A systematic review of qualitative research on the views, perspectives and experiences of hepatitis B and C testing among practitioners and people at greatest risk of infection

Final report

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Background

Hepatitis B and C virus infections represent a major public health problem. In England, and elsewhere in the UK, injecting drug use is the major risk factor for acquiring hepatitis C infection. Injecting drug use is also a risk factor for hepatitis B infection, but over the last decade there has been a decline in its prevalence among injecting drug users (IDUs) as an increase in the provision of hepatitis B vaccination in prisons has provided an important route for accessing IDUs. Mortality and morbidity from chronic hepatitis B and C is rising disproportionately among people from ethnic minorities living in England, demonstrating a growing disease burden from chronic viral hepatitis in migrant communities.

Objectives

The aim of this review was to provide a narrative perspective on how groups identified to be at a high risk of hepatitis B and C infection and practitioners view case finding and testing approaches, their experiences of the communication of test results and subsequent treatment, and what they perceive as the barriers and facilitators to participation in these strategies.

As an alternative to the PICO mnemonic, the SPICE framework, was used to formulate a series of research questions. In order to interpret the findings from the qualitative synthesis of research we used the descriptive themes that emerged to answer each of the review questions.

Methods

The methods of the review of qualities research followed NICE protocols for the development of NICE Public Health Guidance. The search approach taken for the review of qualitative research was comprehensive and included searching of electronic sources, reference checking of included studies and key review articles, hand searching of selected journals and searches of relevant websites. Inclusion and exclusion criteria were applied to results of the search to identify studies of any qualitative design that examined views, experiences and attitudes of groups at an increased risk of hepatitis B and C infection, their close contacts and practitioners. Two reviewers independently screened all titles and abstracts and potentially relevant articles were retrieved and screened by two reviewers independently to determine whether the study met the inclusion criteria. Verbatim findings of studies that were relevant to the review were extracted and themes coded by one reviewer. A second reviewer checked the themes for consistency by reference to a random subset of studies. The methods of synthesis for this review were based on methods for the thematic synthesis of qualitative research. A narrative account of the synthesis was prepared and the results of each study presented in evidence tables. Evidence statements were constructed which took into account the quality and consistency of the findings and the applicability of the evidence for each of the research questions.

Findings

Nine studies were included that focused on groups at risk of or diagnosed with hepatitis B. Eight studies examined the views and perspectives of people from migrant groups and one study examined the perspectives of men with a history of imprisonment. Forty-five studies, including three reviews of qualitative research, were included that focused on groups at risk of or diagnosed with

hepatitis C. In addition, three studies focused on the views and experiences of IDUs and/or prisoners regarding hepatitis B and C and these studies were incorporated with the papers on hepatitis C because of the nature of the high risk groups focused on.

Overall, the quality of the included studies was high. All of the included studies were peer-reviewed journal articles and had therefore been subject to critical assessment prior to inclusion in this review. Studies that were judged to be of low quality had significant reporting omissions that meant it was not possible to have confidence in their reliability. The usefulness of all of the included studies was considered to be adequate and the vast majority of studies reported rich, detailed and convincing findings and conclusions. However, because of a lack of UK studies, the findings of this review may have limited applicability to groups at greatest risk of becoming chronically infected with hepatitis B in the UK.

Among people from high-risk groups identified to be at a high risk of hepatitis B and C infection, their close contacts, and practitioners, what are their knowledge, beliefs and practices in relation to hepatitis B and C?

The evidence identified for this review suggests that people from high risk groups may hold concepts of illness and disease that differ from biomedical understandings. Consequently people from high risk groups may have an incomplete or confused understanding of the various forms of hepatitis and the relationship between hepatitis and HIV. These beliefs appear to play a key role in how people from high risk groups perceive and manage their risk of acquiring hepatitis B and C. Among people from migrant groups, the causes of hepatitis B may commonly be considered to be socio-environmental, giving rise to the perception that risk may be managed by living a balanced life, strengthening the body's nature defences, and modifying individual health behaviours rather than by seeking testing or vaccination. IDUs may perceive themselves as never being completely safe from, or in control of hepatitis C transmission and although steps may be taken to minimise risk through safe injecting practices, the consistent employment of such strategies is difficult.

Evidence statements

Knowledge, beliefs and practices: hepatitis B

Understanding and awareness of hepatitis B among people from migrant groups may be strongly influenced by their personal experiences and cultural beliefs.

People from migrant groups may confuse the various forms of hepatitis and the relationship between hepatitis and HIV, and they may commonly hold less than accurate beliefs about transmission risks. The lack of, or gaps in, knowledge about hepatitis B identified among some healthcare professionals may compound or contribute to inadequate knowledge about hepatitis B among groups at a high risk of infection.

People from migrant groups may commonly cite access to or contamination of food, or cultural practices associated with sharing food and communal eating as the main cause of hepatitis B transmission. Although vertical transmission of hepatitis B was acknowledged in some studies, sexual transmission of hepatitis B was infrequently mentioned; overall, the evidence suggests that groups at a high risk of infection do not perceive hepatitis B as an STI.

Similarly to their beliefs about the causes and prevention of hepatitis B, people from migrant groups may express beliefs about prevention that are influenced by their personal experiences and cultural background. Among people born in East and South East Asia, prevention strategies may commonly reflect the practice of traditional medicine and vaccination may not generally be considered as a primary means of prevention. Religious influences on preventive health strategies may also be apparent, for example, among males who follow the Islamic doctrine.

