some of these held between one and five times per week. The latter was due to other sites served by the outreach clinic spread across a London borough and one full day counted as two clinics. 10/29 (34%) of outreach clinics were held daily. 4/29 (14%) of clinics were run between two and four weeks.

Clinic delivery

30/41 (73%) respondents answered the procedure for seeing clients at the outreach clinic. Clients were offered appointments in 29/30 (97%) clinics whilst 21/30 (70%) clinics offered a drop-in service. Thus, some outreach clinics operated both systems. For example, one clinic offered a drop-in service for testing and appointments for "post-tests and assessment" i.e. follow-up for clients diagnosed with hepatitis C. One clinic offered an alternative to seeing clients face-to-face and operated a telephone service but did not give any other details.

29/41 (71%) respondents confirmed the number of clients that could be seen during each outreach clinic session. 17/29 (58%) of these clinics were able to see between 5-9 clients at a time. Of the remaining 12 outreach clinics, 6/29 (21%) were either able to see between 1-4 clients or 10+ clients respectively. Some of the participants added that the number of clients seen was "very variable". Two respondents who indicated that more than 10 clients could be seen advised that this depended on the venue or whether the clinic was run for a full day.

24/41 (59%) respondents provided details of the role of the member of staff who usually delivered the outreach clinic. 14/24 (58%) of outreach clinics were usually run by hospital nurses. The other 10/24 (42%) clinics were usually delivered by staff from the drug service. Some participants gave additional information about the staffing. For example, two outreach clinics were supported by a medical consultant either weekly or monthly. Also, one participant added that the qualified nurses had advanced phlebotomy training for taking blood.

Summary

Although 41 staff said they ran a hepatitis C outreach clinic only 24 to 31 staff responded to further questions about what the clinic offered, its frequency and systems of delivery. Similar to the host drug clinics (of which two also provided hepatitis C treatment), the hepatitis C outreach clinics offered testing and hepatitis B immunisation. In addition, the outreach clinics provided referral to the hospital for treatment, whilst 11/31 (36%) delivered this in-house. 15/29 (52%) outreach clinics were run weekly. The clinics mainly offered booked appointments with many offering drop-in sessions, or a combination of both. The capacity to see clients was variable with typically up to nine clients able to be seen at a time. 14/24 (58%) outreach clinics were usually delivered by hospital nurses, with the remainder run by drug service staff.

5.3.2 Prevalence of non-attendance

28/41 (68%) respondents indicated the percentage of clients that did not turn up for each outreach clinic session. 13/28 (46%) clinics reported a non-attendance rate of between 10% and 25%. Whilst 9/28 (32%) clinics responded that between 25% and 50% of clients did not turn up. Of the remaining six clinics 3/28 (11%) reported either less than 10% or more than 50% of clients fail to attend respectively.

5/28 (18%) clinics gave additional information. This included: there were no missed appointments with a drop-in system; figures were not recorded but attendance was "strengthened" by dried blood spot (DBS) testing (using blood from a finger prick) and Hepatitis C Trust peer education; the non-attendance rate included clients with advanced liver disease who needed to see a Hepatologist (a doctor specialising in problems of the liver); and clients that started treatment "very rarely" did not turn up.

5.3.3 Reasons for non-attendance – perspective of staff versus clients

The factors staff outlined as reasons for non-attendance will be considered alongside the reasons given by clients from the phase two interviews, with areas of agreement and difference highlighted.

The reasons for non-attendance are presented under the following themes:

- Client characteristics
- Hepatitis C
- Clinic service

Client characteristics

27/41 (66%) survey respondents indicated reasons for non-attendance under this theme which related to clients. A summary of the responses are provided in Table 5.3.

Table 5.3 Survey - Reasons why clients miss appointments – Client characteristics (who answered the question n=27)

Reason	**No. of responses**
Ongoing drug use	23/27 (85%)
Ongoing alcohol use	23/27 (85%)
Forget	23/27 (85%)
Being in custody	16/27 (59%)
Lack of money	15/27 (56%)
Having mental health problems	11/27 (41%)
Multiple appointments with other agencies	11/27 (41%)
Looking after children	8/27 (30%)
Having physical health problems	7/27 (26%)
Lack of social support	6/27 (22%)
Working	6/27 (22%)
Poor venous access	5/27 (19%)
Difficulty with walking	1/27 (4%)
Other: Welfare reforms; All and any of the above; Not prioritising BBV testing when other areas of life need attention; Denial, apprehension about treatment; Clinic time differs from time of prescribing clinic; Bus fares!!; Fear of the unknown; High levels of chaotic lifestyle, coupled with forgetting; Clients being afraid of accessing it and the results; Treating HCV (Hepatitis C) not a priority; Worried about the side-effects of treatment.	9/27 (33%)

23/27 (85%) respondents answered that 'ongoing drug and alcohol use' and 'forget' respectively were the main reasons for clients not turning up to the outreach clinic. One of the respondents wrote:

"Predominantly we see high levels of chaotic lifestyle are part of this DNA [did not attend]. Coupled with forgetting ...".

'Ongoing drug use' and 'forget' were also ranked by the survey respondents as the top two reasons respectively for non-attendance. The third ranked reason for non-attendance was 'scared of the side-effects of treatment' which will be described under the next theme hepatitis C.

The key influencing factor for forgetting given by clients was having a lot of appointments to attend. 11/27 (41%) survey respondents also indicated that 'multiple appointments with other agencies' were a reason for missed appointments with the outreach clinic. Thus, there was agreement amongst staff and clients that drug and alcohol use, forget and having 'multiple appointments' were reasons for missed appointments.

On the issue of the 'prima-facie' reason 'not a priority'; 4/27 (15%) survey respondents added this as a reason for non-attendance. For example:

"Not prioritising BBV [blood-borne virus] testing when other areas of life need attention".

"Substance use is the priority".

"Don't view treating their HCV [hepatitis C] as a priority ...".

Thus, the term 'not a priority' was used by both staff and clients as a reason for non-attendance.

More than half the survey respondents (16/27 (59%) and 15/27 (56%)) indicated that 'being in custody' and a 'lack of money' respectively were reasons for non-attendance. One respondent added:

"Welfare reforms have increased [the rate of] DNAs".

Despite a 'lack of money' being cited as a factor for missed appointments only 9/27 (36%) survey respondents gave the 'high cost of travel' as a reason. These survey findings slightly conflict with what clients reported in the interviews. For example, only three clients gave being in custody or incarcerated as reasons for non-attendance. Also, a greater number clients (n=12) than staff gave the 'cost of travel' as a reason for missed appointments. Thus, between staff and clients there was some lack of

concordance about 'being in custody' and the 'cost of travel' explaining non-attendance.

The least common reason for missed appointments indicated by 1/27 (4%) survey respondents was difficulty with walking. This was probably the one respondent who added "All and any of the above [reasons]". However, for six of the seven clients with 'bad' or 'sore legs' they had difficulty with walking which contributed to non-attendance. Thus, there was a striking discordance between staff and clients about difficulty with walking contributing to non-attendance.

In summary, amongst staff and clients there was agreement that 'ongoing drug and alcohol use' and 'forget' were reasons for non-attendance. A small number of the survey respondents in agreement with many clients also suggested that it was 'not a priority' to attend. There was also some discordance about reasons for missed appointments. In contrast to the survey respondents fewer clients reported being in custody as contributing to non-attendance. However, more clients than survey respondents identified the 'cost of travel' and difficulty with walking (due to 'bad' or 'sore legs') as factors for missed appointments.

Hepatitis C

26/41 (63%) survey respondents indicated reasons for non-attendance under this theme which related to the infection itself. A summary of the responses is provided in Table 5.4. One respondent commented "All and any of the above" and answered all the reasons.

Table 5.4 Survey - Reasons why clients miss appointments – Hepatitis C (who answered the question n=26)

Reason	**No. of responses**
Scared of the side-effects of treatment	21/26 (81%)
Afraid of the consequences of the infection on their health	19/26 (73%)
Asymptomatic – do not feel unwell	19/26 (73%)
The infection carries a stigma	13/26 (50%)
Do not know if the infection is still present or cleared itself	10/26 (39%)
Believe may not die from the infection	9/26 (35%)
Lack of information given at diagnosis about the infection	8/26 (31%)
Believe treatment not curative	6/26 (23%)
Other: Feedback from our patients is that they forget their appointments, we use their drug workers to remind them as well; I think they get a lot information but just don't turn up; All and any of the above; Not prioritising own health – general behaviour unless visibly suffering with symptoms; Other priorities – substance use; Feel that as they have been careful and used clean works etc they have not been put at risk.	6/26 (23%)

21/26 (81%) respondents answered that 'scared of the side-effects of treatment' was the main reason for clients not turning up. Two respondents also wrote:

"Denial, apprehension about treatment".

"... worried about side-effects of treatment".

This factor was also ranked the third most important reason for missed appointments by the respondents. Although fewer clients (n=5) than staff reported not attending because of the side-effects of treatment this was the most common factor cited by the clients linked to the theme 'treatment'.

Thus, there was agreement amongst staff and clients that fear of the 'side-effects' of treatment was a factor for non-attendance.

19/26 (73%) survey respondents indicated being 'afraid of the consequences of hepatitis C on their health' and 'not feeling unwell' (asymptomatic) respectively were reasons for clients' non-attendance. Some of the respondents commented:

"Fear of the unknown".

"Fear of the whole process – which may include treatment, going to die, etc. Some just are afraid to find out".

"Not prioritising own health – general behaviour unless visibly suffering with symptoms".

Although reported by fewer clients (within the mechanisms 'bad news', 'going to die' and 'no symptoms') than staff there was some agreement that these two factors explained non-attendance.

The least common factor for missed appointments indicated by 6/26 (23%) survey respondents was clients believed the treatment was not curative. In the interviews three clients suggested that a belief that treatment was not curative contributed to non-attendance. Thus, there was some agreement amongst staff and clients about treatment perceived not to be curative and non-attendance.

In summary, there was some agreement amongst staff and clients that the 'side-effects' of treatment, being afraid of the impact of the infection on physical health and not having symptoms were the main factors about hepatitis C that contributed to non-attendance. Both staff and clients also agreed that a least common factor for non-attendance was the belief that treatment was not curative.

Clinic service

25/41 (61%) survey respondents indicated reasons for non-attendance under this theme which related to where and how the outreach clinic operated. Although the number of staff answering this theme was similar to the previous two themes the total number of responses was fewer. A summary of the responses is provided in Table 5.5. One respondent commented "All and any of the above" so answered all the reasons given. On the contrary, another respondent said none of the reasons given were applicable because clinics were held at a number of sites and at different times.

Table 5.5 Survey - Reasons why clients miss appointments – Clinic service (who answered the question n=25)

Reason	**No. of responses**
Held on a different day to drug clinic appointment	12/25 (48%)
Unable to get blood sample(s)	11/25 (44%)
High cost of travel	9/25 (36%)
Fearful of meeting other clients and being tempted to score	8/25 (32%)
Difficulty claiming travel expenses back	7/25 (28%)
Clinic too far away	4/25 (16%)
Lack of confidentiality – other clients know what attending for	4/25 (16%)
Held at inconvenient time of day	2/25 (8%)
Other: See above; All and any of the above; Just another appointment to attend; Substance use is the priority; This has changed dramatically now with Dried Blood Spot testing; None of the above, we have clinics at a number of sites and different times.	6/25 (24%)

12/25 (48%) respondents answered that the outreach clinic being held on a different day to the drug clinic appointment was the main reason for clients not turning up. Two respondents commented:

"Clinic time differs from time of prescribing clinic".

"Just another appointment to attend".

Although there was agreement with staff just a quarter of the number of clients (n=3) gave the outreach clinic being held on a different day to the drug clinic appointment as a factor for missed appointments.

From the survey, and ranked a close second for reasons for non-attendance within this theme was being unable to get a blood sample. This factor was indicated by 11/25 (44%) respondents. Thus, although the number of clients versus staff reporting this was fewer, there was some agreement that this factor contributed to non-attendance.

7/25 (28%) survey respondents indicated that 'difficulty claiming travel expenses back' was a reason for clients not turning up. However, only 2/25 (8%) respondents (and the least common factor) answered the outreach clinic being held at an inconvenient time of day was a factor for missed appointments. Thus, whilst there was agreement with clients about reimbursement there appeared to be less concordance about the time of day the clinic was held.

The second least common factor given by 4/25 (16%) staff was the clinic being too far away. Thus, there appears to be some discordance between staff and clients (with twice the number reporting this) about the distance to the clinic being a reason for missed appointments.

4/25 (16%) survey respondents also indicated that 'lack of confidentiality and other clients knowing what clients were attending for' was a reason for missed appointments with the outreach clinic. This was also raised by a client in the interviews. Thus, there appears to be some agreement amongst staff and clients that lack of confidentiality was of relatively low importance in contributing to non-attendance.

In summary, there was agreement amongst staff and clients that the clinic being held on a different day to the drug clinic appointment, difficulty with reimbursement of travel expenses and getting a blood sample contributed to missed appointments. On the contrary there appeared to be some discordance between staff and clients with the latter reporting that the time of day and the long distance to the clinic were more important factors for non-attendance.

5.3.4 Measures to reduce non-attendance

This section of the survey findings describes measures taken by staff to reduce non-attendance and the impact, if any, the interventions had.

28/41 (68%) respondents indicated whether they had taken steps to reduce non-attendance in the outreach clinic. 24/28 (86%) respondents said they had taken measures but, oddly, 25/28 (89%) respondents went on to describe these. For a description of the steps taken and the success of the interventions used see Table 5.6.

Table 5.6 Measures taken and the impact of interventions to reduce non-attendance

Resp't	Steps to reduce non-attendance	Evaluation	Impact of intervention (where information was given by respondents)
1.	Included the BBV (blood-borne virus), drug workers, community psychiatric nurses (CPNs) etc in appointment times.		Increased communication between teams and offered a great deal of flexibility – picking up people who then go to prison, rescheduling appointments etc.
2.	Tied in nurse appointments with clients attending for substitute medication/to see doctor/key worker or at very start of treatment.		Improved rates of testing and immunisations. Able to get clients tested early on in drug treatment so that if they dropped out they knew their status and it could be passed onto the GP. Offered to all new clients using drugs at start of drug treatment.
3.	Contingency management.	Informal.	100% attendance.
4.	Outreach at home, homeless centres and church halls, needle exchange.		The drop-ins at church hall and homeless centres have proved successful and improved figures for testing and vaccinations.
5.	Created open dialogue about hepatitis C among service users, used dried blood spot (DBS) (finger prick) and peer education effectively.	Attempted. Limited data showed success of key interventions.	Proportion of IDUs tested = 73%. Majority of remaining untested likely to sit in shared care, hence alternative strategy required. Recent DBS testing data indicates hepatitis C prevalence among IDUs is circa 23%, considerably less than the previous Health Protection Agency (HPA) prevalence estimates of 50+%. Attrition rates of IDUs at treatment appointments are much lower than the general public. Other learning identified other systemic problems which will need to be addressed. However, greatest challenge is no longer about testing but about getting clients through treatment.

6.	Text those on booked appointments.		N/G
7.	Very flexible appointments, coffee and refreshments available, text reminders.		Think improved attendance but also down to the charisma of the nominated worker who co-ordinates.
8.	Spoke to clients, looking at changing area of clinic.		N/G
9.	(a) Attempt to have methadone prescription altered to co-ordinate with appointment. (b) Text or telephone patient on morning of appointment to remind them of appointment. (c) Offer alternative appointment at hospital if worried about confidentiality issues or meeting ongoing drug users. (d) Liaise with key workers to remind clients of their appointments. (e) Copy letters of appointments to key workers or referrers. (f) Clients given more than one appointment before discharging for DNA (did not attend). (g) Training for drug workers to improve their knowledge of hepatitis C and its potential impact on client health. (h) Occasionally home visits (with key workers) to people who have DNA'd but were seriously worried about their health. (i) Meetings with drug treatment Service Managers to make aware of DNA rates and to improve pathways.		(a) If methadone prescriptions are due on the day of the outreach clinic this works and attendance is good. (b) Text and telephone reminders are also a good way of improving attendance, but can work the other way and clients say on the morning of the appointment they cannot attend (at least you don't sit and wait for them!). However, still reminded client of their appointment in the morning and they have failed to attend. (d) If client has a regular key worker to liaise with that can work well as a reminder to attend appointment. If a key worker is keen and interested in hepatitis they improve DNA rates. (h) The few times undertaken home visits were very successful in getting seriously ill clients to the hepatitis clinic, but obviously this can't be done for everyone. (i) Meetings with managers etc were only marginally helpful. Other – Good quality pre and post-test discussion or a recent diagnosis seems to improve DNA rates.
10.	Changed days of the clinic to try and suit clients.		Only started changing the days within the last month and seen a higher number of clients each time.

11.	Contacted key workers to remind re appointments.		N/G
12.	Inform key workers to assist/change drug clinic date and telephone calls to remind clients.	Not officially reported on.	Very good numbers within clinics. Appears to be good return. The non-attendees are mainly clients that have not been seen before.
13.	Changing to testing on request – offered daily. Staff undergoing training for this currently.		N/G
14.	Good partnership working/communication with professionals working both in and outside the clinic to promote the importance of BBV screening and follow-up with their clients. Just started an appointment system to run concurrently with the outreach clinic to see if will facilitate a better attendance rate for BBV screening interventions.	No report written as yet.	New appointment system is only in its earliest stages, but so far no clients have DNA'd.
15.	Reminders via text, call, outreach. Needle exchange promoting.		Slight increase via reminders, greater pick up via needle exchange.
16.	Active re-engagement.		N/G
17.	Text reminders, letters, moving the clinics to health centres nearer the clients address, outreach to hostels and "on the beat" in the evening with sex workers.		Street sex worker testing and vaccinations – good. Hostels – good. Moving to health centres nearer to homes – not very good often cancelled.
18.	Involvement of drug workers – asked to remind clients of appointment.	No.	Not evaluated – too soon.

19.	Contact clients, other outreach locations, contact key workers.		N/G
20.	(a) An active hepatitis C support group which helps to alleviate anxiety through peer support. (b) Good relationships with the recovery workers who remind clients of the appointments. (c) Created an environment which is non-judgemental, supportive and clinics are held to run alongside other peer support groups and drug clinics. (d) Clients are worked up before consultant appointments.		(a) Helps encourage clients to clinic and provides social support where encouragement and peer support is required. (d) Reduced the number of consultant appointments prior to treatment. Reduced number of missed hospital out-patient appointments. Numbers of patients missing clinic appointments whilst on treatment are negligible. Very few patients drop out on treatment.
21.	Align appointments with script pick up and recovery worker session.	Evident in attendance.	Increase noticeable re DBS testing and vaccinations.
22.	Contact the client to try to re-arrange, also the key worker (if they were the original referrers).		N/G
23.	Offering ad hoc testing when the client requests it and staff available.		N/G
24.	Text messaging service, co-ordinating key work appointment with the hepatitis C clinic.		Some reduction in number of DNAs.
25.	Different venues, drop-in, evening.		Currently treated 250 drug users within addiction services.

N/G = Not given

In summary, 25/41 (61%) survey respondents had taken to steps to reduce non-attendance in the outreach clinic. The measures taken were varied with the more frequent being: liaison with key workers to encourage attendance; incorporating the outreach appointment with the one for a substitution drug treatment script; making changes to the appointment system including drop-in; text or telephone reminders; covering several sites/locations; and offering pre-treatment work-up and treatment for hepatitis C. 16/25 (64%) of respondents reported improvements in attendance, testing, hepatitis B immunisation and uptake of hepatitis C treatment. However, these successes were primarily perceived with little empirical data or formal evaluation undertaken.

Chapter 6: Discussion

6.1 Introduction

This chapter will critically discuss the main findings of the study and, how these will be disseminated. It will describe how the findings relate to the existing literature. The discussion will also examine the implications of the findings from policy, service delivery and educational perspectives (including practice issues that were learnt along the way). In addition, the strengths and limitations of the study will be outlined with areas for possible future research identified.

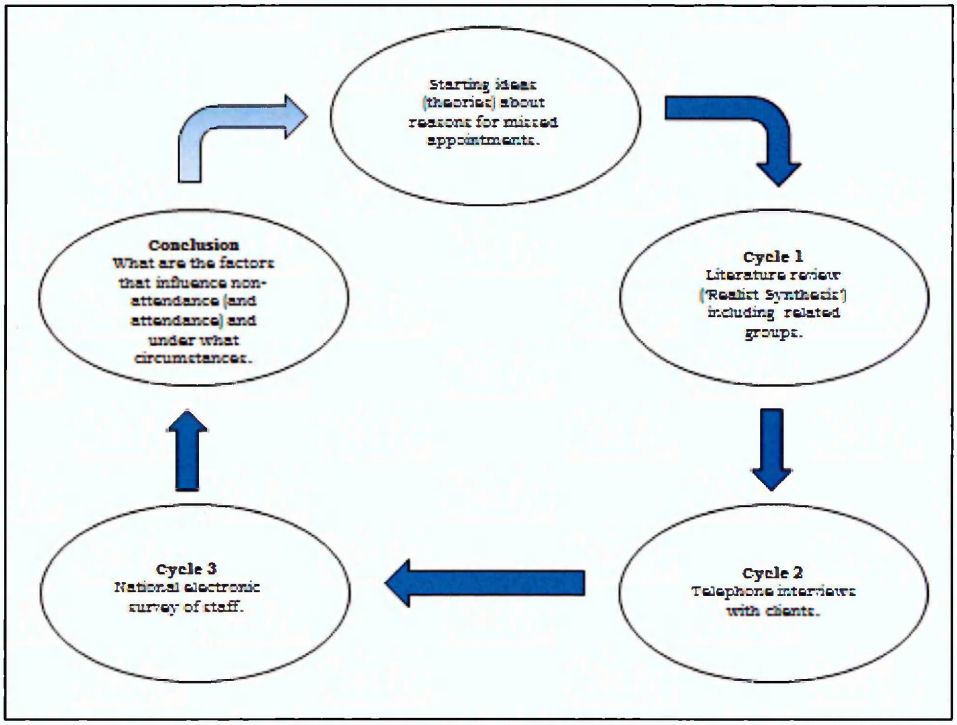
This discussion will continue in the realist mode. Thus, the chapter is comprised of the following sections:

- Realism and non-attendance
- Strengths and limitations of the study
- Findings of the study alongside the existing literature
- Implications for policy, service delivery, education and research
- Dissemination

6.2 Realism and non-attendance

In keeping with a realist theory-led methodology the study comprised of three cycles of theory development, testing and refinement. The three cycles are summarised in Figure 6.1 overleaf. They are now described with examples of how the theories for non-attendance were refined or updated. This is followed by a consideration of how well the three cycles were successfully integrated.

Figure 6.1 Flow diagram of the three cycles of theory testing and refinement



6.2.1 Cycle one - Literature review ('realist synthesis')

Some of the initial ideas or theories about the reasons for missed appointments with the hepatitis C outreach clinic emerged from the literature ('realist synthesis'), including those on the surface or of a *'prima-facie'* nature. Reasons given in the literature also included: low socioeconomic status; ongoing drug and alcohol use which can lead to 'chaotic lifestyles'; mental and physical co-morbidity; a lack of social support; hepatitis C not being a priority for those infected; a lack of understanding of the effectiveness of treatment; fear of having a liver biopsy and imprisonment. Also, there was some awareness in the literature of the underlying mechanisms (and wider contextual factors) that influenced these factors. For example, the need to obtain drugs and alcohol rather keep an appointment because of the fear of suffering from withdrawal symptoms (a feature of 'addiction'). Further, being on a low income and the high cost of travel was a factor for non-attendance. This was a mechanism influenced by the wider welfare reforms and getting people back to work, leading to a reduction in peoples' welfare payments.

However, there was a lack of primary research for the client group in relation to non-attendance which meant a study such as this was needed.

6.2.2 Cycle two - Telephone interviews with clients

Following completion of the literature review a new theoretical position was taken with 34 potential theories for reasons for missed appointments (see Chapter 3 'Literature Review' Table 3.1: 'Summary of the theories about non-attendance') that were to be tested during the client interviews. This cycle of testing led to many of these theories being found relevant to the hepatitis C outreach clinic and which are depicted in the thematic framework (see Figure 6.2 in the section 6.4.1 'It's a little more complicated than that ...'). At least two of the theories were not agreed with or identified by the clients as reasons for missed appointments with the outreach clinic. These were: longer wait for an appointment; and not deserving of medical care. Neither of these was cited as of importance by the client participants. The interviewees also revealed additional reasons for non-attendance (not given in the literature) which included further explanations of a 'substance misusing lifestyle' (which may be labelled as 'chaotic', particularly by outsiders). For example, clients: not being able to use a phone to re-arrange an appointment or to receive appointment reminders (because it was sold to buy drugs); needing to keep a low profile to avoid detection by others including the police; and avoiding town so not being tempted to use drugs with past acquaintances.

The findings from the client interviews informed the questions in the national staff survey.

Since completing the study, two papers about non-attendance and hepatitis C have been published (Astell-Burt et al, 2012; Butt et al, 2013). The findings from both these papers are described in Chapter 3. They were used to test the theories for non-attendance derived from the study (as per cycles 2 and 3), identifying factors that supported or contradicted the latter. This

discussion can be found in section 6.4 'Findings of the study compared with the literature'.

6.2.3 Cycle three - National electronic staff survey

A key objective of undertaking the survey was to test what similarities and differences were given as reasons for non-attendance between clients and staff and, thereby, to assess to what extent the findings from the interviews might be generalisable. There appeared to be many areas of agreement regarding reasons for non-attendance with those most frequently indicated by staff including ongoing drug use (and reporting of 'chaotic lifestyles'), forgetting the appointment, clients scared of the side-effects of hepatitis C treatment, and the cost of travel and difficulty with reimbursement of these expenses. There appeared to be few areas of disagreement about the reasons for non-attendance, although clients being in custody was reported more frequently by staff, and difficulty with walking due to 'bad' or 'sore legs' was given by a greater number of clients.

In summary, there were no items in the survey that were not ticked by at least some of the staff, suggesting that the findings from the interviews may be transferable to other outreach clinics in England.

6.2.4 Integration of cycles

In the absence of direct empirical evidence about the reasons for missed appointments by people with hepatitis C, initial ideas (theories) were developed from the literature mainly from related groups. These theories were tested via telephone interviews with clients who missed an appointment(s) with a local drug service hepatitis outreach clinic. The results from the client interviews were tested (identifying similarities and differences) in a national survey of staff running similar outreach clinics.

Following completion of the three cycles a new theoretical position has been reached. The next cycle will be the testing of interventions including those given in section 6.5.2 'Implications for service delivery'.

6.3 Strengths and limitations of the study

The strengths and limitations of the study are described following the steps of the research process. Thus, this section is comprised of the following sub-headings:

- Realism
- 'Hard to engage' in research
- Participant recall
- Researcher/clinician conflict
- Single site study
- Missing cycle of the study

6.3.1 Realism

Taking a 'realist' approach to investigate the reasons for non-attendance was a strength of the study in a number of ways. Firstly, the ontological and epistemological focus on seeking to understand the underlying causes of phenomena made it an ideal approach for uncovering the 'real' reasons for non-attendance beyond surface explanations, such as 'chaotic lifestyles'. These surface explanations tend to be used by staff and the public to blame individuals for missing appointments and tend to be associated with denial of the complex nature of non-attendance. As explanations they potentially offer little in the way of changing policy and service delivery to improve attendance because little can be done, for example, to undo the so-called chaos of people lives. In contrast, the realist approach taken in the study revealed the complex nature of non-attendance as participants were able to describe many hidden mechanisms for not turning up to appointments. These mechanisms were often linked to each other and played out in different ways.

Further, by drawing on Pawson's (1997) 'realist evaluation' used in social programmes, namely his 'context + mechanism = outcome' (CMO) configuration it was possible to identify the wider contextual factors in which mechanisms (factors) were triggered and resulted in non-attendance. Thus, the realist approach provided valuable insight into the wider factors

that may need to be addressed to improve attendance. Realist evaluation is aligned with the world of policy and practice, which also fitted in with the purpose of a work-based doctorate such as this (see 6.5 'Implications').

In addition, the realist approach made effective use of data and discussion beyond the study itself. This was made possible by undertaking a 'realist' review of the literature ('realist synthesis') (see Chapter 3 'Literature Review'). Thus, by using a combination of grey literature about hepatitis C and conventional peer-reviewed literature largely for related groups it was possible to develop many relevant theories about the reasons for missed appointments with the outreach clinic which were tested during the client interviews. Finally, a realist approach to interviewing (see Chapter 4 'Client Interviews' 4.2.3 'Data collection') enabled the researcher to uncover the reasons for non-attendance through sensitively probing the participants' responses with mutual clarification of what was being said and asked.

6.3.2 'Hard to engage' in research

A considerable amount of time was devoted to getting the methods of the study right. This was due to the challenges of undertaking a project with a group of people that were hard-to-reach in terms of the topic area and engagement in research. Particular attention was given to the qualitative element of the data collection (cycle two) including the use of telephone interviews and the development of the interview schedule. The input of ex-service users from the drug service (known as 'Ambassadors') was particularly valuable at this stage and was a strength of the study. The 'Ambassadors' were invited to make comments and suggestions about the proposed study and the draft documents (see Appendix 3 for the meeting notes). They fully endorsed the use of telephone interviews to gather data because the participants were likely to have been in a familiar environment e.g. their own home and felt more comfortable answering questions. Also, the participants were likely to have more control within the interview because they were not meeting the researcher face-to-face. In respect of the interview guide the 'Ambassadors' were in agreement that as well as asking

participants about their own reasons for not attending they were asked for factors why other people missed an appointment with the outreach clinic. This type of question provided participants with an opportunity to disclose other reasons that might otherwise have been too sensitive or difficult to give. This interviewing strategy could also be seen as a limitation because the study findings were unable to distinguish between what people said about themselves or other people. However, during the analysis there seemed to be little difference between answers to the two types of question anyway.

Remuneration of participants' time is considered by some to be a limitation of studies because it is seen as an inducement. The participants were remunerated for taking part in this study and were given a high street voucher for the sum of five pounds. Other researchers (Jeal and Salisbury, 2004; Neale et al, 2008) believe that remuneration of participant's time is appropriate and is one of the surest ways to obtain a satisfactory response in circumstances where participants might be hard-to-reach or to retain their participation. An interview typically lasted between 15 and 30 minutes with one lasting 45 minutes. Therefore it seemed reasonable to offer remuneration for taking up the participants' time.

A total of 28 clients completed telephone interviews, and this could be seen as a strength of the study. Similar to other studies (Coulson et al, 2009; Swarbrick et al, 2010; Feitsma et al, 2012) the use of telephone interviews appeared to overcome initial concerns about recruiting an adequate sample size. This figure represents a good size sample from a group of people excluded from services and who were arguably hard to engage in research.

6.3.3 Participant recall

Relying on clients recalling why they forgot an appointment with the outreach clinic up to one year ago (in some cases) could be seen as a limitation of the study. Further, in some interviews the participants might have given reasons for not keeping an appointment with the hospital clinic

or another agency rather than the hepatitis C outreach clinic. However, no more than two or three of the 28 participants initially had difficulty recalling missing an appointment with the outreach clinic, and these subsequently remembered with prompting. Also, where the participants did talk about the reasons for not keeping appointments in non-hepatitis C settings this was omitted from the findings. Despite the potential problems of participants recalling events about non-attendance with the outreach clinic and the need to recruit a sufficient number of participants there seemed to be no better alternative and this seemed to be the best approach given the challenges.

6.3.4 Researcher/clinician conflict

Some might argue that being a clinician and researcher was a limitation of the study largely based on a conflict between the two roles. This role conflict may have manifested itself in a number of ways. Firstly, participants may not have felt comfortable about disclosing some reasons for not keeping an appointment because they were unhappy about the service or quality of care they received. Secondly, there may be concerns that the reporting of the study findings may be biased in some way because the researcher has included his own views or opinions about non-attendance from his clinical experience or what he had read in the literature. However, in response to the first point it is worth noting that many of the participants knew the clinician or had heard of him and knew he would be interested in what they had to say even if it was negative comments about the service. Also, the researcher during the interview was testing theories which included negative aspects of service delivery. Thus, participants were invited to openly talk about their experiences of services whether they were 'good' or 'bad'. On the second point, the researcher recognised the importance of reflexivity early on in the study and actively used supervision sessions to help separate what was found in the study from clinical practice or the literature (see Chapter 2 'Methodology and Method' 2.7.3 'Reflexivity'). On reflection, being both a clinician and researcher was probably a strength of the study because of having

knowledge of the topic area, and having insight and empathy into people's experience of non-attendance.

6.3.5 Single site study

A limitation of the project might be that the interviews component was conducted in a single site with reasons for non-attendance given by two outreach clinics situated in just one city in the North of England. However, the study used mixed-methods with a quantitative survey (cycle three) sent electronically to all the DAATs throughout England. The survey was administered to test the findings from the client interviews to assess whether these had national applicability and whether they could be viewed with a wider lens. The survey findings overall seemed to suggest that the reasons for non-attendance in hepatitis C outreach clinics bore many similarities across the country. Although the response rate of 29% for the survey could be seen as a limiting factor, this figure compared favourably with other electronic surveys (Shih and Fan, 2009; Sheehan, 2001).

6.3.6 Missing cycle of the study

A further limitation of the project relates to there being no cycle between the client interviews and the staff survey. The problem with this is that the perspectives of staff could be different from the clients. Further, the local outreach clinic could be different from other clinics nationally. Thus, the study had not established if the views about the reasons for non-attendance held by staff in the local drug service were similar to the clients. Also, a national survey of clients had not been undertaken. This raises the prospect of two breaks in theory development and testing occurring between the interviews and survey

The reasons for this omission were primarily pragmatic, related to resources. This is a limitation of the study although it could be argued not overly serious as the local clinic is in many respects fairly typical of those provided nationally.

The next section sets the key findings of the study alongside the existing literature.

6.4 Findings of the study compared with the literature

Overall, the study revealed a complex picture for non-attendance in a hepatitis C outreach clinic. The next section (6.5) of this chapter will examine the implications for policy, service delivery, education and research. Before doing this, however, in keeping with a realist approach, this section of the chapter will examine how the study findings relate to the existing literature and what these mean for interventions to improve attendance. These are described under two headings:

- 'It's a little more complicated than that ...'
- '... so interventions need to reflect complexity.'

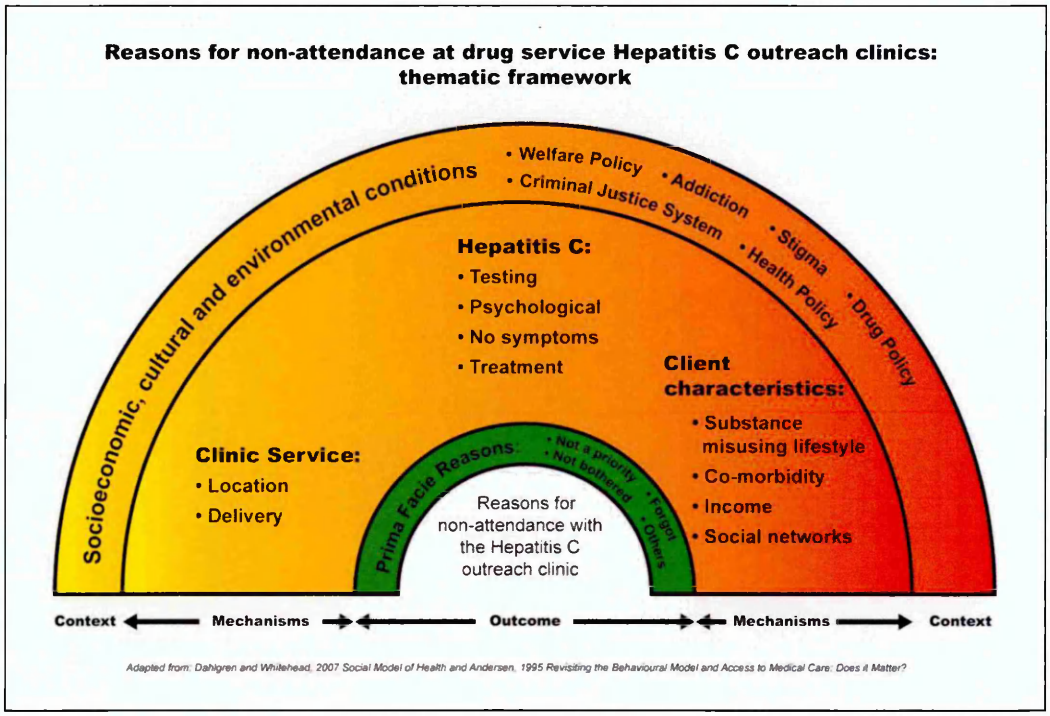
6.4.1 'It's a little more complicated than that ...'

All the participants gave surface or 'prima-facie' reasons including *'not a priority'* and *'forgot'*. The latter is a common explanation for missed appointments in the literature on hepatitis C (sometimes despite reminders) and other similar settings (Carrion et al, 1993; Sparr et al, 1993; Pieper and DiNardo, 1998; Killaspy et al, 2000; Neale et al, 2008; Coulson et al, 2009; Swarbrick et al, 2010; Agarwal et al, 2011; Feitsma et al, 2012; NHS Greater Glasgow and Clyde, 2012; Butt et al, 2013). Apart from memory loss due to advanced liver disease (Butt et al, 2013), which was not a factor in this study, there was a lack of information from the literature about what caused people to forget an appointment. This study revealed numerous different underlying mechanisms for non-attendance and forgetting. As well as the most frequently cited explanation *'multiple appointments'* with other agencies to remember and attend, other factors included using drugs, being homeless, being busy at work and looking after children.

Thus by taking a realist approach the study revealed the hidden underlying factors (mechanisms) beneath the surface. The mechanisms have been put under the themes: (i) *'client characteristics'* (ii) *'hepatitis C'* and (iii) *'clinic*

service' (see Figure 6.2 'Thematic framework'). The mechanisms were experienced differently by different participants, and they were often linked to each other. The mechanisms were always produced within a complex context of factors including addiction, welfare policy and stigma. These findings suggest that strategies to improve attendance need to take into account the array of factors for missed appointments and to address the wider determinants of health including access to services, rather than focusing solely or primarily on individual lifestyles and behaviour.

Figure 6.2 Thematic framework – reasons for non-attendance at drug service hepatitis C outreach clinics



The notions that individuals led a 'chaotic lifestyle' and that the infection is 'not a priority' for drug users are frequently used by staff and commentators to explain poor uptake of screening, lack of engagement with health services and treatment amongst drug users with hepatitis C (Irving et al, 2006; Parkes et al, 2006; Mravčík et al, 2013; SIGN, 2013). These were also spontaneous explanations given by staff surveyed in the present study. For the participants their *'priority'* was to 'score' drugs which was the most

frequently cited explanation for the theme a *'substance misusing lifestyle'*. It was necessary largely to avoid suffering the effects of *'withdrawal'* and may have taken longer than anticipated. In many interviews the participants arguably had well-ordered lives but the organisational focus was on getting drugs above all else. There was a similar finding in a qualitative study of IDUs investigating barriers to accessing health and social services (Neale et al, 2008). Drug users were anxious about experiencing withdrawal symptoms if they were kept waiting to be seen at an appointment. A study about improving access to services for drug users recommended not giving morning appointments to people because they will be experiencing withdrawal and will be preoccupied with obtaining drugs or a substitution drug treatment script (Neale et al, 2007). Giving morning appointments was a factor in this study but it was not simply caused by substance misuse and problems with withdrawal. For example, some of the participants got up late which may have been due to tiredness from medication prescribed to treat mental illness.

Unless health professionals working in hepatitis C have witnessed first-hand the problems of being addicted to drugs or alcohol or have worked in the substance misuse field it is quite likely that they will describe these lifestyles as 'chaotic'. This may be because they know some of the behaviours associated with a substance misusing lifestyle without appreciating the underlying mechanisms and contextual factors that cause these. Health professionals may not appreciate the powerful physiological influence of addiction as well as the cultural and social dimensions of using illicit substances. They may also hold stereotypical views about the reasons why people use drugs or alcohol. Health professionals may believe that it is a simple choice and easy to stop; and such beliefs can result in lack of empathy, stigma and blaming clients. Without this depth of understanding health professionals and services are likely to operate restrictive policies which perpetuate stigma, victim blaming and unequal access to care and treatment.

On the whole the description of a *'substance misusing lifestyle'* was one remembered by the clients rather than currently experienced by them. This was because most, if not all the participants were stable on a substitution treatment script with none having disclosed current drug use.

Again as a 'prima-facie' reason for non-attendance or other non-compliance it is often reported that drug users with hepatitis C are 'hard-to-reach' (Moriarty et al, 2001; Parkes et al, 2006; Bruggmann, 2012; Hepatitis C Trust, 2013). But this study adds insight to illustrate how, at least from the perspective of the clients themselves, it is services that are hard-to-reach not people. There were many reasons why the outreach clinic was hard-to-reach. Firstly, almost 30% of the participants suggested that the long *'distance'* to travel to the clinic contributed to it being a 'difficult journey'. This journey sometimes meant getting two buses which can cause problems. Some of the staff in this study indicated that the clinic being 'too far away' was a factor for non-attendance. In the literature for hepatitis C and related groups travelling to city centre locations was a problem, particularly for those living in rural areas relying on public transport (Hayter, 2005; Morrison et al, 2011; Butt et al, 2013). The mean travel time of 20 minutes to a specialist hepatitis C centre in Scotland was not a factor for non-attendance (Astell-Burt et al, 2012).

Secondly, the outreach clinic was typically held on a different day to the one for a substitution script (to add to the *'multiple appointments'* clients were expected to remember and attend with other agencies). This was itself a reason for non-attendance in this study given by both clients and staff as the latter would take priority for clients. The literature suggests that attendance for hepatitis C screening (and hepatitis B immunisation) is more likely to occur if linked to regular drug treatment service appointments (Agarwal et al, 2011).

Thirdly, the *'cost of travel'* and difficulties with *'reimbursement'* of travel expenses contributed to non-attendance. The costs of travelling to services

has been given as a reason for missed appointments in the hepatitis C literature and for related groups (Pieper and DiNardo, 1998; Booth and Bennett, 2004; Gariti et al, 2008; AIVL, 2010; Morrison et al, 2011; Feitsma et al, 2012; NHS Greater Glasgow and Clyde, 2012; Butt et al, 2013). Both the study findings and the literature in HIV (Morrison et al, 2011) identified the government welfare reforms resulting in reduced benefit payments as influencing the cost of getting to appointments. For hepatitis C patients the cost of travel is particularly a problem when appointments do not coincide with the patients benefit payments (NHS Greater Glasgow and Clyde, 2012).

The HIV literature also recognised the importance of reimbursement of travel expenses in relation to keeping an appointment; this was in turn, dependent on people knowing whether services offered it (Morrison et al, 2011). Although reimbursement was a factor in this study, the participants were generally aware of it being available in drug services but encountered problems with the procedure including having to provide a recent letter from the benefits agency. Further, the offer of reimbursement of travel is arguably meaningless if someone does not have the money to attend in the first place. These factors suggest that services do not make it easy for people to attend by creating lots of appointments for which they do not have the resources or money to attend.

Fourthly, the clinic was hard-to-reach due to factors relating to 'physical' and 'psychological co-morbidity'. Both mental and physical co-morbidity are associated with missed appointments in hepatitis C (Agarwal et al, 2011; NHS Greater Glasgow and Clyde, 2012; Butt et al, 2013). However, there was no description in this literature or, in the main, that for related groups about how co-morbidity contributed to non-attendance. The participants reported suffering from *'agoraphobia'* for example, a fear of leaving the house or meeting people, having panic attacks and staying in their own area to avoid the city and 'crowds'. The staff in the survey also indicated clients having mental health problems were a factor for non-attendance. In the HIV literature, drug and alcohol problems can result in psychoses which makes

clinic attendance difficult (Morrison et al, 2011). This was not a finding in this study.

In this study the participants had difficulty walking due to *'bad'* or *'sore legs'* which for some meant relying on a lift (and this may have only been available on a particular day) and being unable to keep a morning appointment (when one of the outreach clinics was held). In a study of patients with venous leg ulcers, some, largely drug users, reported being unable to attend due to being in pain, feeling unwell and feeling 'stressed' (Pieper and DiNardo, 1998). Although the staff in this study indicated that physical health problems were a factor for missed appointments, only one person raised the issue that clients had difficulty walking.

Finally, the clinic was arguably hard-to-reach in the minds of the participants because they had *'poor veins'* with the clinic being unable to get a diagnostic blood sample. For staff poor venous access was also a factor for non-attendance. This finding is supported in the hepatitis C literature on missed appointments with an additional mechanism of a fear of the procedure triggering drug misuse given (AIVL, 2010; Agarwal et al, 2011). However, this latter mechanism was not reported in this study. Thus, as well as the participants not wanting to know if they had hepatitis C because of the stigma it carried and believing treatment was not curative, testing also had practical difficulties.

These problems getting blood for a complete screening test have recently been addressed (both locally and for other parts of the country) with the availability of DBS (using a finger prick of blood) which are able to detect the presence of the virus (NICE, 2012c) (see 6.5.1 'Policy implications – *Increasing testing and diagnosis*'). However, if the result of the DBS test suggests natural clearance then a follow-up confirmatory blood sample should be performed. Also, for people with ongoing chronic infection blood tests will be required to assess the condition of the liver and the urgency of treatment. This implies that whilst many people may be a little clearer

about their diagnosis they may encounter difficulties being assessed for or commence treatment due to poor venous access and the inability of staff to obtain blood.

Symptoms appeared to be an important component of non-attendance for this study, both in terms of their presence (including those experienced in relation to co-morbidity above) and their absence. In respect of the former, the participants reported a fear of the *'side-effects'* of treatment contributing to missed appointments. The participants were put off keeping an appointment because they heard (often from within their own community) the treatment made people feel ill, that it caused prolonged tiredness and hair loss. Some of the participants described the treatment as "chemotherapy" and also likened it to drug withdrawal. Others were worried about the impact of the potential side-effects on their health and their ability to carry out daily activities (especially as they were not necessarily unwell before). This finding in relation to the *'side-effects'* of treatment was ranked by the staff as the third reason for non-attendance after ongoing drug use and forgot. The *'side-effects'* of treatment as a factor for non-attendance was also reported in the hepatitis C literature (NHS Greater Glasgow and Clyde, 2012; Butt et al, 2013). Within the 'self-protection' theme for missed appointments researchers in Canada found concerns relating to other people in a waiting room guessing a person's diagnosis because they were suffering from the side-effects of treatment (Butt et al, 2013). This perspective was also reported in this study.

People undergoing current treatment for hepatitis C will experience some side-effects including thinning of the hair, tiredness and a drop in blood count (amongst others). However, these are usually well managed with advice and support from a specialist nurse. Since undertaking this study, new treatment with improved rates of cure for patients with genotype (strain) one infection have been available and have been used throughout the country (NICE 2012a; NICE 2012b). Also, newer drugs have recently been licensed but are awaiting approval from NICE before they can be used

in the NHS (Jacobson et al, 2013; Lawitz et al, 2013; World Health Organisation [WHO], 2014). These recently licensed drugs are administered for a much shorter duration than current treatment, with improved rates of cure for all patients. Further, this treatment may be given without using pegylated interferon, and so avoiding its side-effects. The development of new drugs for hepatitis C with improved chances of cure and a future reduction in side-effects is one example where factors for non-attendance are not fixed and change over time. Other examples, which were given by the participants, may include relapse into substance misuse, homelessness, imprisonment and relationships with staff. Any interventions to improve attendance may be time limited.

Another mechanism that contributed to missing the outreach clinic appointment was the asymptomatic nature of hepatitis C or *'no symptoms'*. This was one of the key categories of the theme *'hepatitis C'*, and was a finding also given by staff. In the absence of experiencing signs of infection or liver disease some clients suggested it was reasonable to delay attending the clinic until symptoms developed or they started to be "sick". It was unclear what the clients meant by symptoms or being "sick" but perhaps they meant waiting for jaundice (yellowing of the eyes or skin) to develop or being in pain. The asymptomatic nature of infection contributing to missed appointments was described in the literature on non-attendance in hepatitis C and HIV (Martin, 2005; Morrison et al, 2011; Butt et al, 2013).

Hepatitis C is often referred to as the 'silent epidemic' and a 'silent killer' (Hirsch and Wright, 2000; DoH, 2004; Hepatitis C Trust, 2013). Infected individuals are often asymptomatic, with only 10% reporting symptoms associated with jaundice (Booth et al, 2001). About 75% of those exposed to the virus go on to develop chronic hepatitis (European Association for the Study of the Liver [EASL], 2014). Patients with chronic hepatitis C often have no symptoms but may complain of non-specific complaints, such as fatigue (the most common symptom), muscle aches, anorexia, upper right quadrant pain, and nausea (NICE, 2006). However, these symptoms may be

explained away and put down to lifestyle factors. Therefore, people may not seek medical attention. Symptoms and signs of chronic liver disease occur in the later stages of the disease (Booth et al, 2001). Also, some patients with advanced liver disease (cirrhosis) remain asymptomatic. Death may occur because of the complications of cirrhosis, at a rate of 4% per year, while 1-5% per year in this population will develop liver cancer (hepatocellular carcinoma [HCC]) (Afdhal, 2004). Curative treatment for hepatitis C is less successful if people have advanced liver disease or cirrhosis (Ramachandran et al, 2012). Thus, by not keeping an appointment because of an absence of symptoms clients run the risk of dying from the complications of cirrhosis and reduce their chances of undergoing successful treatment. Not only does this state of affairs leave a health burden for people living with hepatitis C but there will be an ongoing escalating cost to health services as they provide care for people with advanced liver disease whose only option might be a liver transplant.