Knowledge, beliefs and practices: hepatitis C

Despite strong evidence of hepatitis C as normal and ubiquitous among IDUs, the extent to which individuals participate in the social acceptance of hepatitis C varies and some IDUs may reject the notion of hepatitis C as expected and unavoidable. The deliberate use of safe injecting practices and research showing that testing positive for hepatitis C is a highly anxious and distressing experience suggests there is a disjuncture in the normalisation of hepatitis C among IDUs.

There was conflicting evidence as to whether having hepatitis C confirms an IDU identity. Some studies have shown that hepatitis C can provide evidence of belonging to IDU communities. Two studies and one review found that hepatitis C was not considered attractive, inevitable or a way of signifying an IDU identity.

There was strong evidence that IDUs have an uncertain and incomplete knowledge of hepatitis C. Studies showed that IDUs are confused over what the disease is, how it differs from other forms of hepatitis, how the infection is transmitted and what symptoms are involved. Knowledge confusion was also reinforced by the perception that expert and scientific knowledge on hepatitis C is shifting and uncertain. There was evidence that some IDUs are aware of their limited knowledge on hepatitis C.

Hepatitis C is often understood in relation to HIV, which trivialises the seriousness of contracting hepatitis C and may have implications for the use of safe injecting practices and the uptake of hepatitis C services.

There was evidence that safe and responsible injecting practices are employed by IDUs to avoid the transmission of hepatitis C. There was a lack of consensus as to whether safe practices are strictly adhered to in relation to the sharing of drug related paraphernalia.

A number of personal and external barriers were identified that may prohibit safe injecting practices. Trusting injecting relations; withdrawal and uncontrolled drug use, restricted access to needles and syringes at specific times, the prison setting, homelessness, policing and gender were found to act as barriers to the use of safe injecting practices.

What are the views, experiences and attitudes of people from high-risk groups of case finding and testing and communication of test results for hepatitis B and C infection?

People from high risk groups hold complex views about testing; although they may express a motivation to, or actively, seek testing this review indicates that testing may cause shock and anxiety. In particular, routine or unexpected testing, in which consent for hepatitis B and/or C testing is not explicitly sought, can exacerbate anxiety and confusion among people from high risk groups. In instances where limited or inadequate information is provided by health professionals, incomplete or confused understandings of hepatitis B and C infection can persist after testing.

Evidence statements

Views and experiences of testing: hepatitis B

Studies showed that people from migrant groups may express a general motivation for testing and keenness to raise awareness of hepatitis B testing among friends and family. However, there is some evidence among those with experience of testing to indicate that testing may occur without explicit consent being sought. Making testing obligatory was considered as a motivating factor for compliance with testing among Turkish Dutch immigrants.

Views and experiences of testing: hepatitis C

There was evidence that IDUs may actively seek testing due to concerns that they may have contracted hepatitis C through their injecting behaviour. Although a comparison with HIV can lead to a trivialisation of hepatitis C, concern over HIV also provided the opportunity for testing through the joint testing process. Proactive testing was influenced by the nature of drug use and the extent to which IDUs were engaged with mainstream society; IDUs whose drug use was more controlled had a greater tendency to get tested and integration in mainstream society also encouraged testing.

Stigma

The conception of hepatitis B as a 'liver' or 'blood' illness rather than an STI appears to play an important role in tempering stigma associated with hepatitis B. Increasing awareness of hepatitis B as an STI was viewed in one study as potentially contributing to increased stigma among people from migrant groups.

Hepatitis C positive IDUs experience stigma from other injectors, within the wider community and from health professionals. Stigma is perceived to be an outcome of the association between hepatitis C and injecting drug use and hepatitis C as infectious, and may prevent IDUs from seeking hepatitis C testing due to fear of disclosure. IDUs may not disclose a positive hepatitis C status due to fear of a negative reaction, isolation and social exclusion.

The experience of stigma prevented IDUs from seeking hepatitis C testing due to fear of disclosure and prevented IDUs from disclosing a positive hepatitis C status due to fear of a negative reaction, isolation and social exclusion. Stigma also prevented engagement with further prevention education, investigations and treatment and resulted in IDUs receiving inadequate and judgemental health care by health professionals.

What are experiences of people from high-risk groups and practitioners of barriers and facilitators to case finding and testing and subsequent care and treatment?

This review finds that among people from migrant groups and IDUs, a lack of visible symptoms or 'feeling well' is a key barrier to testing uptake. Concerns about stigma may also discourage testing uptake due to fear of discrimination and exclusion. IDUs additionally may experience stigma from health professionals. Language and cultural barriers prevent some people from migrant groups from seeking testing and can limit the role that healthcare professionals play in providing education and outreach to migrant populations. Additional barriers to testing specific to the prison setting include long waiting times, lack of information provision, prioritisation of detoxification and withdrawal, and movement between prisons. Few studies described motivators for testing uptake among people from migrant groups, but taking personal responsibility for their individual health and for the health of others appears to be a key factor for seeking testing. Key motivators for testing among IDUs

identified in this review are convenient and opportunistic testing, and a good relationship with health professionals build on trust and rapport.

Few studies examined views and experiences of subsequent care and treatment among people at a high risk of hepatitis B infection and barriers and facilitators relating to subsequent care and treatment were not identified. A number of factors may serve to discourage IDUs from accessing subsequent care and treatment for hepatitis C. This review indicates that fear of treatment (relating to side effects or a fear of needles), adverse social circumstances, a perceived requirement of abstinence from alcohol and drug use, lack of opportunities to access treatment, lack of information on treatment options and structural factors such as long waiting times between appointments may limit uptake. Receiving support from family, partners and peers, starting family life and concerns over the impact of hepatitis C on significant others (e.g. partners and children), however, can motivate IDUs to engage with treatment. Similar to motivators for testing, perceiving health care professionals to be supporting, concerned and caring, and being encouraged to undertake treatment by health professionals can motivate IDUs to engage in treatment.