Although largely due to beliefs about current treatment (being scared of the *'side-effects'* and believing it was not curative), the absence of symptoms of hepatitis C may also have helped some of the participants put the infection to the back of their mind or forget about it; categorised as *'denial'*. Thus, they did not attend an appointment in order to avoid being reminded of the infection. As well as concerns about treatment the participants wanted to put the infection to the back of their minds because they were scared of others knowing they were infected, and they were keen to avoid the negative effect of having hepatitis C on their mood (including feeling suicidal). Similarly in the setting of HIV, for those who struggle to come to terms with their diagnosis, attending can be a constant reminder of their infection (Morrison et al, 2011).

Buetow (2007) suggests (although without directly referring to empirical evidence) that patients may miss appointments to take control and protect themselves from information about a disease that is serious, chronic and stigmatising. Patients wish to remain individuals and not simply be known

as belonging to a marginalised group. Buetow (2007) proposes that people make a rational choice to miss appointments largely to protect themselves from services they consider threatening to their personal identity. This perspective appears to be supported by the participants in this study, which may be unsurprising since chronic hepatitis C can lead to serious liver problems and carries a stigma.

There is a considerable amount of literature on the stigma associated with hepatitis C which argue stigma may be largely due to its association with drug use (Paterson et al, 2007; Treloar and Rhodes, 2009; Stewart et al, 2012; Chen, 2013; Treloar et al, 2013). In this study on non-attendance the contextual factors stigma, addiction and the criminal justice system combined to cause the need to keep the infection hidden from others. However, stigma operates not just at an interpersonal level but also at a departmental/structural level, for example in the way that patients may not be involved in the development of services or the way guidance is interpreted which may exclude certain groups of patients (Paterson et al, 2007; Treloar and Rhodes, 2009; Chen, 2013).

The study findings have implications for the development of interventions to improve attendance. These implications are discussed in the following section.

6.4.2 '... So interventions need to reflect complexity'

To ensure interventions designed (and implemented) to improve attendance are effective they need to reflect the complexity of non-attendance shown in this study.

The initial and 'prima facie' reasons were unsatisfactory as explanations for missed appointments. Take the example of forgetting: we should wonder why someone without a neurological deficit should forget something that has the potential greatly to improve their quality and quantity of life. It should strike us as odd. This oddity is compounded by the literature that

showed forgetting as a cause of missed appointments even where reminders were sent (NHS Greater Glasgow and Clyde, 2012). A problem with these initial explanations is that they tend to leave us blaming the individuals: for example, we tend to blame people if they forget important things. They also leave us with limited options policy-wise; we cannot change people's memory or make them bothered to keep an appointment. For example, a phone reminder would not work if part of the mechanism behind forgetting an appointment was actually that it was not given priority given the complex pressures the person faces. Thus accepting these explanations at face value has important implications for policy, service delivery, education and research. And perhaps more importantly, not accepting the explanations at face value, in the light of this research has implications in the same areas. These are addressed in the next section.

6.5 Implications

This study was in part fulfilment for a professional doctorate and was a work-based project. Therefore it was important to consider the implications of the study findings on work-related issues. This section examines how the findings relate to current policy, service delivery and educational issues. These implications are presented separately in tabular form. Each table comprises of a brief outline of the 'problem(s)', followed by supporting and/or additional 'evidence' from the study findings and lastly a description of further possible interventions or 'fixes' to address the problem(s). This section of the discussion will finish with consideration of the implications for future research before describing dissemination of the findings.

6.5.1 Policy implications

There are four key policy areas to tackle hepatitis C infection (DoH, 2004; NICE, 2012c; Hepatitis C Trust, 2013; PHE, 2013a; WHO, 2014).
These are briefly described under the headings:

- The prevention of new infections
- Raising awareness of new infections
- Increasing testing and diagnosis

- Engaging infected individuals into care and treatment

The prevention of new infections

In the absence of a vaccine for hepatitis C, prevention of infection from the virus depends upon reducing the risk of exposure to it. In England, IDUs are at greatest risk of infection through the use of contaminated injection equipment. To reduce drug dependence and to stop people injecting, opiate substitution therapy (OST) e.g. methadone, is offered by specialist clinics and some GPs. For those who continue to inject, needle and syringe programmes (NSPs) based in drug services and pharmacies provide clean equipment. To minimise ongoing transmission these prevention measures need to be sustained and expanded.

It is argued that a combination of OST, NSPs and the treatment of IDUs with hepatitis C may reduce the incidence and prevalence of the infection (Martin et al, 2011).

Raising awareness of new infections

In England approximately 160,000 adults are chronically infected with hepatitis C, equating to 0.4% of the adult population (PHE, 2013a). By the end of 2011, approximately 95,000 individuals had been diagnosed with hepatitis C, suggesting a significant number of infections remain undiagnosed (NICE, 2012c). Many people are unaware of their infection because they are asymptomatic (PHE, 2013a). Activities aimed at health professionals and the public to raise awareness of infection need to continue and to increase to ensure that more people at risk of hepatitis C are screened and the number of undiagnosed infections reduced.

Increasing testing and diagnosis

In 2012, more than 80% of IDUs in England reported being tested for hepatitis C, with the levels of testing continuing to rise in this group (PHE, 2013a). However, this level of testing needs to be sustained among those attending drug services and improved within prisons. Also, the use of newer

technologies for testing e.g. DBS (finger prick) typically used in non-traditional settings should be expanded.

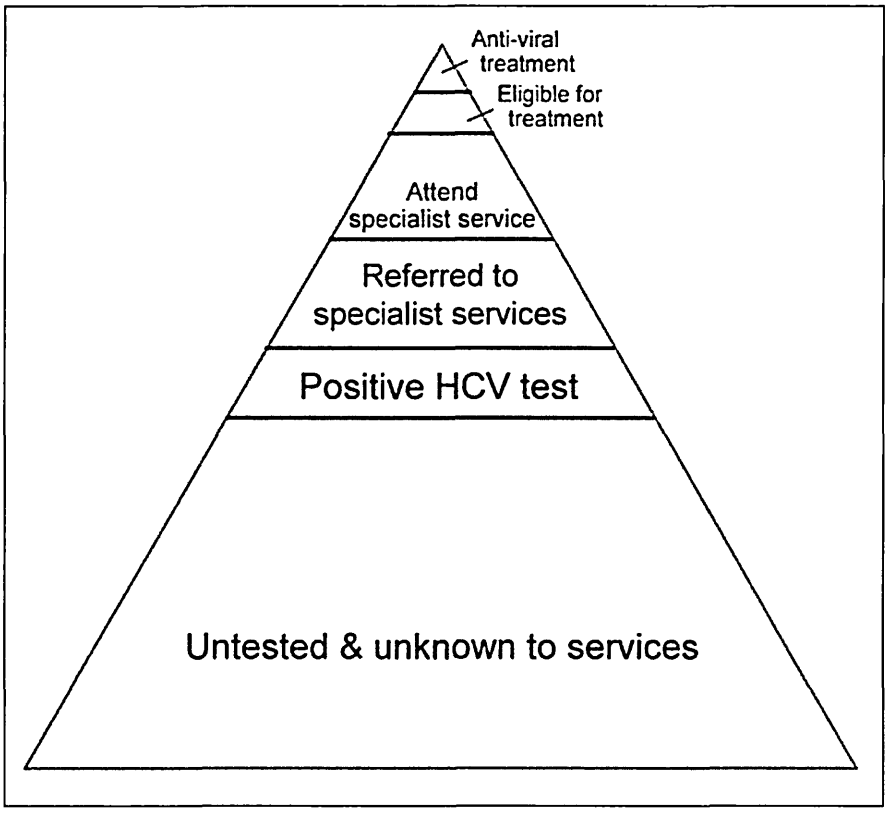
New NICE guidance (2012c) made the following recommendations for drug services:

- Ensure that staff have the knowledge and skills to promote testing and treatment.
- That they are also trained and competent to undertake pre- and post-test discussions and DBS (finger prick) testing (for people with poor venous access).
- Consideration given to training peer mentors and health champions to support this work; and
- The possibility of providing treatment in the community combined with OST, and facilitated by access to specialist phlebotomy services.

Engaging infected individuals into care and treatment

Individuals with chronic hepatitis C should be referred for specialist care and treatment (DoH, 2002). However, many people do not engage with mainstream health services and remain untreated (see Figure 6.3) (Parkes et al, 2006; Maghlaoui, 2012). In England, an estimated 27,500 patients were treated between 2006 and 2011 as per NICE guidance (PHE, 2013a). This equates to treating approximately 3% of those chronically infected per year. A strategy to increase the uptake of treatment has been to provide it in non-traditional settings such as prisons, drug misuse services and health centres. This provision has been somewhat limited with expansion recommended.

Figure 6.3 The disease iceberg for Hepatitis C (reproduced from Parkes et al, 2006)



Each of these policy areas are now considered in light of the study findings with possible 'fixes' identified (see Table 6.1).

Table 6.1 Policy implications (continued overleaf)

Problem	**Evidence**	**Fixes**
Prevent new infections.	• It was a *'difficult journey'* to the drug treatment clinic largely because of the *'distance'* and having to change buses and *'rely on a lift'*. • High *'cost of travel'* and problems with *'reimbursement'* of travel expenses. • Struggle to keep morning appointments. • Other commitments including *'work'* and looking after *'children'*. • Disliked sitting in waiting room at drug clinic with other clients who might still be using drugs (or alcohol). • *'Forgot'* appointment which was linked to other factors including having *'multiple appointments'* to keep and having to prioritise which to attend.	• Expansion of GPs and satellite clinics to provide OST and NSPs. • Services need to be sympathetic and understanding towards clients who may be using public transport and running late for an appointment. The service should try to accommodate them and not turn them away but do so without affecting the appointments of other patients who have arrived on time. • Make reimbursement of travel expenses more user-friendly or provide clients with bus passes. • Provide more appointments in the afternoon. Extend opening hours to evenings and weekends. • Preventive measures tied into existing appointments e.g. NSPs provided in drug treatment clinics.
Raising awareness of new infections.	• The asymptomatic nature of hepatitis C and delayed attending until developed symptoms or became 'sick'. • Scared about testing positive for hepatitis C because: not wanting other people to know about the infection; and did not believe the treatment was curative and *'going to die'* anyway.	Any future activities to raise awareness of the infection needs to address: • The asymptomatic nature of hepatitis C and to avoid delay attending for care and treatment; • The stigma of hepatitis C; and • The effectiveness of treatment.

Table 6.1 Policy implications (continued overleaf)

Problem	**Evidence**	**Fixes**
Increasing testing and diagnosis.	• As well not knowing that treatment was curative, participants believed it was *'not available'*, were fearful of the *'side-effects'* and reported there too *'many appointments'* before starting it. Although there were leaflets about testing there were none about treatment. Also, it would be helpful to speak with someone who has been through treatment. • *'Poor veins'* with staff making several attempts to get a blood sample often without success. Also, an alternative oral swab may have been used which could only detect antibodies and not the virus. Therefore, the diagnosis was unclear. • Expected to attend the outreach clinic on a *'different appointment'* to the one for a script.	• Ensure staff have the knowledge about the treatment side-effects and how they are managed. Also, they should be able to explain the importance of the need for thorough preparation before starting treatment which may involve clients having several appointments. • Provide leaflets in support of verbal information. A leaflet about treatment is shortly to be written by the local specialist hospital clinic. It will incorporate information about: the importance of completing a liver assessment (and not waiting for symptoms to develop) to assess the urgency of treatment (which could be deferred until interferon-free treatment becomes available with no interferon-induced side-effects) and the significance of starting treatment before the development of advanced liver disease (which reduces the effectiveness of treatment); and the number of appointments needed before starting treatment (which may be greater for people who need to make 'lifestyle' changes first e.g. reduce their alcohol intake). The treatment pathway may be illustrated with a flowchart. Also, these appear to be complex messages and research into the nature of these and how they need to be conveyed may be required (see 6.5.4 'Research implications').

Table 6.1 Policy implications (continued)

Problem	**Evidence**	**Fixes**
Engaging infected individuals into care and treatment – expansion of treatment provision in non-traditional settings such as prisons, drug misuse services and health centres.	• There were many factors given for non-attendance with the hepatitis C outreach clinics relevant to this problem. See under 'Prevent new infections' and 'Increasing testing and diagnosis'. • A further reason for non-attendance was because it was *'not hospital'*. It was preferable to go to the hospital because it meant not having to explain that going to drug clinic etc. Also, some participant's did not want other clients at the drug service to know they had hepatitis C.	• See under 'Prevent new infections' and 'Increasing testing and diagnosis'. • Train the staff working in the drug clinic to deliver and monitor treatment with supervision from the hospital hepatitis C clinic. • Ensure 'fixes' to improve engagement with the outreach clinic are applied to the hospital clinic to ensure equitable access to both treatment sites.

6.5.2 Implications for service delivery

Some of the findings of this study have been used to inform changes to service delivery. The study findings will also be used to shape future developments of the service. These are described in Table 6.2.

Table 6.2 Implications for service delivery (continued overleaf)

Problem	**Evidence**	**Fixes**
Limited usefulness of text or telephone reminders in this setting.	See Table 6.1 'Policy implications' and *'Prevent new infections'*. Other reasons given for forgetting an appointment (with few reporting suffering from a poor memory).	• A text or telephone reminder needs to offer an added purpose or incentive for the individual to keep an appointment. This added purpose could entail providing concise and clear messages about hepatitis C taken from the study findings e.g. the asymptomatic nature of hepatitis C, treatment effectiveness and the management of the side-effects, where these might be useful. This area relating to telephone reminders could be a topic for future research and is addressed later (see 6.5.4 'Research implications'). • One local example of incentivising an appointment for hepatitis C is for patients who receive a telephone reminder an abdominal ultrasound scan is arranged on the day of the hospital clinic appointment. This service has been very well received by patients largely because it is one less appointment to attend and they get the result of the scan on the same appointment. • A similar strategy has recently been implemented for the Fibroscan® test (a non-invasive scan using sound waves to measure liver stiffness – a surrogate marker for scarring (fibrosis) of the liver). Following discussion with colleagues in Hepatology (the department specialising in liver conditions) staff ring on the day to see if a Fibroscan® slot is vacant which could be used by a patient attending the hepatitis C clinic. These new ways of working will need to be evaluated in due course (see 6.5.4 'Research implications'). • An incentive for the outreach clinic could be to provide the initial assessment including blood samples and a Fibroscan® test, and future treatment in this setting (and not just at the hospital clinic). This development may result in clients having one appointment at the hospital hepatitis C clinic for an ultrasound scan and to discuss all the results with a doctor, with all other appointments at the drug clinic. Work is currently under way to develop a business case for this community treatment pilot project and this will be informed by some of the study findings.

Table 6.2 Implications for service delivery (continued)

Problem	**Evidence**	**Fixes**
The outreach clinic appointment does not coincide with the one for a substitution drug treatment script.	See Table 6.1 'Policy implications' and *'Increasing testing and diagnosis'.*	Whilst undertaking the study some staff have arranged for the outreach clinic appointment to coincide with a script appointment. But for some clients this has meant seeing a different member of the drug clinic staff on a different day and has the potential to cause some dissatisfaction. Thus, an evaluation of this new way of working will need to obtain some qualitative feedback and not solely a comparison of attendance rates (see 6.5.4 'Research implications').
Getting to the outreach clinic.	See Table 6.1 'Policy implications' and *'Prevent new infections'.*	See Table 6.1 'Policy implications' and *'Prevent new infections'.*
Difficulty obtaining blood samples.	See Table 6.1 'Policy implications' and *'Increasing testing and diagnosis'.*	Whilst undertaking this study a training pack written by the researcher for nurses to obtain blood from the neck (the jugular vein) of patients has been written and ratified by the Nursing Executive of the hospital Trust. This was an original piece of work which extends the role of nurses taking blood from patients. The patients have reported a high level of satisfaction with this intervention, especially those individuals on treatment who require frequent blood tests to monitor their progress.
Clients' drug and alcohol use.	The theme a 'substance misusing lifestyle' comprised of several mechanisms or factors for non-attendance. See also Table 6.1 'Policy implications' and *'Prevent new infections'.*	• See Table 6.1 'Policy implications' and *'Prevent new infections'.* • It is important for the hepatitis C clinic to maintain effective working partnerships with drug services and agencies representing the criminal justice system. Locally staff from these agencies have accompanied clients to appointments with the outreach and hospital clinic.

6.5.3 Implications for education

Some of these current and future service developments had or will have an educational focus (see Table 6.3).

Table 6.3 Implications for education

Problem	**Evidence**	**Fixes**
Lack of information about the hepatitis outreach clinic.	The participants did not know what the outreach clinic was for or who ran it.	• A leaflet titled 'Hepatitis Outreach Clinic' was produced by the researcher in collaboration with staff and a former drug user of the drug service. The latter suggested that a paragraph about confidentiality needed to be included. This issue and other findings from the study were added. Copies of the leaflet (see Appendix 15) have been given to the drug service for distributing amongst their clients and is available from the link: http://nww.sth.nhs.uk/STHcontDocs/STH_PIM/CommunicableDiseases/InfectiousDiseases/pil2810.pdf • The information contained in the 'Hepatitis Outreach Clinic' leaflet (with some additional material based on the study findings e.g. the asymptomatic nature of hepatitis C) was also provided on television screens in the waiting rooms of both drug clinics.
Lack of information given at the hospital hepatitis C clinic about reimbursement of travel expenses.	See Table 6.1 'Policy implications' and *'Prevent new infections'.*	Information about reimbursement of travel expenses has been added to the hospital clinic appointment letter and the 'Welcome to the Hepatitis Clinic' leaflet (see Appendix 16 and 17). Other revisions were made to the leaflet based on the study findings including addressing the fear of having a liver biopsy by providing information about the Fibroscan® test (which is a non-invasive scan for measuring liver stiffness). A copy of the clinic leaflet has been distributed to the drug services, and can be accessed on the link: http://nww.sth.nhs.uk/STHcontDocs/STH_PIM/CommunicableDiseases/InfectiousDiseases/pil904.pdf
Staff misperceptions about a 'substance misusing lifestyle' which blame patients for non-attendance.	See Table 6.2 'Implications for service delivery' and *'Substance misusing lifestyle'.*	The study findings will be used in educational sessions within the hospital Trust and elsewhere to better inform colleagues. Also, the findings will be disseminated widely (see 6.6 'Dissemination').

6.5.4 Research implications

The study findings presented some implications for research, and these are now outlined.

A number of existing and possible new service developments described under 6.5.2 'Implications for service delivery' will need evaluating. The type of evaluation and the cost of this will depend on the research question being asked. Some projects require a theory-led approach using realist evaluation and mixed-methods (similar to this study). This type of project may be expensive. In contrast other projects may have a largely practical application with a single intervention being measured against a control group, e.g. a RCT. This methodology is relatively cheap, and may be used to evaluate the effectiveness of initiatives such as text or telephone reminders. However, Bonell et al (2012) suggest that 'realist RCTs' can in their own right contribute to a realist approach to evaluation.

Some initiatives will also require a cost benefit analysis where additional resource is involved (and particularly where this may be controversial and previously untested). For example, the provision of bus passes for patients on treatment expected to regularly attend the clinic for monitoring lasting up to six months (in anticipation of using newer drugs currently awaiting approval by NICE). The additional cost for a bus pass and successfully treating patients will need to be measured against not treating patients and the costs of managing advanced liver disease. This type of research project is more expensive and would probably need a realist evaluation using the 'CMO' configuration.

As part of the preparatory work for the business case for community treatment in the drug service clients under the care of one of the local drug treatment clinics are being invited to complete a short survey (see Appendix 18). The survey is seeking their preference for where they would like to have treatment and to give reasons for their chosen option. At present all the patients have indicated a preference to have treatment at the drug clinic,

because it is easier to get to and park, and is where they get support about issues relating to substance misuse.

With regards to treatment there appear to be at least two further implications for research. The first relates to devising a leaflet about treatment for which there is much complex information including other aspects of hepatitis C such as the different strains (genotypes) and results of scans and blood tests; patients appear to struggle to understand and remember what they have been told. There has been some discussion within the hospital hepatitis C service about producing a booklet for patients to write in their own test results and the outcome of their clinic appointments. It would seem appropriate to undertake qualitative research into the complexity of information relating to hepatitis C and how best this might be conveyed to patients before producing any materials. A second piece of research in this area could be a mixed-method longitudinal study comparing patients given treatment versus those being monitored. In addition to quantifiable measures such as patient characteristics including measures of liver disease, the patient experience within each group could be captured using interviews and/or focus groups.

Finally, on the issue of complexity, this study revealed many reasons for non-attendance which were played out in different ways. A further piece of research could be undertaken similar to the survey in this study to quantify the key reasons for non-attendance. With the key factors identified the cost of initiatives to reduce non-attendance could then be worked out.

In summary, the findings of the study have resulted in several implications relating to policy, service delivery, education and research. Some of these implications have already been actioned whilst others are in progress or for the future.

6.6 Dissemination

The study findings and implications will be shared with clinicians, managers, participants and patients, through presentations, posters and publications. At present:

- A poster of some of the findings was presented at the Royal College of Nursing (RCN) International Research Conference in Glasgow 2-4 April 2014 (see Appendix 19);
- A book chapter about the application of some of the preliminary findings to a piece of recent guidance about hepatitis C (and B) testing has been recently published (Poll, 2014) (see Appendix 20);
- An oral presentation about the study was given at the Sheffield Hallam University Faculty of Health and Wellbeing Research Day on Wednesday 4 June 2014 (see Appendix 21); and
- A poster focusing on the methodology of the study accepted for the Centre for Advancement in Realist Evaluation and Synthesis (CARES) Conference in Liverpool 27-30 October 2014.

Conclusion

Prior to this study, several suggestions had been made about why patients with hepatitis C miss appointments. These included: relapsing substance misuse; low socioeconomic status; co-morbid mental illness; lack of social support; a poor understanding of the implications of a positive test result; negative perceptions of liver biopsy and treatment; and imprisonment (Jowett et al, 2001). In more general terms 'surface' reasons such as leading a 'chaotic lifestyle', forgetting, being 'hard-to-reach' and the infection is 'not a priority' to people have been given as explanations (Moriarty et al, 2001; Irving et al, 2006; Parkes et al, 2006; Agarwal et al, 2011; Hepatitis C Trust, 2013; Mravčík et al, 2013, SIGN, 2013). Not only is it hard to understand why people (without mental incapacity) would forget or not prioritise keeping an appointment for potentially life-saving treatment but these 'surface' explanations tend to blame individuals for not turning up. This in turn may permit services to avoid taking some ownership of the problem or putting in strategies to reduce non-attendance which have little impact. Thus, it was important to investigate beneath the 'surface' reasons for non-attendance. This was achieved by taking a realist approach.

This study drew on Bhaskar's depth of causation ('critical realism') and Pawson's 'context + mechanism = outcome' (CMO) configuration ('realist evaluation') (Collier, 1994; Pawson, 2013). Thus, the reasons or mechanisms for missed appointments are not directly observed but were hidden within Bhaskar's three layers of reality (Collier, 1994). Further, Pawson's CMO configuration was used to help identify the wider contextual factors in which mechanisms were triggered and resulted in non-attendance. The scientific process under realism is one in which theories are developed, tested and better ones adopted.

This study comprised of three cycles of theory development and testing. In the absence of empirical evidence about reasons for non-attendance in hepatitis C a realist review of the literature ('realist synthesis') incorporating papers from related groups such as those in substance misuse and mental

health was completed. This resulted in 34 theories about missed appointments which were tested during the qualitative telephone interviews with clients. Two papers about non-attendance and hepatitis C published after the study (Astell-Burt et al, 2012; Butt et al, 2013) were compared with the findings (see Chapter 6 'Discussion' - 6.4 'Findings of the study compared with the literature'). There were several reasons why the interviews were undertaken by telephone rather than face-to-face. These included: the nature of the research topic meant participants may not turn up for an interview; most of the clients, like most of the general population, were regular users of mobile and land-line phones and so familiar and comfortable with them; and the relative anonymity of telephone interviews, lack of face-to-face contact and the establishment of confidentiality may enable participants to talk honestly and openly about their experiences (Carr and Worth, 2001). Again, drawing on the work of Pawson, a realist (theory-led) approach to interviewing was taken (Pawson, 1996). Whilst the participants were encouraged to give their own reasons for missed appointments the interviewer sensitively probed their responses where needed and invited them to comment on theories from the literature or given by others. The findings of the interviews informed the questions in the quantitative national survey sent to staff working in other outreach clinics. This was undertaken to test if the findings were transferable to other clinics.

All 28 clients gave surface or 'prima-facie' reasons for non-attendance including 'not a priority' and 'forgot'. Other hidden underlying mechanisms were uncovered including those that influenced these 'prima-facie' reasons. The clients typically gave multiple mechanisms for not keeping an appointment. These were categorised under the themes: (i) 'client characteristics' e.g. 'priority' to score drugs and the 'cost of travel' (ii) 'hepatitis C' e.g. 'no symptoms' and fear of treatment 'side-effects' (iii) 'clinic service' e.g. 'distance' to the clinic and difficulty with 'reimbursement' of travel expenses. The mechanisms were produced within a complex 'context' of factors including addiction, welfare policy and stigma, and were often played out in different ways and linked to other mechanisms.

A framework was developed from the themes (see Chapter 6 'Discussion' 6.4.1 It's a little more complicated than that ...' Figure 6.2). The thematic framework is underpinned by two theories; the social model of health (Dahlgren and Whitehead, 1993) and a model of access to medical care (Andersen, 1995). To explain the complexity of the reasons for non-attendance at hepatitis C outreach clinics this study conceptualises the themes as a rainbow. The rainbow depicts layers of influencing mechanisms (and contexts) for non-attendance. These reflect the layers of social determinants that Dahlgren and Whitehead (1993) propose influence health. Some of the themes within the thematic framework (and sub-themes within the full schematic schema see Chapter 4 'Client Interviews' Table 4.2) were drawn from Andersen's (1995) model of access to medical care. Following completion of the survey of staff there appeared to be general agreement about the reasons for non-attendance.

The study uncovered that participants 'forgot' to attend due to having multiple appointments with other agencies to keep. In addition, the 'cost of travel' and difficulties with 'reimbursement' of travel expenses contributed to non-attendance. Influencing the cost of getting to appointments was the government welfare reforms resulting in reduced benefit payments (DWP, 2014). Also, rather than being 'chaotic' the participants were 'busy' and seemingly organised, with other priorities including the need to score drugs (and drink alcohol) to avoid 'withdrawal'. The latter may have taken longer than anticipated.

Now there appeared to be some sense of the 'real' reasons for missed appointments. With this depth of understanding there were several implications for policy, service delivery, education and research. These included: acknowledging that telephone or text reminders may have limited use; needing to make the best use of appointments e.g. arranging scans on the same day; tying appointments in with substitution treatment scripts; making reimbursement easier or providing bus passes; educating staff about the 'real' reasons for missed appointments including those within a

'substance misusing lifestyle'; and evaluating interventions to improve attendance.

Overall, the study makes an original contribution to knowledge about missed appointments. It revealed a complex picture for non-attendance in a hepatitis C outreach clinic. This has important implications for policy, service delivery, education and research. It has shown the usefulness of a realist approach to a complex clinical problem.

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Appendices

Appendix 1: Permission letter – The three domains of the real (Diagram in Mingers, 2002)

From: John Mingers [mailto:J.Mingers@kent.ac.uk]
Sent: 26 March 2014 12:33
To: Poll, Ray (Infectious Diseases)
Subject: Re: PERMISSION LETTER

Yes that if fine. Glad you found it useful
John

Sent from Samsung Mobile

-------- Original message --------
From: Ray.Poll@sth.nhs.uk
Date: 26/03/2014 11:52 (GMT+00:00)
To: John Mingers <J.Mingers@kent.ac.uk>
Subject: FW: PERMISSION LETTER

Dear Professor Mingers

My initial e-mail was returned. Please see below.

Kind regards

Ray Poll
(0114) 271 1776

From: Poll, Ray (Infectious Diseases)
Sent: 26 March 2014 11:50
To: 'j.mingers@warwick.ac.uk'
Subject: PERMISSION LETTER

Dear Professor Mingers

I am writing to you to request permission to reproduce the materials detailed below.

Figure 1. The Three Domains of the Real on page 299 Mingers, John (2002) *Real-izing Information Systems: Critical Realism as an Underpinning Philosophy for Information Systems.* ICIS 2002 Proceedings. Paper 27. http://aisel.aisnet.org/icis2002/27

I have included the above in my thesis as permitted by the Copyright, Designs and Patents Act, 1988 32(3).

I would now like to deposit my thesis in an open repository which will be published on the internet and I am seeking your permission to include the material noted above.

I would be grateful for your permission to use your material as indicated.

Yours sincerely,

Ray Poll
Nurse Consultant for Viral Hepatitis

Appendix 2: Permission letter – The realist evaluation cycle (Diagram in Pawson and Tilley, 1997 page 85)

Dear Mr Ray Poll,
Thank you for your email.

Please consider this email as written permission to include figure 4.2 from our publication *Realistic Evaluation* as part of your thesis, to deposit on your institutional repository.

Please note:
This permission doesn't cover any 3rd party material found in the work.
The author needs to be informed of this reuse.
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Best Wishes,

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Appendix 3: User involvement meeting notes

Meeting: Research project consultation with the DAAT Ambassadors

Friday 4 November 2011
2.15-3.30 pm
Ground Floor Meeting Room, New Bank House, 100 Queen Street,
Sheffield S1 2WA

In attendance: Ray Poll (researcher), David and Sarah

Ray introduced himself, and thanked the Ambassadors for attending. They agreed for their first names to be used in this meeting summary and for it to be shared with Magda Boo (DAAT Commissioning Manager) and the researcher's supervisory team from the University.

Using the flip-chart he provided an overview of the research project and explained why it matters both to those affected by hepatitis C and to services providing care and treatment.

As per agenda David and Sarah were invited to comment on the following:

Participant information leaflet

5. Expenses and payments.
Sarah felt the opening sentence was a bit harsh and agreed to rephrasing along the lines, "Unfortunately we are unable to pay you for taking part in the study" etc.

6. What will I have to do?
Following discussion about the contact details sheet and concerns about confidentiality and safe-keeping of the form it was agreed to add, "This contact details sheet will be placed securely in the researcher's work pigeon-hole".

10. Will my taking part in this study be kept confidential?
David commented that the only time a conversation of his had been recorded is an interview with the police. Discussion followed about whether to use the phrase 'destroying' the recordings rather than 'erase'. Ray suggested that the word 'erase' was more accurate and this was accepted.

11. What will happen to the results of the research study?
Following prompting by Ray both Ambassadors agreed that this section should include a statement, "At the end of the interview you will be asked if you want a copy of the research report".

Contact details sheet
See above 6. What will I have to do? In addition, Sarah commented that some potential participants may not have phones. Ray added that phones

may be lost or stolen. For these reasons (and others) some eligible clients will be unable to participate.

Consent forms and reimbursement
Both Ambassadors had no issues with these, including the researcher signing the consent on behalf of the participant for the telephone interview.

The acceptability of telephone interviews
Whilst presenting an overview of the project Ray explained the reasons for undertaking telephone interviews versus other methods to answer the question. The Ambassadors were in full agreement that this was an acceptable and appropriate approach. David added that the participants would be in their own environment i.e. at home and feel more comfortable about answering questions. Sarah indicated that the participants would have a sense of being in control because they would not have to meet the researcher face-to-face.

Interview Guide
Overall the Ambassadors were happy with this. David agreed that the first question asking about why 'other' people miss appointments may help participants to feel relaxed and disclose their own personal reasons later. Sarah added that the participant may in fact be talking about themselves by responding to this question. Ray considered whether to ask participants if the reason(s) given why other people missed appointments could apply to them personally.

Sarah commented that the questions seem to focus on the individual and their lifestyle and omitted the clinic environment e.g. waiting room, attitude of staff etc. She offered that some people miss appointments because their first experience of a clinic (not necessarily for hepatitis C) was poor. The interview guide does include the prompt: 'Had you had or heard of any negative experiences of the clinic' but perhaps this needs to be a question in its own right, and to be inclusive of negative experiences of other clinics?

Other ideas for finding more answers to the research question
Ray invited the Ambassadors to suggest additional ways he might capture more information about the reasons for clients missing appointments. They suggested 3 possible options:

- workers at both drug services invite clients to give written responses anonymously to a couple of questions including how to improve attendance
- invite the local hepatitis C support group to give their views about non-attendance and how to improve it
- run a session at both drug services for clients to attend and to give their views

With all 3 options respondents could be invited to participate in the telephone interviews; however it would not be possible to confirm their eligibility because their replies would be anonymous.

Other points raised

During the meeting a couple of points were raised by the Ambassadors which had relevance to the project. These were:

- When clients first attend the drug treatment service (or re-engage, after having relapsed and been discharged) the priority is for them not to use drugs and to be on a regular script of substitution treatment before addressing the issue of hepatitis C. Ray explained that when the outreach clinics were set up this approach was agreed with both drug services. At the same time there was agreement that the risk of hepatitis C and the consequences for those infected should not be unduly delayed and needs to be addressed at the earliest opportunity. For the project it would be helpful to know how long the participant had been in drug treatment for that particular episode, which could be retrieved from their records.

- On the issue of improving attendance it was suggested that telephone reminders might be helpful and running the outreach clinic in conjunction with the routine appointment with the drug service. Ray telephones new patients for the hospital clinic (with some improvement in attendance) and on a few occasions (not consistently) clients with an appointment for the outreach clinic have been telephoned or sent a text by drug service staff. However, the latter has not been evaluated with insufficient numbers being telephoned. In addition, clients have been given a joint appointment for the outreach clinic and with a doctor to review and obtain their script. However, the outreach clinic only runs once a fortnight (morning or afternoon) and the opportunity for joint appointments is severely limited.

Both Ambassadors when asked said they would like a copy of the research report. They also agreed to be contacted at a later date via the DAAT should any further consultation about the project be needed.

The Ambassadors were given the opportunity to review a first draft of this summary and confirmed that it was a true and accurate reflection of the meeting.

RPoll
5Nov2011

Appendix 4: Post telephone interview reflections form

Interview number, date and time:
Background of the participant i.e. age, gender etc
Environment – (e.g. where was the participant, was it conducive to conduct the interview, any background noise etc)
How well did the interview go? (e.g. Did the participant talk freely, were they disturbed, sound relaxed/stressed or uncomfortable etc)
What could I have done better? (e.g. did I ask all questions, notice and follow cues, interrupt or not allow time for participant to think and speak at their pace etc)
Did anything new come up?
Any other comments?

Appendix 5: Permission letter – The main determinants of health (Diagram in Dahlgren and Whitehead, 1993)

Dear Ray

I am really sorry that the permission request was not responded to more quickly.

As I mentioned on the phone, the situation with this diagram is somewhat complicated as there are several versions of it. What the authors have requested is that the attached version is used, with the source given as 'Dahlgren and Whitehead 1993' and the full reference cited in the reference list as follows:

Dahlgren G, Whitehead M (1993). Tackling inequalities in health: what can we learn from what has been tried? Working paper prepared for The King's Fund International Seminar on Tackling Inequalities in Health, September 1993, Ditchley Park, Oxfordshire. London: The King's Fund. Accessible in: Dahlgren G, Whitehead M (2007). European strategies for tackling social inequities in health: Levelling up Part 2. Copenhagen: WHO Regional office for Europe: http://www.euro.who.int/__data/assets/pdf_file/0018/103824/E89384.pdf.

Many thanks.

Mary Jean Pritchard

Mary Jean Pritchard
Publishing Manager
The King's Fund

Telephone: 020 7307 2589
Email: mj.pritchard@kingsfund.org.uk
Website: www.kingsfund.org.uk
The King's Fund, 11-13 Cavendish Square, London W1G 0AN
Registered charity 1126980

Appendix 6: Literature review search strategy

Topic=(non-attend* or fail* to attend or miss* appointment* or non-engag*) NOT Topic=(endoscop* or diabet* or cervical or mammography or breast or neurolog* or dental or paediatric* or dermatolog* or cardi* or cancer or endocrin* or asthma or urolog* or orthopaedics or tuberculosis or ophthalmolog*)
Refined By: [excluding] Subject Areas=(FORESTRY OR PUBLIC ENVIRONMENTAL OCCUPATIONAL HEALTH OR CARDIOVASCULAR SYSTEM CARDIOLOGY OR MATHEMATICAL METHODS IN SOCIAL SCIENCES OR RELIGION OR PARASITOLOGY OR PEDIATRICS OR TRANSPLANTATION OR SCIENCE TECHNOLOGY OTHER TOPICS OR NEUROSCIENCES NEUROLOGY OR RADIOLOGY NUCLEAR MEDICINE MEDICAL IMAGING OR UROLOGY NEPHROLOGY OR ACOUSTICS OR AGRICULTURE OR BUSINESS ECONOMICS OR ART OR SURGERY OR CHEMISTRY OR OPHTHALMOLOGY OR BIOCHEMISTRY MOLECULAR BIOLOGY OR CONSTRUCTION BUILDING TECHNOLOGY OR ENTOMOLOGY OR LINGUISTICS OR DENTISTRY ORAL SURGERY MEDICINE OR ENDOCRINOLOGY METABOLISM OR LITERATURE OR COMPUTER SCIENCE OR GENETICS HEREDITY OR MATHEMATICS OR OBSTETRICS GYNECOLOGY OR MUSIC OR RESPIRATORY SYSTEM OR NUTRITION DIETETICS OR VETERINARY SCIENCES OR ONCOLOGY OR ZOOLOGY OR GERIATRICS GERONTOLOGY OR OPERATIONS RESEARCH MANAGEMENT SCIENCE OR ASIAN STUDIES OR RHEUMATOLOGY OR CELL BIOLOGY OR SPORT SCIENCES OR ENERGY FUELS OR GOVERNMENT LAW OR EVOLUTIONARY BIOLOGY OR ENGINEERING OR ALLERGY OR GEOCHEMISTRY GEOPHYSICS OR ANESTHESIOLOGY OR HISTORY OR ANTHROPOLOGY OR METEOROLOGY ATMOSPHERIC SCIENCES OR ORTHOPEDICS OR MINERALOGY OR RESEARCH EXPERIMENTAL MEDICINE OR BIOPHYSICS OR ENVIRONMENTAL SCIENCES ECOLOGY OR DERMATOLOGY OR OTORHINOLARYNGOLOGY) AND [excluding] Languages=(SPANISH OR GERMAN OR JAPANESE OR FRENCH) AND [excluding] Countries/Territories=(SOUTH KOREA OR ETHIOPIA OR BRAZIL OR GAMBIA OR SAUDI ARABIA OR MOZAMBIQUE OR SOUTH AFRICA OR ISRAEL OR NEPAL OR JAPAN OR PAKISTAN OR NIGERIA OR SUDAN OR SWAZILAND OR PEOPLES R CHINA OR TANZANIA OR HONG KONG OR ZAMBIA OR MALAYSIA)

Initial searches identified papers from unrelated medical specialities, non-medical subjects, and non-western countries. Thus, the above exclusions

were applied. This process did not omit relevant papers because the following remained:

TIFFEN, L and SHERIDAN, S (2002). *Improving take-up of hepatitis C services.* Nursing Times. Vol. 98, Issue 43, 30. [online]. Last accessed 6 November 2010 at: http://www.nursingtimes.net/nursing-practice-clinical-research/improving-take-up-of-hepatitis-c-services/205886.article

NEALE, J, TOMPKINS, C and SHEARD, L (2008). *Barriers to accessing generic health and social care services: a qualitative study of injecting drug users.* Health and Social Care in the Community. **16**(2), 147-154.

COUSINS, C, BAXTER, J, and RUSSELL, S et al (2011). *Non-Attendance at Hospital Clinics for Hepatitis C Among Intravenous Drug Users: Barriers and Potential Solutions: Category: Clinical Lesson.* Journal of Infection. 63 No. 6: e65-e66.

Appendix 7: Data extracted according to type of paper

Empirical papers

Author(s), date of publication	**(a) Title (b) Type of paper (c) UK or not UK (d) Hepatitis C or other (e) Outreach or other (f) Sample size (g) Reasons for non-attendance (h) Limitations (i) How to undertake project**
Booth, Peter and Bennett, Heather. (2004)	(a) 'Factors associated with attendance for first appointment at an alcohol clinic and the effects of telephone prompting.' (b) Empirical – quantitative (retrospective). (c) UK. (d) Other –Alcohol. (e) Other – Alcohol treatment clinic. (f) 100 consecutive patients who were non-repliers, 100 who replied but failed to cancel or attend and 100 who replied and attended. (g) Other papers – lifestyles less stable; more ambivalent about need to seek treatment; length of waiting time; social class V; unmarried; younger age; referred by GP or psychiatrist; lack of telephone (unable to cancel appointment). This paper: younger age (likely confounded with duration of problem); longer distance to travel (cost of travelling); return time (reply form) and total wait to appointment. Increase attendance: inform patients on low income that reimburse travel costs; provide pre-paid travel voucher; faxed or e-mailed referrals; telephone prompting (this paper).
Carpenter, PJ, Morrow, GR, and Del Gaudio, AC et al. (1981)	(a) 'Who Keeps the First Outpatient Appointment?' (b) Empirical – Mixed method. Quantitative prospective data (patient and clinical variables). Qualitative follow-up telephone interviews. (c) Not UK – USA. (d) Other – Psychiatry. (e) Other - Hospital outpatients. (f) 1,106 patients – 759 (68.6%) kept their initial appointment and 347 (31.4%) did not. (g) This paper. - Patients 18-24 years of age were significantly less likely to attend - Patients who reported never having received psychiatric treatment before were significantly less likely to keep their initial appointment - Significantly more patients referred from a medical clinic or local physician kept their appointment than those referred by friends or relatives, an emergency room, another psychiatric facility, or self - A higher percentage of patients who gave vague

	or evasive reasons for seeking help than patients who reported family or martial problems failed to keep their appointment - Patients who did not keep the appointment had to wait for significantly longer period of time for an initial appointment than those who did attend Clients reasons – 28% no longer in need of help; – 25% sought help at other psychiatric facilities; – 22% either made a subsequent appointment at the outpatient service or used another service, for example in-patient, provided at the same faculty. – Only 11.7% reported waiting too long for an appointment. Concluded: An over long wait for treatment leads people to shop around for alternative sources of assistance. Other issues such as not being able to come at the time of the appointment, the clinic being too far away, and fears and anxieties about psychiatric treatment, went largely unmentioned. (h) Missing data for 314 patients who made initial appointment. Telephone follow-up data gathered for 103 (30%) of the 347 patients who failed to keep their initial appointment. (i) Low yield from telephone interviews. Need to identify best method to optimise recruitment of participants.
Carrion, Patricia, Swann, Alan, and Kellert-Cecil, Heather et al. (1993)	(a) 'Compliance With Clinic Attendance by Outpatients With Schizophrenia.' (b) Empirical – Questionnaire – 4 items and one open question. (c) Not UK – USA. (d) Other – Psychiatry. (e) Other – Outpatient clinic. (f) 111 patients between the ages of 21 and 65 years. (g) Other papers – findings related to demographic variables not replicated; long waiting lists, or elaborate appointment procedures; unemployment (transportation difficulties) and substance abuse. This paper – forgot appointment; transportation problems; had to work. Other papers – telephone prompts found to improve compliance, but only for patients who can be contacted. Letter prompts found to be more cost-efficient. (h) Patients in the group modality had more frequent appointments than those seen individually. Subjects were not randomly assigned to the treatment modalities – they may have differed in ways not measured e.g. substance misuse,

	employment status, and use of a social support network. (i) Use short questionnaire with tick items and follow-up responses with interview (telephone or at next drug treatment appointment).
Coodin, Shalom, Staley, Douglas, and Cortens, Barb et al. (2004)	(a) 'Patient Factors Associated With Missed Appointments in Persons With Schizophrenia.' (b) Empirical – quantitative (retrospective) and two measures for patient functional levels. (c) Not UK – Canada. (d) Other – Psychiatry. (e) Other – Hospital outpatients (excluded community outreach visits). (f) 342 outpatients aged between 18 and 79 years. Compared patients who missed less than 20% of their appointments (n=162) with those who missed 20% or more of their appointments (n=180). (g) Other papers (medical and mental health settings) – association with: low socio-economic status; younger age; low level of education; a history of missed appointments; drug or alcohol abuse; poorer social functioning; having severe psychiatric problems and a poor relationship with the physician. This paper (low versus high non-attendees): three years younger; history of substance misuse (both groups); lower level of community functioning (Life Skills Profile) and lower scores on Responsibility, Self-Care, Non-Turbulence and Social Contact. (h) Restricted the analysis to visits with nurse therapists and the lack of a concomitant measure of symptom severity. Difficulty in applying the results of grouped data to individuals in clinical practice.
Coulson, Carolyn, Ng, Felicity and Geertsema, Marjan et al. (2009)	(a) 'Client-reported reasons for non-engagement in drug and alcohol treatment.' (b) Empirical – Semi-structured telephone interview with open question then questionnaire where rated items. (c) Not UK – Australia. (d) Other – Drugs and alcohol. (e) Other – Community-based service (f) 53/66 (80%) non-attendees completed the first question but only 46 (70%) completed the interview. Comparison group 97 attendees. (g) Other studies looked at drop-out/disengagement. This study missed appointments: Extraneous factors (37/74) – busy, forgot, illness, out of area at time of appointment, conflicting work commitment, lack of transport, evicted or moved house. Perceived service shortcomings – communication failure, general negative impression of the service, inflexible opening hours, slow process, found contact unhelpful,

	specific staff issues, disliked physical location. No further need for service – self-sufficiency, engaged with alternative services, received sufficient assistance. Motivational ambivalence – could not be bothered attending appointment/continuing treatment. Characteristics – more likely to be male, unmarried, and living with parents rather than with a partner or children. More likely to report current or past polysubstance use and to have been offered counselling rather than withdrawal support. Those who attended their first two sessions were more likely to have psychiatric co-morbidity and previous treatment for mental health issues, most commonly from GP's. There was no difference between those who attended and those who did not on the basis of time from assessment to first appointment. Suggestions for service improvement – routine telephone calls to those who miss appointments. A number of clients re-engaged following the phone interview. (h) Sample small and drawn from a single service, which limits generalisability. Reporting bias as relies on subjective reports. Indirect gathering of demographic and clinical data from the case notes and the lack of questionnaire data from those who engaged, such that comparison could not be made between the two groups. (i) Need to ask how might improve attendance. Use of open-ended questions. I need to include both outreach clinics. Need to ask participants demographic details but keep relevant and not too many. Include people who did attend.
Cousins, Christopher, Baxter, Joanne, and Russell, Susan et al. (2011)	(a) 'Non-attendance at Hospital Clinics for Hepatitis C Among Intravenous Drug Users: Barriers and Potential Solutions: Category: Clinical Lesson.' (b) Empirical (Abstract)- Questionnaire survey. (c) UK. (d) Hepatitis C. (e) Other – Hospital clinic. (f) Those that did not attend their first appointment (n=29) and those that did attend their first appointment (n=19). (g) No differences between those that did or did not attend across a range of questions: - length of diagnosis - confidence about knowledge of hepatitis C - sources of information about hepatitis C - expected discrimination from health care team - expectations of the first appointment - difficulties with transport - attitudes towards possible improvements to

	services Concluded another independent factor that influences attendance. Hypothesised that differentiating factor is degree of importance that patients placed on their hepatitis C infection. Increase attendance: better patient education about hepatitis C soon after diagnosis in order to increase priority of disease in patients' lives; introduce more peripheral clinics that integrate addiction and hepatitis C services; and telephone reminders for appointments. Most patients in the study felt that both these changes would make attending clinics easier. (i) Provide details of the participants including length of diagnosis. Test hypothesis whether degree of importance that clients place on their hepatitis C influences attendance.
Darker, C, Sweeney, B, and El Hassan et al. (2012)	(a) 'Non-attendance at counselling therapy in cocaine-using methadone maintained patients: lessons learnt from an abandoned randomised controlled trial.' (b) Empirical – Semi-structured interview (adapted version of the 'Reasons for Leaving Treatment' questionnaire). (c) Not UK – Ireland. (d) Other – Drug use. (e) Other – not given. (f) 37 (82%) participants (8 not included). (g) Items within the "motivational inconsistencies" scale were most frequently endorsed as a reason for dropping out of counselling i.e. - 'I lost hope in my ability to change right now' - 'I had no good reason to stop using cocaine' - 'I did not feel motivated enough to keep coming' Least cited as reasons for not attending session was "staff conflicts". For attendees the most important factor which aided their attendance was "good relationship with staff". The least important factor was "boundary concerns". (i) May need to seek factors that helped clients attend. Consider using items from the questionnaire.
Farid, Basem T, and Alapont, Eduardo. (1993)	(a) 'Patients who fail to attend their first psychiatric outpatient appointment: non-attendance or inappropriate referral?' (b) Empirical – One year analysis of referral letters and medical notes. (c) UK (d) Other – Psychiatry (e) Other – District General Hospital (f) 130 referrals – 29 (22.3%) did not attend. (g) Other papers: 18-24 year olds; widespread misconceptions about the nature of psychiatric consultations; referred from emergency

	room – congruence (similarity between patient request and patients perception of the physician goal) and vagueness in the referral letter; lived nearer the hospital and had more diagnoses of personality disorder, social, marital or multiple problems; referral letters were of poorer quality and they had to wait longer for appointments. Improve attendance: pre-attendance interviews reduced non-attendance rate to 13% of the control group. This paper: – Male – Younger (38.7 years versus 47.4 years) – Lower social class (using Registrar General's system of classification by current or previous occupation) – Lived significantly nearer the hospital (less than 5 miles) – Lower quality of referral letter (did not contain adequate history nor specific description of their problems) – Not attended in the past Reduced waiting list by stopping routinely sending second appointments for those who missed first. (i) Did not attend defined as missed at least two appointments. Need to be clear that missed at least one.
Feitsma, W.Nathalie, Popping, Roel, and Jansen, Daniëlle EMC. (2012)	(a) 'No-Show at a Forensic Psychiatric Outpatient Clinic: Risk Factors and Reasons.' (b) Empirical – qualitative (telephone interviews). (c) Not UK – Netherlands. (d) Other – Psychiatry (Forensic). (e) Other – Outpatient clinic. (f) 27/61 (44%) No-show; 84/139 (60%) Follow-up no-show; 41/60 (68%) Follow-up show. (g) Other papers/studies: male gender; low socio economic status; low educational level; long time interval from referral or appointment to next appointment; and vague or evasive problem definitions. Some contradictory findings: young age; single or divorced and unemployment. More consistent findings: forgetting; overslept; other commitments; improvement of psychiatric illness or feeling too physically ill. Forensic psychiatric outpatient care – contradictory findings re: younger (≤ 30 years) males. But clients with aggression problems worse attendees than clients referred by courts/solicitors or clients who had child sex problems. Time spent on the waiting list or geographical proximity did not affect nonattendance. This paper:

	Majority of missed appointments by no-show and follow-up no-show clients was scheduled in beginning phase of clinic contact. Clients who attended all appointments were significantly older than clients who missed one or more appointments. The age differences increased with the amount of appointments missed. The follow-up show clients experienced more family social support than their non-attending counterparts. The latter two groups had a more negative attitude towards appointments. Reasons for non-attendance: - Forgot about appointment 6/22% 19/23% - Work commitments 5/19% 8/10% - Other commitments 3/11% 15/18% - Felt too psychiatrically ill 3/11% 11/13% - Did not receive appt. letter 3/11% 3/4% - Could not afford public transport 2/7% 5/6% - No public transport available 2/7% 2/2% - Clerical error 1/4% 5/6% - No child care/babysitter available 1/4% 2/2% - Refusal of care 1/4% 1/1% Follow-up no-show (continued): - Take care for others 4/5% - Lack of motivation 3/4% - Denial of nonattendance 2/2% - Overslept 1/1% - Negative perception of psychiatry 1/1% - Did not read appointment letter 1/1% - Did not understand appointment letter 1/1% (h) Low overall response rate (41.5%) may have caused non-response bias. All variables based on clients reports, with potential answering bias as a consequence. Some variables of importance could not be assessed, e.g. diagnostic variables as well as institutional factors such as client-therapist relationship. Many factors that affect no-show other than those assessed in this study. However, depending on the setting and the risk factors known from the literature to affect non-attendance, choices have to be made about how to assess no-show. (i) Questionnaire piloted. Undertook telephone interviews. Offered ways to reduce non-attendance. These included: visit clients in prison or in secure clinics before they leave and have to attend outpatient clinic; telephone or written prompt delivered 24 hours before clinic appointment; and organise meetings for relatives at clinic to inform them about forensic care and to make them aware

	of the necessity of social support.
Frischer, Martin and Elliott, Lawrence. (1993)	(a) 'Discriminating needle exchange attenders from non-attenders.' (b) Empirical – qualitative. Interview – detailed questions. (c) UK. (d) Other – Drug use. (e) Other – Drug services. (f) 503 'injectors' – 170 'in-treatment', 165 from needle and syringe exchanges, and 168 out of treatment. (g) Characteristics of attendees versus non-attendees. The latter: injected more different drugs but less frequently; had less knowledge of HIV transmission; were less likely to make and maintain greater reductions in risk behaviour; were less likely to engage in safer practices i.e. less use of condoms with casual partners and more frequent injecting with (and passing on of) used equipment; on average, reported receiving less education (9.9yrs v 10.4yrs); were less likely to be female (although women still in a minority) and less likely to be co-habiting with a sexual partner; were more likely to have received treatment for drug use and had more episodes of treatment. Important to note: not all variables univariately significant but dependent on association with others. Neither housing (permanent accommodation), employment or prison experience discriminated between the two groups.
Gariti, Peter, Levin, Sarah, and Whittingham, Thomas et al. (2008)	(a) 'Why do those who request smoking treatment fail to attend the first appointment?' (b) Empirical – Telephone administered survey – 18 scripted reasons, one open ended question at end (asked if wanted to add anything else). (c) Not UK – USA. (d) Other – Smoking. (e) Other – University (Urban area). (f) 407 candidates seeking admission into a clinical trial. Attendees n= 205 and non-attendees n=202. Telephone survey completed by 91 (45%) of non-attendees. (g) Younger age; African American applicants; unemployed; wait time before appointment with age, race, and employment status. Survey results: work or family obligations; change in schedule; appointment time (employed); location of facility; transportation costs (unemployed). (h) Low survey participation rate and lack of detailed information available about the non-attendees (e.g. reasons for being unemployed, education level, other drug use). Thus the responses may be non-representative of the subgroup. (i) Demographics – employment status.

Hayter, Mark. (2005)	(a) 'Reaching Marginalized Young People Through Sexual Health Nursing Outreach Clinics: Evaluating Service Use and the Views of Service Users.' (b) Empirical – mixed method – questionnaires and semi-structured interviews. (c) UK. (d) Other – Sexual Health. (e) Outreach. (f) 166/250 (response rate of 66%) questionnaires and 20 young people interviewed. (g) Other papers - judgemental attitudes from staff; concerns re confidentiality; difficulties with travelling to city centre locations. (i) Collecting interview data enabled some triangulation of the data and to explore certain aspects of the service in more depth.
Hyslop, Alan, and Kershaw, Peter. (1981)	(a) 'Non-Attenders at an Alcoholism Referral Clinic.' (b) Empirical – Quantitative and qualitative (face to face interviews). (c) UK. (d) Other – Alcohol. (e) Other – Psychiatric Hospital clinic. (f) 100 new referrals – 47 failed to attend. (g) Other papers: 1. Non-attendees received past treatment and possibly disappointed by results. As a group, immature, impulsive and anti-social, so looking for an immediate solution rather than postponed help. 2. Patients not given satisfactory explanation of why should attend. Reasons for non-attendance: too ill to attend; gave unconvincing reason; material and genuine reasons; patient improved; clerical errors and misunderstanding. Other papers: Anger in the voice of the referring physician. Patients not instructed to inform the hospital if could not attend. GP's did not often explain in detail why they wished the patient to attend hospital. This paper speculated reasons: location of clinic i.e. labelled Alcoholism Treatment Unit in a psychiatric hospital some distance from parts of the catchment area. Patients' motivation considered suspect – external pressure from relatives, GP's and others thought to be strong in initiating referral but not attendance. This paper: <u>Acceptable reasons (n=21 patients)</u> – appointment card arrived after the date (n=6); patients left home during the interval (n=4); taken into custody (n=3); misread or lost cards (n=3); on holiday (n=1); too ill to attend (n=1); improvement made appointment unnecessary (n=3). <u>Poor reasons (n=16 patients</u> – changed their minds (n=7); disagreed problems attributable to alcohol (n=5); never agreed to the referral (n=4).

	Non-attendees – unmarried; class V; longer wait to appointment. Attendees – had a car
Jeal, Nikki and Salisbury, Chris. (2004)	(a) 'Self-reported experiences of health services among female street-based prostitutes: a cross-sectional survey.' (b) Empirical – Administered semi-structured questionnaire using open and closed questions. (c) UK. (d) Other – Sexual Health. (e) Outreach (Street). (f) 71 sex workers. (g) Reasons for <u>difficulty</u> attending GP. 52% (37/71) – waiting for available appointments, 51% (36/71) – difficulty keeping appointments made, 45% (32/71) – perception of being judged by staff, 37% (26/71) – difficulty waiting with other patients; felt stared at. Difficult to attend STI clinic 78% (55/71). Why? 45% (32/71) – clinic location, 32% (23/71) – appointment system, 25% (18/71) – time waiting, 25% (18/71) – waiting with other patients perceived as staring, 22% (16/71) – fear of judgement. (h) Sample size relatively small, and lack of recruitment of participants at certain time may have exposed study to bias. The data is self-reported and may make it open to bias. Although group considered to be in social class V – may not have started life in this class. (i) Final question women asked was what they would include if designing a service set up for women who sell sex. I need to ask the participants in my research. Women paid £20 for child care and travelling expenses, but interview 1 hour long. My questionnaire/interview shorter and may not need to reimburse.
Killaspy, Helen, Banerjee, Sube, and King, Michael et al. (2000)	(a) 'Prospective controlled study of psychiatric out-patient non-attendance: Characteristics and outcome.' (b) Empirical – Interview at home. If unable to interview then postal questionnaire sent. (c) UK. (d) Other – Psychiatry. (e) Other – Hospital out-patient clinic. (f) 365 patients included in the study. 224 patients interviewed. (g) New patients – <u>Had a different profile of mental disorder compared with the follow-up population, with a predominance of non-psychotic disorder of lower severity.</u> Attendees more likely than non-attendees to have been prescribed psychotropic medication by the GP prior to referral. New patient non-attendees (n=29) reasons: - Unhappy with referral (n=5, 17%) - Too psychiatrically ill to attend (n=4, 14%)

	- Reported clerical error (n=4, 14%) - Forgot about appointment (n=3, 11%) - Other commitment took priority (n=3, 11%) - Afraid of admission (n=3, 11%) - Other (n=1, 3%): Overslept; Unhappy with treatment; 'Couldn't be bothered'; Lost appointment card; Felt better; Too physically ill to attend; and Bad weather. Follow-up patients – Non-attendance associated with previous history of admission under the Mental Health Act (1983). Follow-up non-attendees (n=74) reasons: - Forgot about appointment (n=20, 27%) - Too psychiatrically ill to attend (n=10, 14%) - Reported clerical error (n=8, 11%) - Other commitment took priority (n=6, 8%) - Overslept (n=6, 8%) - Unhappy with treatment (n=6, 8%) - 'Couldn't be bothered' (n=5, 7%) - No need to attend as no problem (n=5, 7%) - Lost appointment card (n=3, 4%) - Travel problem (n=3, 4%) - Other (n=1, 1%): Felt better; and too physically ill to attend. (h) Carried out in a single inner-city area and unable to generalise the results. Relatively low response rates may have introduced non-response bias in the data obtained. (i) Concerns about interviewing clients at home due to personal safety and client may not be in. Could arrange face-to-face interviews at drug clinic. Need to differentiate whether outreach clinic appointment new or follow-up.
McIvor, Ronan, Ek, Emma, and Carson, Jerome. (2004)	(a) 'Non-attendance rates among patients attending different grades of psychiatrist and a clinical psychologist within a community mental health clinic.' (b) Empirical – quantitative - examined non-attendance rates over 21 months (not new referrals). (c) UK. (d) Other – Mental health. (e) Other – Community mental health team. (f) 482 patients. (g) Other papers – young males; deprived socio-economic background; long wait for an appointment; more unwell; greater social impairment; more likely to require hospital admission; related to withdrawing from treatment; 'simply' forgetting; and patients seeing medical students were more likely to withdraw from treatment.

	Effective strategies to reduce non-attendance: telephone or postal reminders; offering patients a choice of time and date; and writing a personal letter rather than a standard appointment card. This paper: – The non-attendance rate for the clinical psychologist was significantly lower (7.8%) than the rates for the medical staff, which increased progressively for consultant psychiatrists (18.6%), specialist registrars (34%) and senior house officers (SHOs) (37.5%). Hypothesis – continuity of care, clinical competence and differences in clinical style. Quality of care might be higher for patients seeing a consultant. Also, patients may feel they are being given a better service simply by seeing a more senior member of staff. Non-consultant medical staff rotated every six or twelve months, resulting in interruption of clinical care. Why did the psychologist have a lower attendance rate than the psychiatrists? Might be that clinical psychologists tend not to see acutely ill people. In addition, psychologists are not involved in mental health assessments for compulsory admission or other practices perceived to be coercive. Psychology is perceived to be less stigmatising and more acceptable to the patient. Furthermore, clinical style may be important, with psychologists more likely to emphasise principles of therapeutic alliance, collaboration and education, factors that have been found to correlate positively with keeping appointments. (h) Did not directly examine reasons behind findings. Frequent failures to attend by individual clients were not controlled for, and it is possible that a small number of patients who repeatedly failed to attend skewed rates. Furthermore, there may be differences between the patients seen, with consultant psychiatrists being more likely to see chronic attendees, and junior staff seeing patients with a range of clinical profiles, involving short-term interventions or longer-term work. As the study was conducted in a deprived inner-city area, it is possible the findings are not representative.
Mitchell, Alex J, and Selmes, Thomas. (2007)	(a) 'A Comparative Survey of Missed Initial and Follow-Up Appointments to Psychiatric Specialties in the United Kingdom.' (b) Empirical – quantitative survey. (c) UK. (d) Other – Psychiatry. (e) Other – Hospital out-

	patients. (f) 1,555 missed initial appointments April 2003 to March 2004, and 1,186 missed follow-up appointments in April 2004. (g) Other papers. Initial appointment – problems resolved and did not agree that referral was necessary. Follow-up appointment – more unwell; more functionally impaired and have higher chance of subsequently being admitted to hospital. Other studies/papers found: younger; missed previous appointments; scheduled to see a resident physician; lived a greater distance from the hospital; level of distress; disagreement with need for referral; long wait between referral and appointment; no explanation; single; personality disorder or substance use disorder; referred from emergency department; ethnic background; poor family support; not taking psychotropic medications and having health insurance. This paper: – Higher follow-up (versus initial) non-attendance rate – Moderate degree of variation across months with April worst attendance rate and higher rates for missed appointments (mild trend) seen during summer months. Trend to lower missed appointment rates in winter months. – Significantly fewer missed appointments on Fridays – The rate of initial and subsequent missed appointments was highest following self-referral and referrals from the police or probation service. It was lowest for referrals from community psychiatric nurses and social services. (h) The distribution of contacts was not equal across specialties. Only basic demographic data available – no data for age, gender or ethnicity. Could not rule out that comparative month (April 2004) was atypical in some way. Unable to study previous non-attendance among those who had been offered appointments.
Morton, A. (1995)	(a) 'The enigma of non-attendance: A study of clients who do not turn up for their first appointment.' (b) Empirical – Two questionnaires and face-to-face (or telephone) semi-structured interviews. (c) UK. (d) Other – therapy groups (psychology). (e) Other – a 'centre'. (f) Questionnaires – 137/171 (80%) attendees and 18/42 (43%) non-attendees. Interviews – 29/42 (69%) non-attendees. (g) Other

	studies/papers – Age (18-24 years old) (38.7 years v 47.4 years); Male; Lower socioeconomic status; Waited longer for appointment; More often referred by self, friends or relatives, an emergency room, or other psychiatric facility (compared to attendees being referred through a medical clinic or local physician); Parents less likely to attend than clients who did not have children. Clients' reasons (see Carpenter et al, 1981). This study: - Amount of time from referral to appointment significantly differed between attendees (mean 5.0 days) and non-attendees (mean 18.86 days) - Significantly less likely to attend if referred from probation or a social worker - Number of previous addresses in last 5 years and length of time at current address showed trends in the expected direction but no significant difference - Parents with primary responsibility for children, being both the regular and main carer, were significantly less likely to attend Interviews (in person or on the telephone): - Obstructing conceptions (fears/anxieties about appointment and/or joining a group and concerns about the helpfulness of this approach) - Childcare responsibilities - Work commitments - Had wanted an immediate appointment - No longer any need for further assistance - Not heard of centre or received the appointment letter - Forgot - Repeated missing of appointments - Not the right time for assistance (recently bereaved and receiving support from other agencies) Reduce non-attendance – prioritise referrals into urgent and non-urgent with aim of reducing time it takes to see who wants help immediately. Invite clients with childcare responsibilities to visit the crèche and meet with staff, before scheduling an initial assessment interview. Telephoning clients identified at risk of non-attending prior to their appointment. (h) Limitations – Questionnaires were completed by 80% of attendees and 43% of non-attendees. Small sample of non-attendees and difference in sample sizes (with attendees) point to caution in accepting

	significant findings and their subsequent interpretation. (i) Consider using telephone interviews.
Neale, Joanne, Sheard, Laura, and Tompkins, Charlotte. (2007)	(a) 'Factors that help injecting drug users to access and benefit from services: A qualitative study.' (b) Empirical – qualitative interviews. (c) UK. (d) Other – Drug users. (e) Other – Needle Exchanges. (f) 75 current injecting drug users (IDUs). (g) Other papers/studies: Barriers: Structural – lack of services; not enough services to deal with demand; poor information about treatment meaning IDUs do not always know about full range of provision available; bureaucratic hurdles – too much 'red tape'; long waiting lists; limited opening hours; lack of childcare; stigmatising, negative or unsympathetic staff attitudes. These factors can result in decreased motivation. Individual – women, some members of black and ethnic minority groups, homeless people, and prisoners, those who live in rural areas can face particular problems. Drug-using parents can be reluctant to engage because do not want to be separated from their children or fear losing custody of them if their ability to care is questioned. Injectors' generally chaotic and hectic lifestyles can make attending services problematic especially when strict appointment times operate. Psychological state of mind and treatment expectations – some IDUs do not feel their drug use is a problem so do not want to seek help; others too ashamed, embarrassed or guilty about drug taking to approach professionals; some IDUs too anxious to seek assistance in case fail treatment, their confidentiality is not respected, or they discover that they are HIV positive; other IDUs do not access services because they believe that the treatment available is not appropriate for their problems, do not like the support on offer, or assume they are ineligible for help. This study – Suggestions for improving treatment access: More service provision – substitute prescribing services (specialist community services and GPs willing to prescribe); counsellors including mental health; residential detoxification and rehabilitation (especially those that accepted children, provided

	some medication and not too regimented, needle exchange, outreach including home visits for those with new-born babies. Additional support within existing services – formal talking therapies; informal advice and information via drop-in. Free bus passes or financial assistance travelling to agencies; more information and leaflets; greater assistance with housing, education and job-seeking; more diversionary activities, and/or complimentary therapies. Disliked methadone because highly addictive and its side-effects – wanted access to broader range of prescribed medication. Amphetamine injectors appreciate any form of substitute medication. Some drug users (who not committed crime) expressed strong sense of injustice that offenders seemed to receive treatment more quickly and often entitled to free bus passes to enable them to travel to appointments. Better operation of existing services – shorter waiting lists for prescribed medication; private rooms/booths or sound-proofing to preserve confidentiality and privacy; needle exchange open for longer e.g. 24 hours a day; waiting times for scripts reduced if workers stopped repeatedly asking same questions; need for better co-ordination of services when released from prison (often unable to continue treatment in community); helpful to be given realistic information on waiting times and given clear appointment date so could plan and focus, even if wait for treatment could not be shortened; needle exchange should always try to open at same times each day and avoid unscheduled closures, even if could not offer longer opening hours; pharmacies should try to be more flexible when substitute medication could be collected (same as other customers) - creates problems for those working, had to travel long distance, were unwell, or had many other commitments elsewhere e.g. housing, criminal justice or social welfare services; agencies could be more accommodating of heroin users needs by not giving early morning appointments – will be experiencing opiate withdrawal and so preoccupied with obtaining either illegal drugs or methadone script; more willing to treat couples together so can support each other; review waiting room arrangements so IDUs not left together in environment where discussing drugs, dealing drugs and threatening behaviour can occur. Staffing-related improvements – Under-resourcing of

	drug services caused by high staff turnover and/or understaffing detracted from quality of treatment that could be provided. Professionals should be less judgemental of injectors, more welcoming, more understanding of their problems and more encouraging when they make progress. Felt that such changes would collectively help to reduce some of the stigma, shame and embarrassment that injectors commonly experience when they first contact agencies and might encourage those with drug problems to retain contact. Having better trained staff and more former drug users working in drug services. Other factors enabling service access: Supporting relationships – Although a few participants reported that had deliberately hidden their addiction from family members (ashamed or embarrassed, did not want to upset their family, or afraid of relatives reaction) many more emphasised how important family had been in enabling them to seek and obtain help. Those who were not emotionally supported by their family could feel there was very little help in trying to address their drug taking. Most common providers of support were mothers. Emotional and practical forms of help provided. Phoning drug agencies to arrange treatment appointments and accompanying them (including to generic services). As well as easing anxieties about treatment (and not attending at last minute) helped overcome transport problems by making journey easier and cheaper. Other forms of practical support: money (including to buy drugs and prevent committing crime); accommodation; meals and child care. Provided stability to begin to address drug use and other problems. Emphasised importance of assistance received from friends, peers, neighbours and partners e.g. information about availability and nature of local drug services, and embarked on treatment together. Individual drugs workers, GPs and pharmacists helpful. Their qualities: friendly, approachable, understanding and honest which put them at ease and helped them open up. Also, flexible e.g. readily accessible for a chat. Praised professionals who gave extra effort. Some drugs workers accompanied to appointments at other services, acted as advocates, and helped build up confidence. In addition, having drugs workers and probation officers who willing to assist with other needs encouraged them to engage with

	services. Personal circumstances and life-events – Most important being a parent, and especially becoming a parent. For example: making sure children not taken into care or getting back from care; wanting to see more of children; not wanting children to know used drugs; and being tired of having little money to spend on children. Other life events: bereavements; family illnesses; periods of poor mental health; having a leg amputated. Professionals more sympathetic and willing to help when experiencing personal difficulties. Personal circumstances: having transport made it easier to attend appointments; being vulnerable increased an individual's priority for drug treatment and housing; being in the criminal justice system which seemed to result in fast access to substitution treatment; and moving into a new home which gave stability to address drug misuse and other problems. An injector's state of mind – Being more motivated and feeling positive contributed to seeking help. Factors associated with increased motivation: feeling less depressed about lives; growth in self-confidence and will-power; and decreased feelings of shame and embarrassment. Changes facilitated by: supportive drugs worker; getting married; becoming a parent. Also, having been helped by a previous treatment encounter. In addition, individuals: made a firm decision to be drug-free; tired of using drugs; disliked life that complicated or ruled by addiction; wanted to stop committing crime; or afraid of dying. Others recognised being a parent, going to college, getting a job or owning a house more important than drug taking. (h) Caution advised in generalising the findings to other locations. Further, the participants mainly recruited via needle exchange (NEX) programmes. The views and experiences of individuals not using NEX services are omitted. In addition, it was largely not possible to identify robust differences between the views and experiences of the various sub-groups of injectors. This was because injectors often belonged to more than one sub-group, drew on both their current and previous treatment seeking experiences, and reflected on others needs as well as their own. Furthermore, some of the factors identified as enabling access were only reported by relatively small numbers of participants. This prevented the authors from ascertaining whether or not there were meaningful patterns in the responses based on

	injectors' demographic or drug use characteristics. (i) Participants given expenses.
O'Neill, A and Kerr, A. (1991)	(a) 'Non-attendance at a psychiatric day hospital new patient clinic.' (b) Empirical – Data from referral letter and questionnaire sent to patient. (c) UK. (d) Other – Psychiatry. (e) Other – Day Hospital. (f) 267 new referrals of which 40 (15%) did not attend. (g) No 'significant' difference between attendees and non-attendees with respect to: sex, age or distance from home address. But weighed towards non-attendance were: young male patients and marital problems. Small excess of non-attendees from 'working class area' (defined as area of high density of small housing where most inhabitants wage earners). Patient significantly more likely to attend if referring doctor specified a particular consultant. Likely to attend if previously seen on a domiciliary visit. Of significance, average waiting time longer in non-attendees (34 days) compared to attendees. Percentage of non-attendees by month showed peaks in April, July and September. Due to staff and patient holidays (children at home from school) which led to longer waiting times. 14 (38%) replies to questionnaire sent to non-attendees: - Some patients unhappy and unsure about nature of treatment available at clinic - 35% afraid of treatment - 42% felt uneasy discussing treatment - 60% said they would have like more information - 71% gave 'excuse' that did not require to attend as illness had improved during waiting period for appointment - Delay in getting appointment mentioned by 42% of non-attendees (h) Limitations: A further study with larger numbers might bring forth other factors affecting attendance. (i) Sending a questionnaire yielded a low response rate.
Peeters, F and Bayer, H. (1999)	(a) 'No-show for initial screening at a community mental health centre: rate, reasons and further help-seeking.' (b) Empirical – postal survey with two questions with response possibilities given, and an open section. (c) Not UK – Netherlands. (d) Other – Mental Health. (e) Other – Community Mental Health Centre. (f) 1716 patients of whom 165 (9.6%)