Evidence statements

Barriers and facilitators to testing: hepatitis B

Barriers to testing include an absence of clear symptoms of infection, practical obstacles such as inconvenience and time constraints, and language and cultural barriers, which may discourage some people from seeking care and may limit the role that healthcare providers play in providing education and outreach to people from migrant groups.

Primary motivating factors for testing among people from migrant groups are related to concerns for individual health, concern for others health, and the health of the wider community.

Barriers and facilitators to testing: hepatitis C

A number of barriers to hepatitis C testing among IDUs were identified. Perceiving themselves to be at low risk of hepatitis C infection, a lack of visible symptoms of hepatitis C infection, fear of a positive test result, the use of needles and fear of disclosure were found to prevent the uptake of hepatitis C testing among IDUs. Three studies reported barriers to testing specific to the prison setting including long waiting times, lack of information provision, prioritisation of detoxification and withdrawal, and movement between prisons.

Convenient and opportunistic testing and a ‘one-stop shop’ approach for all hepatitis C services was regarded as a convenient approach among IDUs. There was evidence that some IDUs were unaware that they had been tested for hepatitis C and concern over informed consent to testing was noted by a number of authors. Although an opportunistic approach can increase testing compliance, a lack of informed consent may also contribute towards uncertain knowledge of hepatitis C among IDUs and limit the impact of testing on behaviour.

Trust and rapport with health professionals and drug treatment staff acted as motivators to testing. Support and encouragement from health professionals also facilitated engagement with testing among IDUs.

Barriers and facilitators to treatment: hepatitis C

Fear of the side effects associated with hepatitis C treatment and the circulation of 'horror stories' and unsuccessful treatment cases among peers prevented IDUs from engaging with treatment. A fear of needles was also common and using needles during the treatment process was a challenge to overcome when considering treatment. In contrast, anxiety over hepatitis C, witnessing peers suffer from symptoms of hepatitis C infection and hearing stories of successful treatment cases among peers encouraged treatment uptake.

Socio-economic and family circumstances can lead to treatment being de-prioritised among IDUs.[4] Studies have shown that a preoccupation with drug use, chaotic lifestyles, long waiting times between appointments and employment contributed towards IDUs missing and forgetting treatment appointments, thus increasing the possibility of treatment drop out.[5] The assumption of abstinence as a requirement for hepatitis C treatment and continued substance use among IDUs acted as a barrier to treatment.

Receiving support from the family, partners and peers, starting family life and concerns over the impact of hepatitis C on significant others (e.g. partners and children) motivated IDUs to engage with hepatitis C treatment.

There was evidence that not experiencing symptoms was a barrier to treatment as IDUs did not perceive hepatitis C as impacting on their health and as such did not feel treatment was required. When health problems were experienced, IDUs were more likely to access hepatitis C care and treatment.

One study found that imprisonment was viewed by health professionals as both a barrier and a facilitator for hepatitis C treatment; transportation of prisoners between prisons and length of sentence were viewed as interfering with the treatment process whereas the structured environment of prison and availability of peer support during treatment were regarded as beneficial.

Two studies found that a lack of opportunity to access treatment and a lack of information on treatment options act as barriers to hepatitis C treatment. Increasing knowledge on hepatitis C through the provision of information by health professionals encouraged IDUs to consider their treatment options.

Perceiving health care professionals to be supportive, concerned and caring, and being encouraged to undertake treatment by health professionals was found to motivate IDUs to engage in hepatitis C treatment. There was evidence across a number of studies that IDUs preferred hepatitis C services, including treatment, to be situated in one setting such as drug treatment programmes and methadone substitution settings. These services were also seen as useful in providing information of hepatitis C treatment.

What are people from high risk groups and practitioners' views and perspectives on opportunities for changing behaviour in relation to hepatitis B and C testing and subsequent care and treatment?

Few studies examined views and experiences of subsequent care and treatment among people at a high risk of hepatitis B infection. Lack of information and knowledge at the time of diagnosis of hepatitis B or C infection is perceived by people from high risk groups as impacting negatively on health and may prevent opportunities for behaviour change. Evidence suggests that convenient and

opportunistic testing is an important facilitator of hepatitis C testing among IDUs and increasing knowledge of hepatitis C through the provision of information by health professionals may encourage hepatitis C positive IDUs to consider their treatment options. This review indicates that IDUs prefer services for hepatitis C, including treatment, to be situated in a "one-stop" setting.

Evidence statements

Views and perspectives on opportunities for changing behaviour: hepatitis B

One study reported that people with a diagnosis of chronic hepatitis B, including first and second generation immigrants, had little recollection of providing consent to test and did not receive adequate information at diagnosis. This lack of information and knowledge was perceived as impacting negatively on their health and preventing opportunities for behaviour change. Both patients and community workers expressed concerns about a lack of provider knowledge with regards to hepatitis B.

Views and perspectives on opportunities for changing behaviour: hepatitis C

Studies showed that the experience of being informed about the outcome of hepatitis C testing can be highly confusing. Limited and inadequate information provision by health professionals can lead to confusion over the meaning of a positive diagnosis and substantial gaps in knowledge.