	did not attend. (g) Other papers – culture, psychosocial determinants, mode of referral, and accessibility of professional services. This paper: Characteristics: more frequently referred; referred for first time (characteristics of those acquainted with service – previous experience – might be different); more prevalent among those referred by other services (not GP or self) – may be less motivated to start new or additional treatment, or referral experienced in different way e.g. single contact with worker less obliged to attend than if advised by GP with whom have long-standing relationship. No differences for gender or mean age. Questionnaire characteristics – no differences. This paper reasons: - 31.9% faced too long wait for first appointment or able to get earlier appointment - 29.8% 'strong hesitations'/not motivated despite persistence of the problem - 21.3% resolution of the problem. ? patients found a way of coping/problem solving. - 6.4% no adequate transportation Other non-categorised reasons: spouse not felt motivated to attend; forgot appointment; 1 respondent too many problems; spouse suddenly imprisoned. (h) Questionnaire respondents over-represented by no-shows of last months of study period. Low response rate, reliable generalisation may be limited. Missing data such as type of mental health, social class, education level, and disability. Cannot be certain reasons given by respondents accurate and reliable.
Pieper, Barbara, and DiNardo, Ellen. (1998)	(a) 'Reasons for Nonattendance for the Treatment of Venous Ulcers in an Inner-City Clinic.' (b) Empirical – 45 item (with demographic details) closed questionnaire administered verbally. (c) Not UK – USA. (d) Other – Venous ulcers (majority had history of injecting drug use). (e) Other – Urban primary care clinic. (f) 36 people with venous ulcers and 115 people without wounds. (g) Other papers/studies - Patient factors: younger patients; older and highly educated people; men tended not to arrive whilst women tended to cancel; women poor attendance for radiograph appointments; lack of transportation; homelessness; embarrassment or fear; afternoon appointment or at the end of the

	week, unclear appointment details or perceived themselves as forgetful; chronic disease that required routine follow-up; did not feel well, experienced resolution of their symptoms, they forget and difficulty obtaining transportation; asymptomatic condition, vacation, and work problems. Clinic factors: unclear indication of purpose of appointment; misunderstood information; incorrect appointment made by staff; dissatisfaction with the clinic; long wait from scheduling appointment to actual appointment date. This paper: - No ride (n=20, 56%) - No money (n=14, 39%) - Out of town (n=14, 39%) - Forgot (n=12, 33%) - In too much pain (n=11, 31%) - Funeral (n=10, 28%) - Harsh weather (n=10, 28%) - Felt better (n=10, 28%) - Didn't feel like going (n=10, 28%) - Felt too sick (n=9, 25%) - Someone I knew was sick (n=8, 22%) - In jail (n=8, 22%) - In hospital (n=8, 22%) - Bus late (n=7, 19%) - Stressed (n=6, 17%) - Slept through it (n=6, 17%) - Social service appointment (n=6, 17%) Examined for differences between people with and without venous ulcers. The former had significantly more 'Social', 'Illness', 'Personal', and 'Total' reasons for non-attendance compared with the latter. However, participants with venous ulcers had significantly fewer 'Clinic' problem-related reasons for missing appointments when compared with patients without wounds. (h) Small sample. Used a new instrument and patient recall over a year. (i) Questionnaire piloted.
Snape, Catherine, Perren, Sara, and Jones, Lesley et al. (2003)	(a) 'Counselling – why not? A qualitative study of people's accounts of not taking up counselling appointments.' (b) Empirical – qualitative. Semi-structured interviews and written comments. (c) UK. (d) Other – Counselling. (e) Other – GP practice. (f) 20 interviewed and 24 provided written comments. (g) Time – length of time waiting for appointment. Time of day of the appointment and frequency (particularly if involved taking time off

	work). Stigma associated with counselling or suffering mental health problems played a part. Different from seeing GP for 10 minutes – how explain need to take 2 hours off. Urgency/desperation – Referral in crisis but often have to wait. People pushed distress into background and could not face it re-surfacing when appointment offered. Others waited so long and life had moved on – counselling no longer appropriate. Combination of work, location, timing of appointments, and other demands made it difficult to attend. When distressed lacked ability to respond to appointment invitation, let alone organised self to attend. Impact of referral consultation – Problems not taken seriously by GP. Some felt doctors input was sufficiently therapeutic and did not need referral. Some felt better for being referred. However, frustrated if help did not materialise. Information – Not knowing what to expect from counselling. Self-image – People felt responsible for own recovery, either alone, or with support from family/friends. The wait for an appointment reinforced this belief. Views of counselling – Reservations about benefits of counselling – negative past experiences. Organisational aspects – Some not received an appointment letter; some tried to cancel but failed. (h) Response rates were low. Approximately 20% of the sample responded, and 10% per cent were interviewed. (i) May have to consider asking participants to give written comments in the absence of a sufficient number agreeing to be interviewed.
Swarbrick, C, Foley, E, and Sanmani, L et al. (2010)	(a) 'Do *do not attends* at a genitourinary medicine service matter?' (b) Empirical – Quantitative (retrospective data) and qualitative (telephone interviews). UK. (d) Other – GUM. (e) Other – Hospital clinic. (f) 48% (182/383) of DNA's interviewed. (g) 40% (57/182) forgot they had an appointment; 31% (57/182) personal reasons – childcare issues, carer responsibilities, menstruation and appointment no longer necessary; 25% (16/182) working and unable to attend; 4% (6/182) studying and unable to attend. 84% (152/182) reported SMS telephone reminder useful in keeping appointments. (h) None identified. (i) Problem contacting DNA's by phone. I need to gather some data and follow-up by phone if client agrees.

	A clinic's non-attendance rate is not necessarily a marker of accessibility. Patients may be able to simply re-book.
Tiffen, Louise, and Sheridan, Susan. (2002)	(a) 'Improving take-up of hepatitis C services.' (b) Empirical – qualitative feedback. (c) UK. (d) Hepatitis C. (e) Other – Hospital clinic. (f) Not given. (g) Many of those who missed appointments: - Were not sure what to expect - Feared visiting the clinic, and had mental images of advanced disease and death - Were apprehensive about medical terminology, specifically 'liver biopsy' Improved attendance at hospital clinic by: taking stepped approach i.e. structured visits to general practice and then to hospital. Blood test results available at each client's first specialist appointment. Clients able to decide whether ready to be referred to the hospital. Some clients did not need to be seen at the hospital and the Hepatologist would review them in general practice. Also, clients were given more detailed information including leaflets about hepatitis C and the hospital clinic. Staff wrote a leaflet to help demystify the liver biopsy procedure (avoided the use of 'biopsy' in the title). (h) The baseline sample size of 11 referred patients to measure the non-attendance rate was small. Also, the respective percentage of clients that attended and did not attend exceeds 100%. The number of clients from whom feedback about missed appointments was not identified. The paper does not say how the qualitative feedback was collected. Although the percentage attendance rate had improved, both the number of clients and the period of time since the introduction of the initiative had not been identified. Also, the attendance and non-attendance rate after the initiative adds up to less than 100%.
Weinerman, Rivian, Glossop, Vi, and Wong, Randy et al. (2003)	(a) 'Time of Day Influences Nonattendance at Urgent Short-Term Mental Health Unit in Victoria.' (b) Empirical – Two stages. "No show" questionnaire given to patients. Second modified questionnaire including question about social support completed by researchers from charts. (c) Not UK – Canada. (d) Other – Mental Health. (e) Other – Clinic. (f) 120 patients – 60 first-time no-shows (FTNS) and 60 attended their first session. (g) Other papers.

	Complex interplay of demographic, clinical and process variables including patients' resistance to seeing psychiatrists. Comprehensive review of 89 studies identified: wait time; previous therapy; presenting problem; socioeconomic factors; and referral source. Improve attendance: telephone and written prompts; 24 hour pre-appointment. This study: - Age - Sex - Referral source - Patient acuity - Time until first phone contact - Time until first appointment - Day of first appointment - Presenting problem - Time of day of appointment (odds ratio of patients attending an afternoon rather than a morning appointment was 3.6) - Presence of existing other treatment (h) Study limited owing to post hoc nature. Did not evaluate detailed socioeconomic or geographical status, which made it difficult to evaluate whether distance or lack of transportation contributed to first time no show. "... a single multifaceted profile has limited practical value in reducing first time no show".

Empirical/Conceptual papers

Fraser, Suzanne. (2010)	(a) 'Hepatitis C and the limits of medicalisation and biological citizenship for people who inject drugs.' (b) Empirical/Conceptual – Qualitative – Interviews. (c) Not UK – Australia. (d) Hepatitis C. (e) Other – Range of services and organisations. (f) 3 from 30 interviews. (g) 1. Social and material disadvantage e.g. lack of support and homeless. 2. Suspicious of the medical profession. 3. Doctor knows best (paternalistic). Addiction medicalised – patient suffering from a disease of the will. Contradicts contemporary mainstream models of the clinical encounter which recognises patient independence, individuals' right and responsibility to make rational informed decisions based on the information given by health professionals, but free from their influence. (i) Need to consider reimbursing participants time and travel.

Magnes, Reuven Manfred. (2008)	(a) 'Out-patient appointments: a necessary evil? A literature review and survey of patient attendance records.' (b) Empirical/Conceptual – Literature review and quantitative (serial cross-section survey). (c) UK. (d) Other – Psychiatry. (e) Other – Hospital out-patient clinic. (f) Attendance records of 36 patients. (g) Other papers/studies: - Length of waiting time, forgetting. But no data reached significance ($p<0.05$) when non-attending new patients were compared with non-attending follow-up patients. - Severity of illness (see Killaspy et al, 2000). Follow-up patients were more severely ill than new patients and follow-up non-attendees were more severely ill than follow-up attendees. Non-attending for 12 or more months made admission significantly more likely in follow-up patients. - Deprivation. Non-attendees had socio-economic situations of high deprivation as measured by Jarman index (see McIvor et al, 2004). - Doctors training. Clinical psychologist's patients had lowest rate of non-attendance (7.8%) followed by those of consultant psychiatrists (18.6%), specialist registrars (34%) and senior house officers (37.5%). Factors such as continuity of care, perceived clinical competence and the provision of non-medical interventions might have an impact on attendance rates. - Male - Youth - Substance misuse Improve attendance (this paper) – Simple orientation statement taking less than 30 seconds to read sent two weeks prior to appointment. Ratio of 1.25 attendance an improvement after sending reminder (and not due to chance). Unclear when best to send reminders as prompts sent at 14 days seem to work as well as prompts 3 days prior to appointment. Rest of variance unaccounted for and due to other variables e.g. levels of socioeconomic deprivation, transport, weather, and child-care or doctor-patient relationship which could influence attendance. (h) Limitations – Reliability of the study could be improved if larger out-patient numbers were used and comparisons made with other out-patient settings in adult psychiatry or comparisons with consultant or senior house officer clinics. Correlation does not prove causation. Therefore the relationship between reminders and attendance

	must be a complex one. This is worthy of further study because of the significant effect of confounders and the unknown meaning that the patient attaches to the prompt and the uncertainty about when best to send a reminder. (i) In terms of severity of illness may need to explore if asymptomatic nature of hepatitis C influences attendance. The participants are likely to come from a 'deprived' background but what does this mean for the clients and how may it influence non-attendance.
Neale, Joanne, Tompkins, Charlotte and Sheard, Laura. (2008)	(a) 'Barriers to accessing generic health and social care services: a qualitative study of injecting drug users.' (b) Empirical/Conceptual – Face-to-face semi-structured interviews. (c) UK. (d) Other – IDU's. (e) Other – Needle exchanges. (f) 75 current IDU's. (g) Other papers – injector's generally chaotic and hectic lifestyles can make attending services problematic, especially when strict appointment times operate. This paper: - Limited access to a telephone made it difficult to make or confirm appointments (with GP) - Problems attending pharmacies if had paid jobs, were away from home for any length of time or had conflicting appointments at other services. - Non-attendance at hospital outpatients – no transport; nobody to accompany them (particularly no relatives/friends who might provide a lift or offer moral support); too anxious about experiencing symptoms if kept waiting; afraid of being diagnosed with a serious medical condition, such as hepatitis or HIV/AIDS; forgetting dates and times, too tired to attend (stimulant injectors, especially when trying to reduce or stop use). (h) Participants recruited from one country, therefore caution in generalising findings. Interviewees recruited from needle exchange services which are easily accessible and widely used. Some individuals who don't use services are omitted from the study. (i) Participants given £10 (either cash or supermarket voucher) to cover their out of pocket expenses.

Buetow, Stephen. (2007)	(a) 'Non-attendance for health care: When rational beliefs collide.' (b) Conceptual/discussion. (c) UK. (d) Other. (e) Other. (f) N/A. (g) Instrumental: Precautionary principle – individuals protect themselves from the harms of medicine; Risk tolerance – risk of having a health problem or coming to harm low therefore do not attend; Priorities other than health – function day-to-day better without addressing health issues e.g. smoking/drinking alcohol relieves stress. More concerned with present rather than future/possible harms. Cultural – expected to care for others over personal health; Desire for patient control – Avoid dependence on health professionals and being seen as sick. Non-attendance can strengthen patients control over their health (seek informal care). Individuals wish to protect themselves from information about an illness that is serious, chronic and stigmatising. Wish to remain an individual and not seen simply as part of a targeted community health initiative e.g. immunisation programme; Advantages of sickness – If 'sick' may be exempted from unwanted role expectations and get attention from others. Non-instrumental: Selflessness – Protect other people (loved ones/friends and health professionals) from the burden of their illness. Scarce resources should be allocated to patients with greater needs; Living in accord with nature – Natural part of life to experience pain and suffering, seen as a personal challenge not a threat. Health care not meant to extend health beyond its natural limits. (h) N/A. (i) Raises the query whether the research question should include patients who have chosen not to make an appointment? The answer is probably no, as widens topic too much.
Hills, Laura. (2009)	(a) 'How to Handle Patients Who Miss Appointments or Show Up Late.' (b) Conceptual/discussion. (c) Not UK – USA. (d) Other – No speciality. (e) Other – Setting not specified. (f) N/A. (g) Patients are afraid to attend – emotional barriers often the problem. The delay from making the appointment and keeping it adds to this ambivalence. Appointment too far in advance. They owe the practice money. The patient does not appreciate the need for the appointment – they may be feeling fine, be busy and the appointment far in advance. The patient is not

	seen on time – patients may construe being kept waiting as form of disrespect worthy of retaliation. The patient is short of money – patients may be less inclined to take time off work to attend an appointment if don't get paid. Patient could not schedule a convenient time – some appointment times in high demand. Patients do not know how much notice needed to cancel appointment or why need it – patients do not know how appointment system works, think it is fluid and subject to negotiation. They think staff just went onto the next patient. Patients think staff do not care if keep appointment. Paper gives advice on how to deal with patients who miss appointments.
Lefforge, Noelle, Donohue, Brad, and Strada, Marilyn. (2007)	(a) 'Improving Session Attendance in Mental Health and Substance Abuse Settings: A Review of Controlled Studies.' (b) Conceptual/Discussion. (c) Not UK – USA. (d) Other – Mental Health and Substance Abuse. (e) Other – Community and hospital clinics. (f) N/A. (g) Attendance Improvement: Effective when employ multiple, empirically derived intervention strategies. Need adequate resources; ease of administration; and targeted to population being served. Initial appointment: 1. Schedule appointment to occur as soon as possible. In substance misuse needs to be same day, otherwise within one week. 2. Warn patients of consequences of missed appointments. 3. Give patients opportunity to re-schedule appointments. 4. Telephone calls and reminder letters – Correspondence needs to be received by patient within 48 hours of initial call to clinic. Appointments must be scheduled within reasonable amount of time if calls/letters to be effective. Calls/letters successful when include review of the patients' expectations from the appointment, including care/treatment to be given, addressing the problem that led to the referral, convey benefits of attending, and discuss obstacles to prevent non-attendance with a plan to overcome these. Calls/letters should end with a verbal/written commitment from the patient that they will be attending, and show concern for the patients' well-being. 5. If resources allow, health professionals could visit patients' homes and enlist family members to attend. Subsequent appointments: 1. Parking passes, food

	coupons, small monetary incentives. 2. Offering refreshments/snacks. 3. Give patients positive feedback/praise. If public posting of attendance need consent. 4. Offer transportation if resources available. 5. Implement a lottery and patients earn lottery entries for attended sessions. Patients are then selected from the lottery pool and awarded prizes. 6. Deposit (monetary) policy, and may match deposit. However, subsequently withdrawing incentives can negatively impact on attendance. 7. Automatically re-schedule appointments but non-attendance rates increase. 8. Offer childcare, but limited uptake and needs researching. (h) Many of the studies use small sample sizes, which limits generalisability. So does heterogeneity across study samples. Failed to consider the importance and impact of cultural factors e.g. neglected to include basic demographic information such as gender, ethnicity. Also, the influence of external (court, school, significant other), ethnic and cultural factors on attendance has not been investigated. Consequently, whether these factors have an impact on attendance improvement. Many of the studies failed to give sufficient detail about the nature of their intervention procedures. (i) Need to ask participants how they would improve attendance. Consider ethnic and cultural issues – some participants may be from Eastern Europe. Need to ask country of birth.

Grey literature

Agarwal, K et al. (2011)	(a) 'Tackling the Problem of Hepatitis C, Substance Misuse and Health Inequalities: A Consensus for London.' (b) Grey literature - A framework document. Some qualitative (patient focus groups). (c) UK. (d) Hepatitis C. (e) Other – Substance misuse services. (f) Not given. (g) The document refers to a project ('PREVENT') which aimed to improve the provision of blood borne virus (BBV) services to patients in treatment for substance misuse. Within focus groups patients gave their views about factors affecting attendance at BBV screening and hepatitis B immunisation sessions. These were: • Convenience – Easy access being crucial particularly the location and convenience of

	services. Attendance for hepatitis B immunisation is more likely to occur if linked to regular drug treatment service appointments. • Remembering appointments – Appointment reminders by phone, text or e-mail are useful. • Current drug and alcohol use – This strongly predicts non-attendance but interventions including motivational interviewing and voucher reinforcement may help. • Mental health – Co-morbid mental health problems also predicts non-attendance. Similar interventions used for substance misuse are recommended. • Physical health and wellbeing – Poor physical health and risky drug or sex-related practices are strong motivations for seeking BBV testing. • Needles and blood taking – Patients reported poor venous access and triggering drug misuse as reasons for avoiding BBV screening. A strong preference was expressed for dried blood spot (DBS) testing. Key requirements for future service model include: • Expert phlebotomy services or access to dried blood spot (DBS) testing should be available. • Patient education leaflets about treatment should be developed and provided in an appropriate language. • Consider locating hepatitis treatment services in same place as drug treatment services. • Treatment should be provided by a multi-disciplinary team linking appropriate resources such as psychiatric assessment, psycho-social support, treatment for alcohol dependence, housing support and oral substitution treatment (OST).
Australian Injecting and Illicit Drug Users League (AIVL). (2010)	(a) 'Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use.' (b) Grey Literature – Discussion document. (c) Not UK – Australia. (d) Hepatitis C. (e) Other (f) N/A (g) Identified barriers to testing. It suggests that the same factors also provide insights into why appointments are missed at other stages of the care pathway. The authors add that the poor quality of initial testing can have an impact how people engage in the future about their condition. A combination of barriers (identified via research) that can act in isolation or together include:

	• A lack of awareness of their need for testing. • Myths and misinformation about risk factors. • A lack of an appropriate testing situation – Within drug services some people may feel coerced into being tested for fear of delays in getting onto a drug substitution script. Also, it may not be the right time to be tested for BBVs having just started on substitution drug treatment. In other health care settings there may be a high level of stigma and discrimination around disclosure of injecting drug use which causes concerns for people about the possible negative impact on their ongoing care including restrictions on other medications. • Complacency about hepatitis C – A lack of information and understanding about the need for confirmatory testing (to establish ongoing chronic infection) and the value of ongoing monitoring can result in people developing complacency about disease progression, adopting lifestyle measures to minimise harm to the liver and disengaging with the health system. • Not prioritising hepatitis C. • Fear of the result. • Vein care issues. If there are visible signs of recent injecting drug use people may not attend for testing or ongoing monitoring for fear of this being discovered. Also, a significant deterrent in keeping an appointment is past difficult experiences with staff unable to get the required blood sample even after exhausting all possible sites. • Cost issues and poverty – Additional or specialist diagnostic tests are not always covered by 'Medicare'. People may be in conflict with healthcare staff over non-payment of fees or fines. In addition, there is the added cost of transport to get to appointments. This is also a factor for employed people particularly those on low incomes. As well as the barriers, the research participants also identified factors that contributed to them agreeing to be tested. These were put under four themes: • Convenience and ease of the testing situation; • Feeling comfortable and safe in the testing environment particularly because the testing was carried out by a trained peer worker;

	• Were uncomfortable disclosing their injecting drug use (IDU) status to their regular doctor or expected to be treated poorly in clinical settings; and • Were motivated by a recent risky incident. (h) N/A. (i) N/A.
NHS Greater Glasgow and Clyde. (2012)	(a) 'Greater Glasgow Hepatitis C Outreach Service Evaluation Report.' (b) Grey literature – Service evaluation using quantitative and qualitative data. (c) UK. (d) Hepatitis C. (e) Outreach. (f) 195 infected patients had been lost to hospital follow-up. (g) The patients were approached and asked for 'barriers' that prevented from engaging with the hospital. It was not possible to make contact with 18% (n=35) of the patients who had probably left the addiction service or had been imprisoned. Also, 24% (n=47) of the patients had re-engaged with the hospital clinic. Of the remaining patients the following reasons were given for missed appointments: • 25% (n=49) cited ongoing addiction issues; • 21% (n=40) gave social issues; and • 12% (n=24) reported concurrent physical or mental health issues. The evaluation also sought the views from both hepatitis C addiction nurses and hospital clinical nurse specialists about the patients' reasons for missed appointments. The reasons they gave were: • Informed choice – some patients wanted to know their status but declined further care and treatment. • Fear of the results of the liver assessment and finding out they had serious liver disease. Patients may consider it better not to know, particularly if they are asymptomatic. • Fear of being judged by other people. • Self-stigmatisation and feeling that not entitled to care due to previous drug use. • Concerns about confidentiality and being seen by other people. • Concerns or misinformation about hepatitis such as having a liver biopsy, it is a death sentence, and treatment is ineffective. • Patients tested too early and before they are ready to engage with hepatitis C services. • Patients who drink alcohol excessively know this

	is a barrier to progressing along the care pathway. • Loss of momentum and delays between stages of the care pathway. • Despite support some patients fear or do not understand what will happen at the hospital. • Some patients report that they forget about appointments although this is less of an excuse given the encouragement and reminders from the addiction service and hospital. • Ongoing alcohol and/or drug use. • Money to travel to the hospital, especially if appointments do not coincide with the patients' benefits payments. • Past bad experiences of hospital care and some patients perceive there is a risk of "being treated like a junkie". • Some patients feel there is no urgency to see a hospital specialist because hepatitis C is described as a "slowly progressive disease". (h) N/A. (i) N/A.
Martin, John C. (2005)	(a) 'Hep C Patients First Gastroenterologist Visit More Often: Research.' (b) Grey literature – quantitative study. (c) Not UK – USA. (d) Hepatitis C. (e) Other – Hospital. (f) 66 patients referred for a hepatitis C evaluation – 18% missed their initial appointment. (g) Some experts suggested the early absence of symptoms and a possible lack of effective communication by the referring doctor about the reason for referral may be two factors for non-attendance. In contrast patients with other conditions may be more motivated to attend because they are experiencing symptoms such as diarrhoea, abdominal pain or difficulty with swallowing. (h) N/A. (i) N/A.
Morrison, C et al. (2011)	(a) 'A report on a study exploring non-attendance at specialist clinical HIV services in Scotland.' (b) Grey literature – qualitative (interviews). (c) UK. (d) Other – HIV. (e) Other – NHS, Voluntary and non-NHS statutory services. (f) 70 professionals/stakeholders and 13 people living with HIV. (g) Although the views of both staff and patients were sought, the findings have not been differentiated for the purpose of simplifying reporting them for this review. Thus, the collective reasons given for non-engagement included:

	• Mental health, personal support and stigma – Reaction to a positive diagnosis can include shock and denial. Some people may over-react and believe they are just going to die. Other people may move out of the area to be anonymous elsewhere and avoid engaging with services. Also, individuals may not attend because they are not unwell. For those who struggle to come to terms with their diagnosis, engagement can be a constant reminder of their infection. People suffer from depression or anxiety which may not be formally identified or diagnosed. Following relationship breakdown people reported feeling isolated and a lack of support. Due to stigma and discrimination people may not attend services because the staff are 'unfriendly' and they fear being seen by others they know. • Ethnicity, culture and faith – They may also fear the response from health professionals about their religious and cultural beliefs. Faith leaders offer a cure for HIV via prayer or dissuade individuals using services or treatment. Misinformation is common due to HIV being perceived as a consequence of 'bad' behaviour, where there is a mistrust of treatments, where information about current treatments is inaccurate (based on knowledge of less effective treatment provided in peoples' countries of birth), and where a service's commitment to confidentiality is not understood. In addition, individuals using family or friends to interpret may be worried about being judged or a breach of confidentiality. It is not the norm to keep fixed appointment times. When it hurts taking blood this is interpreted by individuals that staff mean to hurt them. People may have witnessed friends or family die which leaves them with a pessimistic outlook of living with HIV and its treatment. • Migration or political status - People without formal 'leave to remain' are often frightened to register and access primary health care. Also, individuals fear they have to pay for health services. Asylum seekers are afraid to engage with providers because they will be reported to official agencies including the Home Office. Those with migration issues are often mobile and have stressful personal circumstances. They

	may also be unwell. • Substance and alcohol misuse – Alcohol misuse can lead to 'chaotic lifestyles' and difficulties with keeping appointments. Also, drug and alcohol problems can result in psychoses which make clinic attendance difficult. • Information and communication issues – Literacy difficulties make it difficult to understand the information required to access and to engage with services. • Locality or geography – Travelling, particularly if using public transport, to services can be a challenge for people living in rural or island communities. But people may choose to attend city or urban clinics to remain anonymous and protect their confidentiality. Travel costs can be met but this is dependent on staff informing people or individuals asking. • Poverty, employment and benefits – This theme is against the backdrop of the welfare reforms and getting people back to work. Travel costs and loss of pay may contribute to non-engagement with services. A fear of disclosure of HIV status can result in people not following up extra benefit or housing entitlement. Some people work in jobs where employers are not flexible and unquestioning when it comes to attending medical appointments or being unwell. In addition, some individuals 'disappear' into work to distract themselves from their HIV status. • Being in prison. • Caring responsibilities – Some people will also be a carer for a partner, family member, child or friend. For a small number of women childcare was a barrier to engagement. Also, there was a fear amongst some women that where services know their status this might influence decisions made about child welfare. • Co-morbidity – People are likely to suffer ill-health from a number of chronic illnesses. Being unwell including mentally makes clinic attendance difficult. <u>Ways to improve engagement</u>: • Experience of attending clinic – Local clinic provision; flexible and personalised services i.e. accommodating people who find appointment systems difficult by seeing them if/when they turn up, welcoming partners, family members or

	friends who supporting the patient, and meeting patients in non-clinical settings; longer clinic hours. • Starting treatment and adherence – For a person who is well and adhering to treatment – minimise attendance by providing home delivery of medication whilst monitoring the person at less frequent intervals. • When a person fails to attend - Preventing DNA's – Encourage patients to make their own appointments; phone or text reminders the day before or morning of appointment; offering the patient the choice of accessing a different member of clinic staff where been conflict between patient and staff member. Responding to DNA's – Clinic staff can telephone individual and ask them to re-arrange appointment; clinic staff might also contact another agency involved with the patient to find out how they are and if there are current issues which might affect attendance; might contact GP or visit person at home; write to patient, communicate with GP and then subsequently discharge from the clinic. • Working with the voluntary sector – Practical assistance with accompanying a person to clinic appointments; practical support with transport. (h) Sample size relatively small. Findings not representative of experience of all people living with HIV, nor should be taken to be generalisable. In speaking with professionals there was a risk of some level of misinterpretation by professional, or reporting of a distorted (or partial) reality of a person's lived experience. (i) Initially invitation sent to 48 non-attendees (not attended for 'some time') without reply.