There is conflicting evidence as to whether an awareness of hepatitis C status can lead to behaviour change. A positive hepatitis C diagnosis can lead to IDUs adopting healthier lifestyles, such as eating more healthily and reducing alcohol and drug use. Studies have also shown that alcohol and drugs are used as a means of coping with a positive diagnosis. There is evidence that IDUs take care to prevent hepatitis C transmission and disclose a positive hepatitis C diagnosis to avoid transmission. Testing positive for hepatitis C can also reinforce existing risk behaviour and one UK study found limited evidence of a direct reduction in risk behaviour. Another UK study indicated that there is evidence that a positive diagnosis may actually lead to an increase in injecting in order to deal with depressive feelings and denial. Testing negative for hepatitis C can also reinforce risky behaviour in that some IDUs assume previous injecting practice to be safe following a negative diagnosis.

Conclusions

Recommendations for practice

The evidence identified through this review of qualitative research suggests that there are modifiable factors among groups at a high risk of acquiring hepatitis B and/or C that could be addressed through interventions that aim to encourage uptake of testing.

Appropriate interventions are required to improve knowledge and awareness of hepatitis B and C infection among high risk groups. In particular, it appears that much could be done to improve the quality and level of information available to high risk groups before and after testing. Development of intervention materials should take into consideration how biomedical information can be tailored to incorporate meaning relevant to the socio-cultural context of high risk groups, but without contributing to stigma or increasing fear and confusion. Efforts should also be extended to address knowledge and information gaps among healthcare professionals and other providers of healthcare that may be accessed by people from high risk groups (e.g. practitioners of complementary and alternative medicine).

Due to the stigma associated with hepatitis B and C infection, interventions that aim to increase uptake of testing need to consider how the positive outcomes of testing can be exploited, for example, by promoting the benefits of taking responsibility for not only individual health, but also the health of family and friends, and the wider community.

Structural factors, such as long waiting times between appointments, which discourage uptake of testing and subsequent care and treatment, should be addressed by increasing opportunities for people from high risk groups to access testing and other services. In particular, convenient and opportunistic testing appears to be an important facilitator of hepatitis C testing among IDUs. Interventions should also focus on building trust and rapport between people from high risk groups and health professionals, for example by addressing cultural and linguistic barriers to care or by targeting stigmatised attitudes to particular high risk groups.

Recommendations for research

Research is lacking on the views and experiences of groups in the UK who at greatest risk of becoming chronically infected with hepatitis B. In the wider literature, there is a lack of research that has explored the views and experiences of people from high risk groups who have been diagnosed with chronic hepatitis B.

With regards to groups at a high risk of acquiring hepatitis C or becoming chronically infected with hepatitis B, research is lacking on what people from high risk groups think could be done to increase uptake of testing. There is therefore a need for research that engages with people from high risk groups to identify interventions, strategies and approaches that they consider suitable. It is imperative that views are sought from a diverse range of populations and that particular efforts are made to explore the views of migrant and vulnerable populations.

1 Introduction

1.1 Aims and objectives

This review was undertaken to support the development of guidance by the National Institute for Health and Clinical Excellence (NICE) on the most cost-effective ways of offering tests to those at risk of infection from hepatitis B and C.

One of a series of four evidence reviews, the aim of this review was to provide a narrative perspective on how groups identified to be at a high risk of hepatitis B and C infection and practitioners view case finding and testing approaches, their experiences of the communication of test results and subsequent treatment, and what they perceive as the barriers and facilitators to participation in these strategies.

1.2 Research questions

As an alternative to the PICO mnemonic, the SPICE framework (Booth, 2006) was used to formulate the following research questions suited to a qualitative review:

1: Among people from high-risk groups identified to be at a high risk of hepatitis B and C infection, their close contacts, and practitioners, what are their knowledge, beliefs and practices in relation to hepatitis B and C?
2: What are the views, experiences and attitudes of people from high-risk groups of case finding and testing, communication of test results and/or subsequent treatment for hepatitis B and C infection?
3: What are the experiences of people from high-risk groups and practitioners of barriers and facilitators to case finding and testing and subsequent care and treatment?
4: What are people from high-risk groups and practitioners views and perspectives on opportunities for changing behaviour in relation to hepatitis B and C testing and subsequent care and treatment?

1.3 Background

Hepatitis B and C virus infections represent a major public health problem. Between 1992 and 2008; a cumulative total of over 69,000 laboratory-confirmed diagnoses of hepatitis C infection were reported to the Health Protection Agency (HPA) in England and estimates suggest that around 142,000 adults in England and Wales are living with chronic hepatitis C (Health Protection Agency, 2009). The overall incidence of hepatitis B is low in the UK. Based on laboratory-confirmed cases of acute hepatitis B infection reported between 1995 and 2000 Hahné *et al.* (2004) estimated an incidence rate of 3,780 hepatitis B infections per year in England and Wales (7.4 per 100,00 persons per year) resulting in an estimated 269 new chronic infections per year.

In England, and elsewhere in the UK, injecting drug use is the major risk factor for acquiring hepatitis C infection. Nearly 50% of injecting drug users (IDUs) in England have antibodies to hepatitis C and data indicates that over the last decade, levels of transmission among IDUs have remained high (Health Protection Agency *et al.,* 2010). Over the last decade the uptake of hepatitis C testing has increased among IDUs in England, rising to 81% in 2009. However, anonymous monitoring of IDUs indicates that around half of those testing positive are unaware of their hepatitis C status (Health

Protection Agency *et al.,* 2010). Injecting drug use is also a risk factor for hepatitis B infection, but over the last decade there has been a decline in its prevalence among IDUs (Health Protection Agency, 2010). In particular, an increase in the provision of hepatitis B vaccination in prisons has provided an important route for accessing IDUs (Hope *et al.,* 2007).