Appendix 8: Data extraction tool

Title:	
Authors:	
Year:	
Journal:	
Type of paper: - Empirical - Conceptual/Discussion - Grey literature	
UK/not UK	
Hepatitis C or other	
Outreach or other	
Sample size	
Relevance: (a) Reasons for non-attendance (b) How to undertake project Limitations	

Appendix 9: Study information leaflet

Sheffield Hallam University

Participant information leaflet

Study title:	Explaining non-attendance at drug service hepatitis C outreach clinics: perspectives of clients and staff.
Chief investigator	Mr Ray Poll
Telephone number	0114 271 3561

Study Sponsor: Sheffield Hallam University

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please talk to others about the study if you wish, and ask us if there is anything that is not clear.

Thank you for reading this leaflet.

Participant name:

You will be given a copy of this information leaflet to keep

1. What is the purpose of this study?

The purpose of this study is to find out the reasons why clients referred to the hepatitis C outreach clinic are often unable to attend their appointments. Although it is a study for an educational course, it is hoped that the results will provide information that can be used to improve attendance at the clinic.

2. Why have I been invited?

All patients who have missed appointments in the past will be invited to take part. It would be valuable to draw on your experience for this study.

3. Do I have to take part?

Your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. Your refusal to participate or wish to withdraw would not influence in any way your current or potential future medical care.

4. What will happen to me if I take part?

If you participate in the study you will be interviewed by the researcher (probably by telephone although it could be face-to-face), who will ensure it is a good time to talk. He will explain what you are consenting to, go through the consent form, and sign it on your behalf (for a telephone interview) if you agree to take part. The researcher will ask if it is okay to tape the interview. This is entirely your decision. If you decline the use of a tape recorder the researcher will write notes. The interview will take approximately fifteen minutes to complete.

The researcher will ask your permission to look at your clinic notes to get details that will not be asked during the interview because time is limited. Again this is entirely your decision. If you say 'no' to this you can still take part in the interview.

In the unlikely event that after the interview you do not recall taking part in the study and have difficulty retaining information (called 'loss of capacity'], the researcher would like to keep the data you provided and use it confidentially (with the replies from the other participants] to help answer the research question. If you have any objections to this please let the researcher know before the interview.

5. Expenses and payments.

Unfortunately we are unable to pay you for taking part in this study. However, you will be reimbursed for your time and offered a five pound voucher which can be spent in Boots the chemist.

6. What will I have to do?

If you agree to take part in the study we will ask you to provide your name and telephone number(s) on the enclosed separate sheet. This sheet with contact details will be put in an envelope, and then securely placed in the researcher's work pigeon-hole to collect. As stated earlier, the researcher will then phone you to confirm your consent to taking part before doing the interview. On some occasions the interviewer may be available to do a face-to-face interview when you are attending the drug service. If you do not have a phone

number the researcher would like to do a face-to-face interview and will ask you to provide a contact address to arrange this.

7. What are the possible disadvantages and risks of taking part?

Some of the issues raised by this study may bring up unhappy memories or experiences. For example, of a past or current lifestyle, contact with health and social services, and/or raise anxieties about living with or being at risk of hepatitis C. In this situation it might be helpful for people to discuss these with a member of the team. Please find at the end of this leaflet the names of staff (including their contact details) should you wish to make an appointment for further advice or support. You can also discuss where to go for further help at the end of the interview if you wish.

8. What are the possible benefits of taking part?

Some people gain pleasure in contributing to research and education, and feel that they are being helpful. For example, the results of the study may be of practical benefit by offering ways of improving attendance at clinics. Also, participants will have an opportunity to describe past events and experiences that they may not have shared before. As a result, participants might find the study uplifting, and prompt them to seek further care of their hepatitis C by making another clinic appointment.

9. What if there is a problem or I want to complain?

If you have any queries or questions please contact:

Principal investigator: Mr Ray Poll,
Nurse Consultant,
ray.poll@sth.nhs.uk
0114 271 3561

Sheffield Teaching Hospitals NHS Trust, the Royal Hallamshire Hospital.

Alternatively, you can contact my supervisor:

Peter Allmark, Principal Lecturer and Chair Faculty Research Ethics Committee p.allmark@shu.ac.uk
0114 225 5727

Sheffield Hallam University, Centre for Health and Social Care Research.

If you would rather contact an independent person, you can contact Ann Macaskill, Chair University Research Ethics Committee,
a.macaskill@shu.ac.uk
0114 225 4604

10. Will my taking part in this study be kept confidential?

It might be that in the interviews something of concern arises relating to your health and safety, including an unmet need and it may be necessary to share this with other professionals. Also, if it is believed that a criminal act has occurred, a third party may be seriously harmed or death may occur the police may be informed. These situations will be discussed with you at the time and your consent will be sought where possible. The researcher will act in accordance with his professional Code of Conduct and consult with his supervisor to discuss what to do and/or inform them of any action taken.

The interview will be recorded (with your permission) and then written up

word for word. The researcher will check that the recording and the written transcript are the same. He will then erase the recording. The transcript will be kept on a password-protected computer. Identifying details will be taken out of any final report and any publication so people reading these will not be able to identify you or others. The written transcripts will have all links to you removed at the end of the study and will then be kept for as long as they might be useful in future research.

The documents relating to the administration of this research, such as the consent form signed by you (or by the researcher on your behalf for telephone interviews) to take part, will be kept in a folder called a project file. This is locked away securely. These documents will be destroyed three years after the end of the study.

11. What will happen to the results of the research study?

A copy of the report of the findings from the interviews can be obtained from the drug service. The results of the full study will be included in a dissertation and submitted as partial fulfilment of a doctoral degree. A copy of the dissertation will kept in the university library as a resource for staff and students.

It is hoped that the study will be of local, regional and national interest to health professionals working in the field of hepatitis C, with its findings shared at conferences and published in national journals.

12. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University.

13. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the South Yorkshire Research Ethics Committee.

14. Contact details for advice or support about hepatitis C.

Please contact the persons below for an appointment if needed.

Ms Thea Williams, Hepatitis C Social Worker,
thea.williams@sheffield.gov.uk
0114 226 1142
The Forge Centre, near the Royal Hallamshire Hospital.

Mrs Fran Rayner, Viral Hepatitis Specialist Nurse,
fran.rayner@sth.nhs.uk
0114 271 3561

Sheffield Teaching Hospitals NHS Trust, the Royal Hallamshire Hospital.

15. Further information and contact details.

For general independent advice about taking part in research please contact Ann Macaskill, Chair University Research Ethics Committee,
a.macaskill@shu.ac.uk
0114 225 4604

For further details about this specific study please contact:
Peter Allmark, Principal Lecturer and Chair Faculty Research Ethics Committee

Appendix 10: Contact details sheet

Sheffield Hallam University

PARTICIPANT CONTACT DETAILS FOR TELEPHONE INTERVIEW

Study title.
Explaining non-attendance at drug service hepatitis C outreach clinics: perspectives of clients and staff.

I agree to being contacted about the above study. My contact details are as follows (please complete the boxes below):

Contact details:

Title e.g. Mr, Miss	
First name	
Last name	
Preferred telephone number	
Alternative telephone number (if any)	
Is it okay to leave a message?	**Yes / No (circle which applicable)**
Contact address (only complete if no phone number)	
Date	
Signature	

Appendix 11: Permission letter - Basic structure of the realist interview (Diagram in Pawson and Tilley, 1997 page 165)

Dear Ray Poll,
Thank you for your email.

Please consider this email as written permission to include figure 6.4 from our publication *Realistic Evaluation* in your thesis to be posted on your institutional repository.

Please note:
This permission doesn't cover any 3rd party material found in the work.
The author needs to be informed of this reuse.
A full academic reference to the original material needs to be included.

Best Wishes,

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Thank you for considering the environment before printing this email.

Appendix 12: Interview guide

Explaining non-attendance at drug service hepatitis C outreach clinics: perspectives of clients and staff.

Interview Guide

Thank you for giving me your phone number (telephone interview) and agreeing to talk with me about appointments with the hepatitis C outreach clinic at Guernsey House/Fitzwilliam Centre.

Many people miss appointments with the clinic and I would value your experience in understanding the reasons why. If the reasons were known it might be possible to do things to improve attendance.

Are you still happy to take part? Do you have any questions? Are you happy for the interview to be recorded?

The interview will probably take no longer than fifteen minutes.

Questions:

Can you tell me what made it difficult for you to keep an appointment with the hepatitis C outreach clinic?
Prompts:
- Busy doing other things (not a priority), forgot appointment, did not know what appointment for, not unwell, problems with travel (cost and distance), wrong time of day, fearful of health consequences and/or tests

Is there anything about the clinic environment or the way people are treated that may influence if they turn up?
Prompts:
- Others experience
- Your own experience
- Other clinics, e.g. local doctor, benefits, job centre
- Hepatitis C clinics

What do you think are the reasons for other people not attending the hepatitis C outreach clinic?
Prompts:
- Busy doing other things (not a priority), forgot appointment, did not know what appointment for, not unwell, problems with travel (cost and distance), wrong time of day, fearful of health consequences and/or tests

Telephone and/or text reminders have been tried to improve attendance at clinics. How would they work? Who would they work for? Why would they work?

So in summary .....

I have no further questions. Is there anything else you would like to bring up, or ask about, before we finish the interview?

A copy of the report with findings from the interviews will be available from the drug service from November 2012.

Thank you for your time and taking part.

Appendix 13: Consent form

Sheffield Hallam University

Participant consent form

Study title:	Explaining non-attendance at drug service hepatitis C outreach clinics: perspectives of clients and staff.
Chief investigator	Mr Ray Poll
Telephone number	0114 271 3561

Participant name	

	Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them	**Please initial each box**
1	I confirm that I have read and understood the information leaflet dated 28 November 2011 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.	
3	I agree for the interview to be taped.	
4	I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the Sponsor, the Research Ethics Committee and from the NHS Trust, where it is relevant to this research. I give permission for these individuals to have access to my records.	
5	I agree for the researcher to access my clinic records to obtain relevant background details.	
6	I agree to take part in this study	

To be filled in by the investigator on the participant's behalf

The participant agrees to take part in the above study

Name of investigator	Date	Signature

To be filled in by the person obtaining consent

I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.

Name of investigator	Date	Signature

Filing instructions

1 original in the Project or Site file
1 copy in the clinic notes

Appendix 14: National survey to health professionals

Non-attendance at drug service hepatitis C outreach clinics: an evaluation.

1. Do you run an outreach service within a drug clinic for people with or at risk of hepatitis C?	Yes	□	No	□

2. What does the drug clinic offer to clients in addition to the hepatitis C outreach clinic? (tick all that apply)

Substitution treatment e.g. methadone	□
Needle exchange	□
Counselling	□
Key working	□
Blood borne virus testing	□
Hepatitis B immunisation	□
Other (please specify)	□

3. What does the hepatitis C outreach clinic offer to clients? (tick all that apply)

Pre-test discussion and information	□
Blood borne virus testing	□
Post-test discussion and information	□
Hepatitis B immunisation	□
Hepatitis C treatment	□
Referral to hospital for treatment	□
Other (please specify)	□

4. How frequently does the hepatitis C outreach clinic run?

Daily	□
Weekly	□
Fortnightly	□
Monthly	□
Other (please specify)	□

5. How is the outreach clinic delivered? (tick all that apply)

Appointments made in advance	□
Drop-in	□
Other (please specify)	□

6. How many clients can be seen during each outreach clinic session?

1-4 clients	□
5-9 clients	□
10 or more clients	□

7. Which member of staff usually delivers the hepatitis C outreach clinic?

Hospital Doctor	□
Hospital Nurse	□
Drug service staff	□
Other (please specify)	□

8. At each outreach clinic session, approximately how many clients usually do not turn up?

Less than 10%	□
Between 10% and 25%	□
Between 25% and 50%	□
More than 50%	□
Any other comment you deem important.	

9. What do you think are the reasons why clients miss appointments with hepatitis outreach clinics? (Client characteristics, tick all that apply)

Ongoing drug use	□
Ongoing alcohol use	□
Being in custody	□
Having mental health problems	□
Having physical health problems	□
Difficulty with walking	□
Poor venous access	□
Working	□
Lack of money	□
Lack of social support	□
Looking after children	□
Forget	□
Multiple appointments with other agencies	□
Other (please specify)	□

10. What do you think are the reasons why clients miss appointments with hepatitis outreach clinics? (Hepatitis C, tick all that apply)

Do not know if the infection is still present or cleared itself	☐
Lack of information given at diagnosis about the infection	☐
Afraid of the consequences of the infection on their health	☐
Asymptomatic – do not feel unwell	☐
Believe may not die from the infection	☐
Believe treatment not curative	☐
Scared of side-effects of treatment	☐
The infection carries a stigma	☐
Other (please specify)	☐

11. What do you think are the reasons why clients miss appointments with hepatitis outreach clinics? (Outreach Clinic, tick all that apply)

Held on different day to drug clinic appointment	☐
Held at inconvenient time of day	☐
High cost of travel	☐
Difficulty claiming travel expenses back	☐
Clinic too far away	☐
Fearful of meeting other clients and being tempted to score	☐
Lack of confidentiality – other clients know what attending for	☐
Unable to get blood sample(s)	☐
Other (please specify)	☐

12. From the answers you have given please identify below 3 you consider the most important reasons for missed appointments. Rank them in order of importance with 1 being the most important.

	1st	2nd	3rd
Ongoing drug use			
Ongoing alcohol use			
Being in custody			
Having mental health problems			
Having physical health problems			
Difficulty with walking			
Poor venous access			
Working			
Lack of money			
Lack of social support			
Looking after children			
Forget			
Multiple appointments with other agencies			
Do not know if the infection is still present or cleared itself			
Lack of information given at diagnosis about the infection			
Afraid of the consequences of the infection on their health			
Asymptomatic – do not feel unwell			
Believe may not die from the infection			
Believe treatment not curative			
Scared of side-effects of treatment			
The infection carries a stigma			
Outreach clinic held on different day to drug clinic appointment			
Outreach clinic held at inconvenient time of day			
High cost of travel			
Difficulty at outreach clinic claiming travel expenses back			
Outreach clinic too far away			
Fearful of meeting other clients at outreach clinic and being tempted to score			
At outreach clinic, lack of confidentiality – other clients know what attending for			
At outreach clinic, unable to get blood sample(s)			
Please specify any other answers in ranked order			

13. Have you taken any steps to reduce non-attendance in the outreach clinic?	Yes	☐	No	☐
If yes, please describe below the steps you have taken.				

14. Have you evaluated the impact of these interventions?	Yes	☐	No	☐

15. If you answered yes to question 14, would you be willing to share the report?	Yes	☐	No	☐
Any other comment				

16. Please describe how successful the intervention(s) was.

17. If needed, would Ray be able to contact you to clarify your responses to the survey?	Yes	☐	No	☐

If you wish to receive a copy of the research report please provide contact information below.

Many thanks for taking the time to complete this survey.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Hepatitis Outreach Clinic: Information for patients

Who is at risk of getting hepatitis C?
The greatest risk of getting hepatitis C is through the sharing of blood contaminated equipment, for example spoons, filters and water, by injecting drug users, with approximately 1 in 2 being infected.

What is the Hepatitis Outreach Clinic?
The hepatitis outreach clinic gives you the chance to talk to an experienced nurse from the hospital team about hepatitis C (and Hepatitis B and HIV). In particular, it provides the opportunity to talk about treatment for hepatitis C and what this involves. Even if you are undecided or do not wish to access treatment at this time, the nurse can still arrange an appointment with the hospital clinic for further assessment, care and advice.

When is the Hepatitis Outreach clinic?
The clinic is held every two weeks at the following times:

- Guernsey House – Tuesday morning 10am to12midday
- The Fitzwilliam Centre – Thursday afternoon 1.30pm to 4.00pm

How do I get an appointment?
You can ask your doctor, key worker or the receptionist to arrange an appointment. These last about 20 to 30 minutes.

Will information about my hepatitis be kept confidential?
The outreach clinic will not tell your partner, family and friends about your hepatitis, but you will be encouraged to discuss it with them so that they may offer you further support. With your consent the outreach clinic will usually inform the drug team and your general practitioner (GP) about your hepatitis particularly if you are referred to the hospital for further care and treatment.

Will I get my travel expenses back?
You may be entitled to claim back bus fare or mileage expenses if you are on certain benefits. To claim back travel you will need to bring with you proof of benefit and all public transport tickets.

Is there a vaccine to prevent infection?
Although there is not a vaccine to prevent hepatitis C and HIV, there is for hepatitis B. Please ask your doctor or key worker about hepatitis B vaccination.

Can these infections be cured?
We can cure hepatitis C for most people. Although we can treat HIV and hepatitis B, these infections cannot be cured.

What if I want to know more about treatment?
If you would like more information about the care and treatment provided at the hospital, please ask the nurse at the outreach clinic.

Where can I get more information?
If you would like more information, please talk to the nurse at the outreach clinic, or you could try the sources of information listed below:

The Sheffield Hepatitis C Support group
Please contact Thea at the Forge Centre on 0114 3054142 for further information.

The Hepatitis C Trust
Website: http://www.hepctrust.org.uk/
Confidential helpline ring: 0845 2234424 or 020 7089 6221 (Monday to Friday 10.30am to 4.30pm).

Appendix 16: New patient clinic appointment letter

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

{PTTIT} {PTFNAMES} {PTSNAME}
{PT PTAD1}
{PT PTAD2}
{PT PTAD3}
{PT PTAD4}
{PT PTPCODE} {TODAY: D3}
Hospital no: {OPRCNOTE}

NHS No: {PTNHS}

Dear {PTTIT} {PTSNAME}

On : {OPDTIME: DA} at {OPDTIME: D8}
Clinic : {OPCLCD}
Specialty : Infection and Tropical Medicine

Location : E3 Outpatients (E Floor)

If you are unable to attend the above appointment, please contact us as soon as possible on (0114) 2713560 to arrange another date.

Please note, if you miss your appointment without cancelling it then you will not be offered another appointment without a further referral.

The NHS constitution says that you have the right to start your Consultant led treatment within a maximum of 18 weeks from when we receive the referral from your doctor, if both you and your doctor decide that treatment is needed within this time frame.

You may receive an automated reminder to confirm your appointment. Should you wish not to receive this service please let the clinic receptionist know on your next visit.

Please allow enough time for your journey. Parking is extremely limited on all hospital sites. You may prefer to use public transport.

You may be entitled to claim back bus fare or mileage expenses if you are on certain benefits. To claim back travel you will need to bring with you proof of benefit and all public transport tickets.

Further, if you are given a prescription in clinic there will be the usual charge, unless you are able to provide proof of exemption.

We are an Academic Directorate and actively involved in medical student teaching and conducting research. You may be approached with regard to this but are under no obligation to participate.

On behalf of the Team I look forward to seeing you.

Dr [*Name*]
Consultant Physician

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Welcome to the Hepatitis Clinic

E3 Outpatients
Royal Hallamshire Hospital

Department of Infection and Tropical Medicine

Telephone:
0114 **271 3560** Appointments
0114 **271 1884** Nurses

We have written this leaflet to tell you about the Hepatitis clinic and answer some of the more commonly asked questions about hepatitis and the clinic.

We hope that you find this leaflet helpful. However, if after reading it you still have some questions, please feel free to ask any of the clinic staff.

What is the Hepatitis clinic?
The Hepatitis clinic is where we care for and treat people who have infections of the liver. There are various infections that can affect the liver, mainly caused by hepatitis viruses. A virus is a germ that is too small to see even under a microscope. In this clinic we deal mainly with patients who have the **Hepatitis B** or **Hepatitis C** viruses.

Where is the clinic?
The clinic is in E3 Outpatients on E floor of the Royal Hallamshire Hospital.

How often are the clinics?
There is a Hepatitis clinic every week.

Please feel free to write the date and time of your appointment in your leaflet.

Date / /___ Time :_____

How long will my appointment last?
Your first appointment at the clinic will usually last 2 hours. Follow-up appointments are usually shorter. We ask you to arrive for your appointment in good time to avoid delays. However, delays can occur because some patients need extra support, and clinics can get very busy. If you have been kept waiting more than 30 minutes for your appointment please ask to speak to the nurse in charge and bring it to their attention.

What happens when I come to the clinic?
When you arrive, please go to the reception desk and let us know that you have arrived. The receptionist will politely ask that the information we have including your address, telephone number and general practitioner (GP) is correct. We will then ask you to sit in the waiting area until a nurse calls you. When you are called, the nurse will weigh you and take your blood pressure. This is a good time to let the nurse know if you have any particular health problems or for you to ask any questions you might have about the clinic or hepatitis.

What happens next?
All new patients will see a doctor or specialist nurse, experienced in the care and treatment of patients with hepatitis. They will ask you some questions about yourself and your illness, arrange a physical examination if you need one and then take a blood sample for testing. You can have a friend or relative with you during your appointment if you like. The Royal Hallamshire Hospital is a teaching hospital. Your doctor will ask your permission for student doctors to be present at your appointment. It will not affect your care should you choose to decline this and your doctor will politely ask them to leave.

Will I need to have any other tests?
All new patients will be offered:

- An abdominal ultrasound scan to provide information about the surface and the general shape of your liver, as well as any significant changes from its normal appearance.
- A Fibroscan® test which uses sound waves to measure the degree of liver stiffness, or scarring (known as fibrosis).

Both these procedures use a probe, like a microphone, which is moved across the surface of the skin. They are not painful procedures and usually take no more than twenty minutes each to complete.

Will I have to have a liver biopsy?
Some patients need a liver biopsy because it is a good way of seeing if your liver is damaged. If you do need a biopsy, you will need to come into hospital for a day. If you live alone or more than half an hour's journey away you may need to stay overnight. Biopsies are not usually arranged on your first visit to the clinic.

Will I get treatment for my infection?
Whether we offer to treat you is something that the medical team in charge of your care will decide. This decision is based on the results of your tests and on guidelines from the government that say when treatment should be offered but your views and wishes will be important in reaching the final decision.

If you have hepatitis B infection treatment is usually only given if damage to the liver is likely.

If you have hepatitis C infection then treatment may be given whether damage to the liver has occurred or not. However, some people are not referred for treatment straight away because they need a longer period of assessment, and to give treatment the best chance of working some people are asked to make lifestyle changes first, such as keeping their alcohol intake to a minimum or to lose some weight.

What other help can you offer me?
At the clinic, we have experienced nurses and doctors to give you support during your treatment and care.

In addition, there is a social worker to provide emotional and lifestyle support, a dietitian to give advice on achieving an adequate level of nutrition, and a clinical psychologist to assess mental wellbeing and give support if necessary.

Does treatment work?
The treatment for Hepatitis C has improved over recent years and in many cases treatment results in complete clearance of the virus. The treatments for Hepatitis B have also improved over recent years and whilst they cannot cure the condition, they will help to lower the amount of virus and reduce the risk of liver damage.

Will information about my hepatitis care be shared with other professionals?
In the interests of providing you with additional support it may be necessary to involve the expertise and support of other members of the multi-disciplinary team such as the social worker and psychologist in your care. This would be discussed with you and getting your agreement is important. In preparation for treatment for Hepatitis C it is routine to meet with either or both of these members of staff for assessment to help ensure that you are able to go ahead with treatment and are fully supported during it. If you are already receiving care and support from another department or agency for an underlying condition or for any other reason it is usual to inform them about the care and treatment you are getting in this clinic. This includes your general practitioner (GP) who will be kept informed about your progress.

Will I get my travel expenses back?
You may be entitled to claim back bus fare or mileage expenses if you are on certain benefits. To claim back travel you will need to bring with you proof of benefit and all public transport tickets.

Who can I contact if I have any concerns when I get home?
You can speak with one of the specialist nurses working in the clinic

Telephone: **0114 271 3561**

08.30 am to 05.00 pm

Monday to Friday

If they are not able to speak with you then please leave a message (giving your name and telephone number) and they will telephone you back.

Outside of these hours you can telephone your local doctor (GP) or the 24 hours NHS Direct helpline: **111**

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Hepatitis C Treatment Survey

Locally treatment for hepatitis C is given at the Royal Hallamshire Hospital. We would like to know if people would be interested in getting this treatment at Guernsey House. This may mean having one appointment at the hospital and the others at Guernsey House.

If it is possible, would you like to have your hepatitis treatment at Guernsey House instead of the hospital? (Please place an **X** in a box).

Yes	
No	

If you like to list your reasons for your choice it would be helpful to us.

Thank you.

Sheffield Infection Group

'It's a little more complicated than that' – reasons for missed appointments with a hepatitis C outreach clinic.

Ray Poll[1], Peter Allmark[2], Angela Tod[2]

[1]Dept of Infection & Tropical Medicine, Sheffield Teaching Hospitals & [2]Centre for Health & Social Care Research, Sheffield Hallam University

Background

Non-attendance in the drug service hepatitis C outreach clinic means clients miss the opportunity of referral for hospital treatment. A qualitative study was undertaken to investigate the problem.

Aim

To identify the reasons why clients miss appointments with two drug service hepatitis C outreach clinics.

Method

Clients with a history of not attending the outreach clinic were invited to participate. A contact details sheet was completed by those agreeing to take part. Verbal consent was re-taken and recorded before the telephone interview commenced.

Results

28 telephone interviews were undertaken from April to June 2012. All the participants gave immediate 'prima-facie' reasons for non-attendance. Many wider social, cultural, and environmental factors were identified as influencing these 'prima-facie' reasons (see Figure 1. Thematic framework). The 'prima-facie' reasons were:

- 'Not a priority' to attend because of the need to score drugs partly to avoid the effects of withdrawal;
- 'Forgot' to attend mainly because of having multiple appointments with other agencies to keep; and
- 'Not bothered' to attend due to drug and alcohol use.

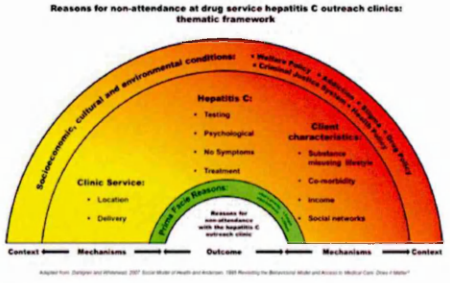

Figure 1.

The participants typically gave multiple factors for not keeping an appointment (see case study below). A complex and variable picture emerges that is more intricate than the initial 'prima-facie' reasons.

Case study.

Howard needed a blood test to confirm his hepatitis C status but he had poor veins. He was not *"bothered"* about an appointment if there was no signs of infection and *"everything was alright"*. Staff had tried in the past with *"big needles"* but were unsuccessful so there was *"no point in going"* to the outreach clinic. Howard also described not wanting to get tested for fear of testing positive. Other reasons he gave for not attending was the outreach clinic being held on a different day to the one for his drug substitution treatment script. This meant attending two appointments in one week. It was a long distance to the clinic and involved getting two buses. Also the cost of travel was expensive.

Discussion

All the participants gave straightforward explanations for non-attendance. These 'prima-facie' reasons are also often adopted by health professionals. This leads to individuals being blamed for missed appointments and labelled as 'hard-to-reach', 'chaotic' and so on. However, the study offered insights into a substance misusing lifestyle and revealed many underlying 'causes of the causes'.

Conclusions

The reasons for missed appointments at a hepatitis C outreach clinic are more complex than the initial explanations given. The underlying causes need to be understood if we are to consider solutions to improve attendance.

Appendix 20: Book chapter

Chapter 11: Preventing ill-health – Assessing the potential impact of NICE guidance to promote and offer hepatitis C testing within drug services

Introduction

Hepatitis C is a blood-borne virus that primarily affects the liver. Without treatment it can cause advanced liver disease (cirrhosis), liver cancer (hepatocellular carcinoma [HCC]) and sometimes death (National Institute for Health and Clinical Excellence [NICE], 2006). Infection disproportionately affects people from the poorest sections of society, who "... have not succeeded in education, have little work experience, lack supportive relationships and often suffer with poor mental health ..." (National Treatment Agency [NTA], 2012 p4). Thus, the lifestyle of those susceptible to infection is embedded in the wider social, environmental and economic determinants of health (Dahlgren and Whitehead, 2007). Although hepatitis C is a global health problem, the focus of this chapter is on the UK.

Marmot (2010) proposes that an investment in ill-health prevention will reduce health inequalities, and will improve the health and life expectancy of the population. In this endeavour he recommends using NICE programmes to deliver interventions because they are evidence-based, include an "inequalities filter" and are assessed for cost-effectiveness (Marmot, 2010). NICE produces evidence-based guidance on treatment, procedures and devices which represent high quality care and value for money for the NHS (NICE, 2012a). NICE also produces public health guidance recommending the best ways to prevent disease and promote wellbeing.

This chapter presents some findings from a qualitative research project that explored the reasons for missed appointments at drug service hepatitis C outreach clinics. The findings are used to explore the potential effectiveness of a new piece of NICE guidance (2012b) for promoting and offering testing to people at high risk of hepatitis C (and B). The guidance is in keeping with a priority for Marmot (2010), namely to prevent and diagnose conditions early that are strongly related to health inequalities.

Thus, the chapter comprises of three sections:

- The health burden of hepatitis C and current policy to tackle this
- An outline of the research project and some of the findings
- Discussion of the findings and how these might impact on implementation of the testing guidance for hepatitis C.

Theory and policy: the health burden of hepatitis C

There are approximately 123 million people chronically infected with hepatitis C worldwide (Shepard et al, 2005). In England (a low prevalence country), 85,565 people were diagnosed up to 2010, although it is estimated that 161,320 people are actually infected (Health protection Agency [HPA], 2011). Many people remain undiagnosed, largely because of the

asymptomatic nature of infection. About 90% of infections are attributable to injecting drug use, with approximately half from this group infected (HPA, 2012a).

Despite the chance of a cure for the majority of chronically infected people, only about 20% were treated between 2006 and 2011, with just 3% treated each year (HPA, 2012b). In England, it is predicted that by 2020, approximately 16,000 individuals will be living with cirrhosis or HCC if their hepatitis C remains untreated (HPA, 2012b). Not only is there a health burden for people with hepatitis C, but also an escalating cost to health services. Both the number of hospital admissions and liver transplants performed has risen as a result of hepatitis C-related disease (HPA, 2012b).

In England (and elsewhere), action plans and work programmes are in place to tackle hepatitis C, with four key areas identified:

(a) The prevention of new infections
(b) Raising awareness of infection
(c) Increasing testing and diagnosis
(d) Engaging infected individuals into care and treatment.

(a) Prevention of new infections

To reduce drug dependence and stop people injecting, opiate substitution therapy (OST) e.g. methadone, is offered by specialist clinics and some general practitioners (GPs) (NICE, 2007). For those who continue to inject, needle and syringe programmes (NSPs) based in drug services and chemists provide clean equipment (NICE, 2009). It is argued that a combination of OST, NSPs and the treatment of injecting drug users (IDUs) with hepatitis C may reduce the incidence and prevalence of the infection (Martin et al, 2011).

Marmot (2010) agrees that OST is an essential part of drug policy but reminds services of the need to address peoples' "individual factors" or social issues e.g. homelessness, to ensure treatment is accessible. He adds that "medicalising" drug use (*versus* criminalising it), by referring people to drug courts comprising health and social care professionals, can lead to an increased uptake of drug treatment and a reduction in mortality (Marmot, 2010), thereby recognising and being inclusive of the wider determinants of health which can negatively impact on access to healthcare services (Dahlgren and Whitehead, 2007).

(b) Raising awareness of infection

Reducing undiagnosed infection is a priority, with articles in professional journals, magazines and newspapers and in television and radio programme broadcasts. Internet websites have flourished, including one inviting people to undertake a quick anonymised questionnaire to assess their infection risk (NHS Choices, 2012). Leaflets and posters are displayed in general practice surgeries and clinics, and educational sessions are provided for professionals and risk groups in a variety of settings, including hostels and

prisons. Recent developments include the Royal College of General Practitioners certificate in hepatitis C (and B) for primary care professionals, and the establishment of World Hepatitis Day (28 July) with testing often available at events.

With a good start in life being fundamental to the avoidance of later inequalities, Marmot (2010) recommends that school children are equipped with knowledge and skills to resist experimenting with drugs and entering a life of addiction.

(c) Increasing testing and diagnosis

To improve access to testing for marginalised groups (including IDUs), this may take place in general practice surgeries, ante-natal clinics, drug misuse services, prisons, and Genito-Urinary Medicine sexual health clinics (Department of Health [DoH], 2004). Locally, two drug service hepatitis C outreach clinics have been established to increase rates of diagnoses (and attendance for treatment) but many patients do not keep their appointment.

New NICE guidance (2012b) to promote and encourage people at risk of infection to be tested has been published. The recommendations for drug services include:

- Identifying a hepatitis lead with knowledge and skills to promote testing and treatment, with consideration given to training peer mentors and health champions to support this work;
- Ensuring that there is a local care pathway into specialist care for infected people, including the possibility of providing treatment in the community combined with OST, and facilitated by access to specialist phlebotomy services;
- Offering and promoting testing to all service users, with annual screening for people who test negative for hepatitis C but remain at risk of infection; and
- Ensuring that staff have the knowledge and skills to promote testing and treatment, and are trained and competent to undertake pre- and post-test discussions and dried blood-spot (DBS) testing (for people with poor venous access).

(d) Engaging infected individuals into care and treatment

Individuals with chronic hepatitis C should be referred for specialist care and treatment (DoH, 2002). Hospital-based specialist nurses run clinics to assess patients, and to commence them on treatment and monitor the side-effects of this. However, many people do not engage with health services and remain untreated (Maghlaoui, 2012). Non-attendance with the local drug service hepatitis C outreach clinics also means patients miss the opportunity of referral (by this route) to the hospital for care and treatment.

One successful strategy has been to make services more accessible, with treatment provided in non-traditional settings such as prisons, drug misuse services and health centres (Lewis et al, 2012). This provision has been somewhat limited, with expansion recommended (HPA, 2012b).

In summary, despite policy and action plans to prevent transmission, to raise awareness and to increase testing, with established pathways into curative treatment, many people with hepatitis C remain undiagnosed or untreated.

There are several possible reasons why people remain untreated: too few specialist nurses to deliver the service; different clinical interpretations of guidelines, with groups of patients treated in some areas and not others; and patients missing appointments (Stephens, 2012). The latter is the focus of the qualitative research discussed in this chapter.

Research and findings

This study investigated the reason for missed appointments with drug service hepatitis C outreach clinics. The rationale for the research approach and some of the study findings now follows.

The research approach

In the absence of previous research, the reasons why people with hepatitis C miss clinic appointments appear uncertain. Explanations are often based on assumptions of 'chaotic lifestyles' and that people are 'hard-to-reach'. It could be argued that these terms blame individuals for their ill-health and non-engagement with health services, and fail to examine 'upstream' wider social and economic determinants of health (Dahlgren and Whitehead, 2007). The Leeds Declaration in 1993 suggested that public health's past reliance on traditional epidemiological data from bio-medical quantitative studies must be challenged, with gaps in understanding filled by using more appropriate qualitative methods (Long, 1994). As well as making sense of the causes of ill-health, lay people's knowledge is important in understanding their experience of health services. They are likely to ascribe different experiences and meanings to health and illness that are not always captured using quantitative methods.

Having identified a gap in knowledge this study sought explanations from patients about missing appointments. Qualitative semi-structured interviews enabled participants to express their point of view and reflect a real world situation. Telephone interviews were used in preference to face-to-face interviews because:

- the nature of the research topic meant participants may not turn up for an interview;
- drug users may live in parts of the city which due to a high rate of crime might be considered unsafe to visit (Marcus and Crane, 1986);
- the cost of undertaking telephone interviews, in terms of time, effort and money is lower (Denscombe, 2003); and
- the relative anonymity of telephone interviews, lack of face-to-face contact and the establishment of confidentiality enables people to talk honestly and openly about their experiences (Carr and Worth, 2001).

At a routine drug service appointment, staff offered the clients with a history of not keeping an appointment with the outreach clinic an information leaflet giving a brief explanation of the study, and invited them to participate. Those with a written or verbal diagnosis of hepatitis C (including past or current infection) or clients seeking testing were included. Clients agreeing to be interviewed were asked to complete and sign a contact details sheet giving a preferred telephone number to the researcher.

Research findings

Twenty-eight interviews were completed. For the purposes of this chapter, the findings from these interviews will focus on three areas:

(i) Beliefs and expectations about hepatitis C
(ii) 'Bad' veins
(iii) Poverty.

(i) Beliefs and expectations about hepatitis C

One theme emerging as important to missed appointments related to beliefs and expectations about hepatitis C (derived from different sources including other infected people). These varied and sometimes conflicted within and between participants. For example, some people felt the infection trivial and others believed there to be no effective treatment, so there was no point in turning up. Some illustrations are given here.

Asymptomatic nature of infection

There was a perception that not experiencing any symptoms of infection or that the infection is not severe and at a "low level" meant it was reasonable not to take further action.

"…. there is a bit of a myth what I have heard from some people that hepatitis it doesn't really matter if you have got it because it won't affect you for such a long time anyway or maybe it won't affect you at all..." (Male, aged < 30 years old).

Treatment: effectiveness and side-effects

For some people there was no point in attending because they mistakenly believed treatment may not cure the infection and it just makes you less infectious to other people. Others were scared of the side-effects of treatment because they heard that peoples' hair falls out and so likened it to "chemotherapy". Some were worried about the impact of potential side-effects on their health and daily activities.

"Another thing that put me off …. a bit as well is like treatment you know people saying to me it makes you really ill and things like that" (Male, aged < 30 years old).

(ii) *'Bad' veins*

A further explanation for missed appointments related to drug use and addiction. Sub-themes identified within this category, include the physical consequences of drug use and people having 'bad' veins. People were put off

keeping appointments because they anticipated staff would not get a blood sample, which also resulted in not having a clear diagnosis.

Poor experience of blood tests
People reported health professionals dismissing patients' advice of where to locate a vein, using needles that were too big and attempting several times without success.

"..... we hate it, absolutely hate it. ... It takes ages to get any kind of blood out even a dribble and when you tell somebody where to go they'll be going .. oh no, no, no like they know best but you end up coming out looking like that thing off .... With cotton wool balls all over us where we've been speared a million times" (Female, aged < 50 years).

Unclear about diagnosis
Due to difficulties with getting blood, some people reported not being tested at all or they were uncertain about their diagnosis because alternative methods to blood such as mouth swabs were unable to identify whether the infection had gone or if it was still present.

"..... I had never been tested until I'd seen P.... till he did me that swab test in my mouth and he said it's showing antibodies but that could mean that you have had it or you have got it. I would need to go for a blood test next and that puts me off ..... there is no way I can come to you and you take blood out of me....." (Male, aged < 40 years old).

(iii) Poverty
The last emerging theme to explain missed appointments is poverty. People claiming benefits described the high cost of travel to services, and participants experienced difficulties in getting re-imbursement of their travel expenses.

High cost of travel
Participants suggested the cost of travel to services was prohibitive, which was exacerbated if they had to attend an additional appointment in the same week, or if their usual benefit had been reduced for non-qualification of entitlement, e.g. they were subsequently deemed not sick and fit to work or because they owed the council money.

".... It's like expensive now on buses. It's like £5 for an all day saver and some people..... haven't got that kind of bus fare" (Male, aged < 40 years).

Re-imbursement of travel expenses
Whilst some people received re-imbursement of their travel expenses with the drug clinic, others did not, including if they attended other agencies.

"And I think what's the point of me bloody going when I am not going to get me bus fare back" (Female, aged < 50 years).

In summary, peoples' experiences of missing appointments provided some revealing explanations, including: misperceptions and differences of opinion about the consequences of infection and its treatment; the difficulties with health professionals getting blood and not having a clear diagnosis; and being on benefits with the high cost of travel and not getting fares reimbursed.

Application to practice

From what the research participants said about missed appointments with the hepatitis C outreach clinic, it would appear that the new NICE guidance (2012b) has largely addressed the difficulties with testing they described. The guidance recognises that people at risk of infection may have poor venous access and drugs services staff need to be trained and competent to perform DBS tests as an alternative to taking blood. The participants also said that where an alternative means of testing had been used in the past, i.e. mouth swabs, a positive result only told them that that they had been exposed to the infection. Thus, because a blood test was still needed to establish if the infection was present they missed an appointment and remained unclear about their diagnosis and whether they needed treatment. The new guidance (NICE, 2012b) addresses the problem of an unclear diagnosis by recommending laboratories used by drug services (and other testing centres) ensure that the additional test to confirm if the infection is still present is automatically performed following an initial positive result. This policy will enable people tested at their first visit to be clear about their diagnosis and for staff to discuss referral for treatment with those chronically infected. As described under '(a) prevention of new infections', it is important that staff address the social factors which may impair people's ability to attend for treatment (Marmot, 2010).

The feedback from research participants about missed appointments also identified some issues related to treatment beliefs regarding hepatitis C, such as not knowing whether it could cure the infection, if treatment was always necessary and when it should be started, whilst others had heard negative stories about its side-effects. The new testing guidance (NICE, 2012b) recommends staff should have the knowledge and skills to promote treatment. Thus, the staff should then be in a position to dispel any inaccuracies or myths that people hold and inform them of the benefits of attending for specialist care and of curative treatment, despite the absence of symptoms. This research identified some of the particular issues the participants voiced about treatment, which staff should be aware of and discuss with hepatitis C infected individuals. For Marmot (2010) an early diagnosis is a priority in helping to reduce inequalities. The treatment for hepatitis C is more likely to be successful with an early diagnosis and before the development of advanced liver disease (Foster et al, 2007). In addition, following a diagnosis, people will be usually offered advice and support to make lifestyle changes to minimise further harm to the liver e.g. reducing their alcohol intake, and to avoid infecting others by not sharing drug injecting equipment. Again, it is important that this advice and support

addresses the wider social determinants of health to help people make positive lifestyle changes (Marmot, 2010).

Regarding the last theme to emerge from the research, poverty, this was both a consequence of ill-health, with people being unable to gain employment, but also a determinant of ill-health, with individuals less able to access essential services (Dahlgren and Whitehead, 2007). The research participants talked about the high cost of travel, which was more keenly felt as most were on benefits. Some described this problem as being exacerbated if they had to attend additional appointments or had to make choices as to how best to spend their limited income. For these reasons, it was important to the participants that they were able to get their travel expenses reimbursed, which was a difficulty for some. The new testing guidance (NICE, 2012b) for drugs services recommends the possibility of providing community treatment alongside OST, which will require regular blood tests and monitoring. This, alongside the testing recommendations (including the giving of results) will create additional appointments for clients to attend. Neither the guidance, nor Marmot (2010) appears to explicitly recognise the financial problems of people on low incomes having the money to attend more appointments, particularly if they are to be offered treatment. The research participants suggested services consider allocating people a monthly bus pass to help with attendance at appointments. This has been identified elsewhere to help IDUs access and benefit from services (Neale et al, 2007). Arguably this could be money well spent, as more people could be treated and cured of their infection, potentially avoiding the high healthcare costs associated with managing advanced liver disease (outlined at the beginning of the 'theory and policy' section).

Therefore it can be concluded that, when measured against findings of qualitative research into missed appointments with hepatitis C outreach clinics, the new NICE guidance (2012b) has the potential for more people to be tested for hepatitis C, and to be informed of curative treatment for which they can be referred to a specialist service. However, the qualitative research findings also indicate the guidance fails to adequately address the issue of poverty on patients' ability to keep appointments and the subsequent impact of this on their access to treatment. Addressing this issue will entail working in partnership with benefit agencies to ensure that patients are kept updated and informed of entitlement and that access to this is not complicated. This may be difficult to achieve in the context of the current climate of significant welfare benefit reform (Department of Work and Pensions, 2012). Actions taken locally have included the appointment of a specialist social worker, able to broker services on behalf of patients, considering ways to reduce the number of appointments patients are asked to attend, and providing support for patients claiming their travel expenses. Thus, whilst the NICE guidance (2012b) has been successful in addressing a number of issues, from the patients' perspective it has neglected to address some of the issues which patients consider have the greatest impact on their ability or willingness to access hepatitis C testing and treatment. Had NICE used qualitative research to complement epidemiological and other

quantitative research the guidance may have more fully addressed the needs of patients and arguably further reduced health inequality in the area of hepatitis C.

'It's a little more complicated than that' – reasons for missed appointments with a hepatitis C outreach clinic.

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DProf student 2009/10

Methodology and method

- Realist approach
  - Depth of causation (Bhaskar)
  - Context + Mechanism = Outcome (Pawson)
  - Theory-led
- Two phases
  - Qualitative telephone interviews (clients)
  - Quantitative national survey (staff)

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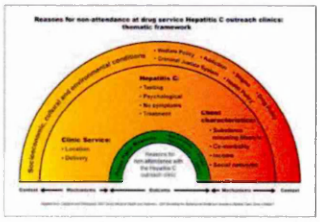
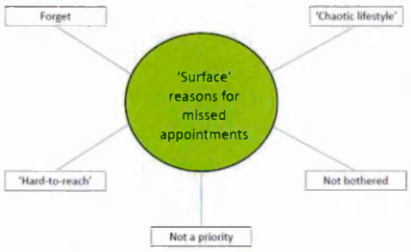
Complexity

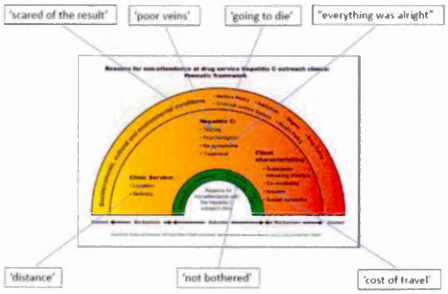


What are the reasons for non-attendance at drug service hepatitis C outreach clinics?

Case study

Howard needed a blood test to confirm his hepatitis C status but he had *'poor veins'*. He was *'not bothered'* about an appointment if there was no signs of infection and "everything was alright". Staff had tried in the past with "big needles" but there was "no point in going" to the outreach clinic. Howard also described not wanting to get tested for fear of testing positive. He would not want other people to find out he was infected and was scared he was *'going to die'*. Other reasons he gave for not attending was the outreach clinic being held on a *'different day'* to the one for his drug substitution treatment script. This meant attending two appointments in one week. It was a long *'distance'* to the clinic and involved getting two buses. Also, the *"cost of travel"* was expensive.





Implications

- Neck (jugular vein) blood training pack
- Tie in appointment with script
- Make reimbursement easier/Provide bus pass
- Information about treatment
- Telephone/text reminders limited use
- Make best use of appointment
- Must evaluate interventions