Mortality and morbidity from chronic hepatitis C is rising disproportionately among people from ethnic minorities living in England (Mann *et al.,* 2008) demonstrating a growing disease burden from chronic viral hepatitis in immigrant communities (Ahmed & Foster, 2010). Higher rates of hepatitis B infection have been identified among immigrant women in antenatal screening studies (Boxall *et al.,* 1994; Bhattacharya *et al.,* 2008) and studies of blood donors have indicated higher rates of hepatitis B and hepatitis C among South Asian populations (Soldan *et al.,* 2000; Health Protection Agency, 2009). Based on the analysis of cases with South Asian names, Hahné *et al.* (2004) estimated that the overall incidence of acute hepatitis B infection in South Asians was more than two times greater than the estimated overall incidence in England and Wales and the prevalence of viral hepatitis in immigrants from South Asia living in England is such that nearly one in 20 people born in Pakistan and living in England has chronic viral hepatitis (Uddin *et al.,* 2010). Sentinel surveillance data suggest that hepatitis C testing is increasing among people of South Asian origin (Health Protection Agency, 2009).

2 Methodology

2.1 Search strategy

The search approach taken for the review of qualitative research was comprehensive and aimed to identify all the potentially relevant studies. It is widely acknowledged that qualitative research is difficult to find and therefore a combination of strategies was utilised to locate evidence including searching electronic sources, reference checking of included studies and key review articles, hand searching of selected journals, and searches of relevant websites. All searches were conducted in accordance with the second edition of Methods for the development of NICE public health guidance (2009).

2.1.1 Electronic sources

The following electronic sources were searched:

- ASSIA (Applied Social Science Index and Abstracts) via CSA Illumina
- British Nursing Index via EBSCOhost
- CINAHL (Cumulative Index of Nursing and Allied Health Literature) via EBSCOHost
- Cochrane Library via Wiley (CDSR, DARE)
- EMBASE via NHS Evidence Health Information Resources
- EPPI Centre databases
- ETHOS (Electronic Theses Online Service)
- King's Fund catalogue
- MEDLINE via Ovid
- MEDLINE In Process via Ovid
- PsycINFO via EBSCOHost
- Social Care Online via www.scie-socialcareonline.org.uk/
- Social Science Citation Index via Web of Science
- Sociological Abstracts via CSA Illumina

Search strategies were developed for each database using a combination of free text and thesaurus terms as appropriate. An example Medline strategy is presented in Appendix 1.

2.1.2 Hand searching

Following the initial screening of titles and abstracts retrieved from the electronic sources, references identified as potentially relevant were examined to identify the five journals with the highest yield of references. The five journals selected were: Australian Health Review, Gastroenterology Nursing, International Journal of Drug Policy, Journal of Community Health, and the Journal of Viral Hepatitis. All journal issues (and supplements) published between 2008 and 2011 were hand searched comprising a total of 113 issues.

2.1.3 Relevant websites

The following websites were searched:

- British Association for the Study of the Liver
- British Liver Trust

- European Association for the Study of the Liver
- Foundation for Liver Research
- Health Protection Agency
- Hepatitis C Trust
- Institute of Hepatology
- Mainliners
- US Centers for Disease Control and Prevention
- World Health Organisation
- NHS Evidence specialist collections (gastroenterology and liver diseases, infections, ethnicity and health and public health

2.2 Inclusion and exclusion criteria

2.2.1 Type of participants

Studies of groups at an increased risk of hepatitis B and C infection, their close contacts and practitioners were eligible for inclusion. Groups of particular relevance included current and former injecting drug users (IDUs) and people from migrant groups, specifically first generation immigrants from countries with a high or intermediate prevalence of hepatitis B and/or C.[1,2] Studies that focused solely on general population groups or groups at a low risk of hepatitis B and/or C infection were excluded. Studies containing mixed 'low' and 'high' risk populations were eligible for inclusion where it was possible to attribute the findings to particular high risk populations.

2.2.2 Types of studies

Studies of any qualitative design, for example, ethnographic studies, studies that used a phenomenological or grounded theory approach, or participatory action research were eligible for inclusion. The qualitative elements of mixed methods research were also screened for inclusion. Studies that used structured questionnaires as the sole method of data collection or report only quantitative data not elicited from the patients or providers themselves were excluded.

2.2.3 Type of outcomes

A range of outcomes were relevant including: views, experiences and attitudes of case finding and testing, communication of test results and/or subsequent treatment among groups at an increased risk of hepatitis B and C infection, and the affects of knowledge, beliefs or practices in relation to hepatitis B and C; patient and practitioner perspectives on barriers to, and opportunities for, changing behaviour in relation to hepatitis B and C testing and subsequent care and treatment, and the affects of attitudes or practices among health professionals. Studies that examined broader experiences associated with hepatitis B and C among groups at greatest risk of infection were also eligible for inclusion.

[1] According to WHO, prevalences of >8% are typical of highly endemic areas and prevalences of 2–7% are found in areas of intermediate endemicity.

[2] Areas of high endemicity for hepatitis B include Southeast Asia and the Pacific Basin (excluding Japan, Australia, and New Zealand), China, sub-Saharan Africa, the Amazon Basin, parts of the Middle East, the Arctic, and the central Asian Republics. Areas of intermediate endemicity for hepatitis B include the Mediterranean and Eastern Europe.

2.3 Study selection

Two reviewers from a team of four (LJ, EMC, GB and LP) independently screened all titles and abstracts retrieved from the database searches according to the inclusion and exclusion criteria described. Potentially relevant articles were retrieved and screened by two reviewers independently to determine whether the study met the inclusion criteria.

At the title and abstract screening stage all studies conducted with populations in a developed or high-income country and meeting other aspects of the inclusion criteria were retrieved for further screening. At the full text screening stage, studies were coded according to the following characteristics in order to filter out priority papers on groups and topics of particular relevance to the research questions: infection focus (hepatitis B, hepatitis C or both), characteristics of the population (e.g. injecting drug users; people from migrant groups; men who have sex with men; those who received blood products before 1990) and the topic focus (e.g. general knowledge and beliefs regarding hepatitis B and/or C, screening, treatment).

2.4 Data extraction and quality assessment

Verbatim findings of studies that were relevant to the review were extracted onto a suitable form in Microsoft Access along with brief information about the methodology, quality and applicability of the study. Key themes and sub-themes were coded according to the meaning and content of the findings of each study using NVivo 9 software. Coding of each study was undertaken by one reviewer from a team of two (AA and LP) and a second reviewer (LJ) checked the consistency of the key themes and sub-themes that emerged by reference to a random subset of the studies identified for inclusion. Two reviewers independently assessed the quality of the individual studies. Disagreements were resolved through consensus and if necessary a third reviewer was consulted.

2.5 Methods of analysis/synthesis

Analysis of the characteristics of the included studies identified that the included studies fell into two distinct groups. The first set of studies typically examined the views and experiences of people from migrant groups in relation to hepatitis B and the second set of studies typically examined the views and experiences of IDUs in relation to hepatitis C. Findings were therefore synthesised in separate analyses for these two groups of studies.

The methods of synthesis for this review were based on methods for the thematic synthesis of qualitative research. By examining the findings of each included study, descriptive themes were independently coded by one reviewer. Once all of the included studies had been examined and coded, the resulting themes and sub-themes were discussed as a team (AA, LP and LJ) to examine their relationship to the research questions. The qualitative synthesis then proceeded by using these ‘descriptive themes’ to develop ‘analytical themes’, which were interpreted by the review team (AA, LP and LJ) in light of the overarching research questions.

A narrative account of the synthesis was prepared and the results of each study presented in evidence tables. Evidence statements were constructed which took into account the quality and consistency of the findings and the applicability of the evidence for each of the research questions.

3 Summary of study identification

3.1 Results of study selection

A total of 6,255 references were identified from the searches of electronic sources. Based on title and abstract screening, 284 references were identified as potentially relevant. Following hand searching, a further 36 articles were identified but after removal of duplicates only one article was considered potentially relevant. No additional articles were identified through the screening of reference lists or review articles. A total of 285 studies were therefore retrieved as full text articles.

In the first round of full text screening, from the 285 potentially relevant papers we sought to identify qualitative studies that examined perspectives on, or experiences of hepatitis B and/or C infection regardless of whether the study focused on a high risk group. A total of 105 studies met these criteria and were entered into the second round of full text screening. Of the remaining studies identified as potentially relevant, 169 were excluded, four were duplicates and seven were unavailable within the timescales for the review. Reasons for exclusion are noted under *Section 3.1.2 Excluded studies* and references for the exclude studies and unavailable studies are presented in Appendices 3 and 4, respectively. Across the 105 qualitative studies, 13 studies focused on groups at risk of or diagnosed with hepatitis B, 89 studies focused on groups at risk of or diagnosed with hepatitis C and three studies focused groups at risk of or diagnosed with hepatitis B and/or C. Forty-eight qualitative studies were subsequently excluded from the review (reasons for exclusion are noted under *Section 3.1.2 Excluded studies*). The process of study selection is summarised in Figure 1.

3.1.1 Included studies

Hepatitis B

A total of nine studies were included that focused on groups at risk of or diagnosed with hepatitis B. Eight studies examined the views and perspectives of people from migrant groups and one study examined the perspectives of men with a history of imprisonment.

Hepatitis C

Forty-five studies were included that focused on groups at risk of or diagnosed with hepatitis C. Forty studies explored the views and experiences of injecting drug users (IDUs), including those with and without a positive diagnosis for hepatitis C. Six of the 45 studies also explored the views and experiences of healthcare professionals serving IDU populations. Of the remaining studies, three studies examined the views and experiences of prisoners and two studies focused on drug users attending drug treatment services (including opioid substitution treatment services).

Hepatitis B & C

Three studies focused on the views and experiences of IDUs and/or prisoners regarding hepatitis B and C. All three studies were included in the review and incorporated with the papers on hepatitis C because of the nature of the high risk groups focused on.

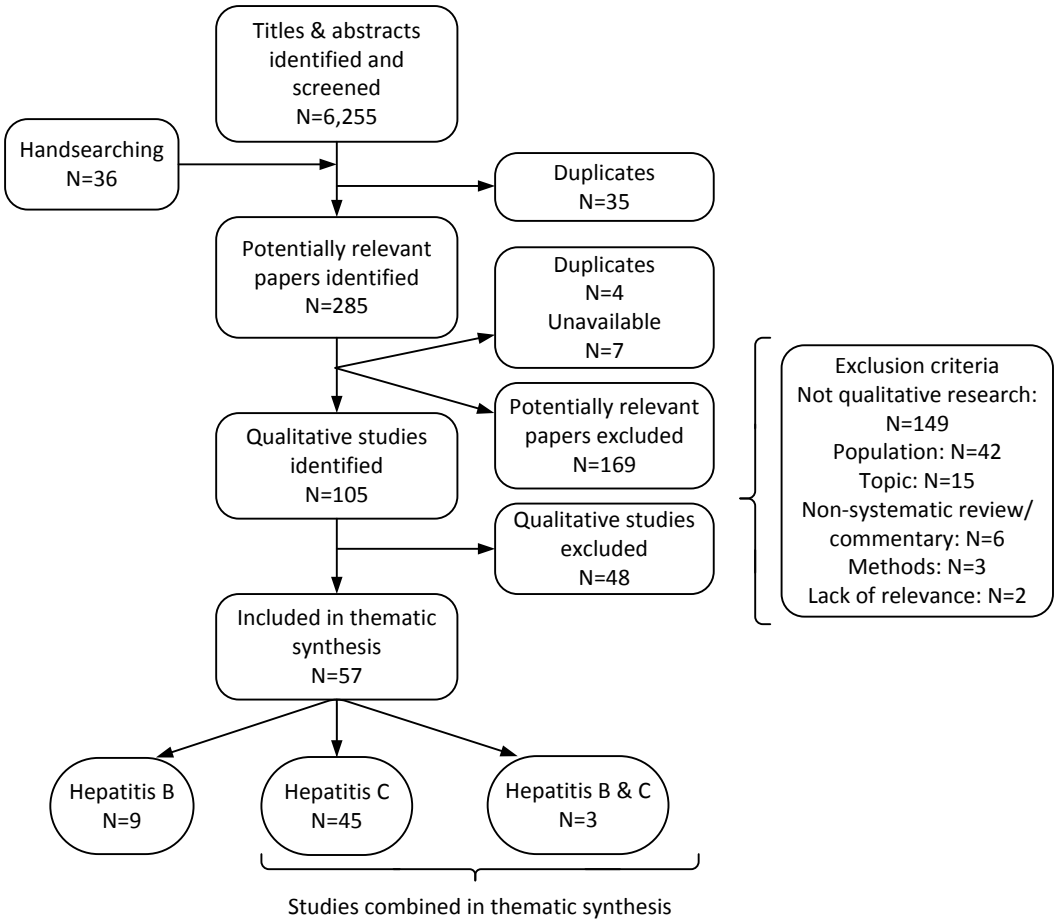

Figure 1. Study selection flow chart

3.1.2 Excluded studies

A total of 217 papers were excluded from the review across both rounds of screening. One hundred and forty-nine papers were excluded as they did not report on the findings of qualitative research; although these articles may have examined testing, knowledge and practices among the populations of relevance, they reported only quantitative findings. A further 42 studies were excluded as the population focus of these studies was not considered to be at a high risk for infection within the scope of the review and 15 studies were excluded as the topic of the study was of limited relevance, for example, they were concerned only with the experience of treatment for hepatitis C. Three studies were excluded due to poor reporting of methods and six papers identified as non-systematic reviews and/or commentaries were also excluded. Two further studies were excluded during the coding process due to lack of relevance to the review.

3.1.3 Overlap between other reviews of qualitative research and this review

Three studies were identified as reviews of qualitative research (Rhodes & Treloar, 2008; Treloar & Rhodes, 2009; Paterson *et al.,* 2007). A total of 54 studies were included across the three reviews and with the exception of 3 studies, all studies were identified in the searches conducted for this review. The three additional papers were not considered potentially relevant and therefore did not enter the process of study for this review. Of the 51 studies that were considered for inclusion is this review, 19 studies were included and 32 studies were excluded. Table 8 in Appendix 7 summarises the overlap between the three reviews of qualitative research and this review.

4 Views, perspectives and experiences of practitioners and groups at an increased risk of hepatitis B infection

4.1 Overview of papers

Nine studies met the inclusion criteria for the review and underwent quality appraisal. The majority of the studies were concerned with social and cultural influences on hepatitis B related behaviour and were generally undertaken to inform the development of culturally appropriate interventions. None of the included studies were conducted in the UK. Summary characteristics are summarised in Table 1 and full data extraction tables are presented in Table 5 in Appendix 5.

- Two studies addressed barriers and facilitators related to hepatitis B education, testing and vaccination (Chang *et al.,* 2008; Burke *et al.,* 2004) and one study focused on behavioural and socio-cultural determinants associated with hepatitis B screening (van der Veen *et al.,* 2009).
- Two studies examined beliefs and behaviours about hepatitis B and liver cancer (Choe *et al.,* 2005; Chen *et al.,* 2006).
- Three studies explored knowledge and understanding about hepatitis B illness, testing, and vaccination; two among migrant populations (Burke *et al.,* 2010; Chen *et al.,* 2006) and one among young men leaving prison (Buck *et al.,* 2006).
- Two studies focused on medical providers: one explored beliefs, attitudes and practice patterns of healthcare professionals related to hepatitis B (Hwang *et al.,* 2010) and the other described perspectives of people living with chronic hepatitis B and how they and healthcare professionals responded to their infection (Wallace *et al.,* 2011).

Six studies (Burke *et al.,* 2004; Burke *et al.,* 2011; Chang *et al.,* 2008; Chen *et al.,* 2006; Choe *et al.,* 2005; van der Veen *et al.,* 2009) explored the views and perspectives of people from migrant groups. In five studies, conducted in North America (four studies in the USA and one study in both Canada and the USA), migrant groups included were predominantly from East and South East Asia; including Vietnam (Burke *et al.,* 2004), Cambodia (Burke *et al.,* 2011), China (Chen *et al.,* 2006; Chang *et al.,* 2008) and Korea (Choe *et al.,* 2005). One study (van der Veen *et al.,* 2009) explored the views and perspectives of the Turkish population in the Netherlands. The study by Hwang *et al.* (2009) focused on medical providers serving Asian American communities and Wallace *et al*. (2011) explored the perspectives of people living with chronic hepatitis B in Australia, including participants born in Vietnam, China, Cambodia, Afghanistan, North America, Greece, Turkey and Australia. Buck *et al.* (2006) examined the perspectives of men with a history of imprisonment, the majority of whom identified themselves as African American, Caucasian or Hispanic.

Table 1. Summary of included studies: Hepatitis B

Reference	Country	Participants	Data Collection Method
Buck *et al.,* 2006 [+]	USA	42 incarcerated men recruited from state prisons in California, Mississippi, Rhode Island, and Wisconsin	Semi- structured interviews
Burke *et al.,* 2004 [++]	USA	47 Vietnamese-Americans (24 men and 23 women) living in the Seattle Tacoma metropolitan area of Washington State	Five open-ended qualitative interviews and six focus groups

Reference	Country	Participants	Data Collection Method
Burke *et al.,* 2011 [+]	USA	97 Cambodian-Americans (48 men and 49 women) living in the Seattle-Tacoma metropolitan area of Washington State	Eight group interviews
Chang *et al.,* 2008 [++]	USA	47 Chinese-American adults from the San Francisco Bay Area	Six focus groups
Chen *et al.,* 2006 [++]	USA & Canada	40 North American Chinese men and women (20 in Seattle and 20 in Vancouver)	40 semi-structured, in-depth interviews
Choe *et al.,* 2005 [++]	USA	First-generation adult Korean immigrants from the Seattle and Tacoma area	30 semi-structured interviews and 18 focus groups
Hwang *et al.,* 2010 [++]	USA	23 Asian and non-Asian physicians stratified by medical specialty (primary care physicians, liver specialists, and other providers)	Three focus groups
van der Veen *et al.,* 2009 [++]	The Netherlands	First and second generation Turkish-Dutch migrants	Seven single sex focus group
Wallace *et al.,* 2011 [++]	Australia	13 men and seven women diagnosed with hepatitis B – six born in Vietnam; five in China, three in Cambodia, two from Afghanistan, others from Australia, North America, Greece, and Turkey; 40 staff and volunteers of non-government organisations in Victoria, NSW, South Australia and Queensland	20 semi-structured interviews and four focus groups with staff

4.2 Quality assessment

Seven studies (Burke *et al.,* 2004; Chang *et al.,* 2008; Chen *et al.,* 2006; Choe *et al.,* 2005; Hwang *et al.,* 2010; van der Veen *et al.,* 2009; Wallace *et al.,* 2011) were assessed as good quality (++ rating) and two studies (Buck *et al.,* 2006; Burke *et al.,* 2011) were assessed as being of moderate quality (+ rating). The full results of quality assessment are presented in Table 7 in Appendix 6. Issues that affected the validity of the included studies included inadequate reporting of research methods, in particular with regard to the criterion of trustworthiness. In two studies (Buck *et al.,* 2006; Hwang *et al.,* 2010) the research context was regarded unclear. For example, in the study by Hwang *et al.* (2009) the characteristics of the health professionals that participated in the study, particularly those termed 'other providers' were not described in sufficient detail. In addition, none of the included clearly described the role of the researcher and therefore it was difficult to judge the 'status' of the researcher or researchers and how this affected the collection of data.

4.3 Key themes

The themes developed from the qualitative synthesis of research on hepatitis B were categorised as follows; 1) Hepatitis B knowledge and beliefs; 2) Barriers and facilitators to hepatitis B testing; and 3) Experiences of diagnosis and clinical management. Where possible, extracts of data from the articles have been used to exemplify each theme and details on participants' sex have been reported when available. Table 2 summarises the identified themes and sub themes.

Table 2. Identified themes and sub themes

Theme	Sub-theme	Number of articles

		discussing theme
Hepatitis B knowledge and beliefs	A lack of understanding and awareness of hepatitis B according to the Western medical model	8
	Cultural influences on the causes of hepatitis B and hepatitis B transmission	4
	Stigma	5
	Cultural influences on preventive behaviours	4
Barriers and facilitators to hepatitis B testing	Unexpected experiences and uncertain perceptions of hepatitis B testing	6
	Facilitators to hepatitis B testing	4
	Barriers to hepatitis B testing	5
Experiences of diagnosis and clinical management	Poor experiences of diagnosis	1
	Negative views of clinical management	1
	Disclosure	1

4.4 Findings

4.4.1 Hepatitis B knowledge and beliefs

Lack of understanding and awareness of hepatitis B according to the Western medical model

Awareness and understanding of hepatitis B was discussed in eight studies (Burke *et al.,* 2004; Buck *et al.,* 2006; Choe *et al.,* 2006; Chen *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009; Burke *et al.,* 2011; Wallace *et al.,* 2011). Many people from migrant groups across the included studies were aware that hepatitis B was associated with liver disease and that it was endemic in their countries of origin (Choe *et al.,* 2006; Wallace *et al.,* 2011). Hepatitis B was recognised by some as being contagious (Chen *et al.,* 2006; Chang *et al.,* 2008) and as potentially leading to cancer of the liver (Burke *et al.,* 2011; Chen *et al.,* 2006; Choe *et al.,* 2006). Medical providers who participated in the study by Hwang *et al.* (2010) were of the opinion that the risk and prevalence of hepatitis B was often underestimated by those most at risk.

> *"I feel that even in Chinese American population, the appreciation is… they know hepatitis B is no good, but they really, not quite realise how serious that is." [Primary care provider; Hwang et al., 2010; pg. 224]*

Among people from migrant groups, particularly those from Cambodia and Vietnam, diverse terms for hepatitis B were used by different people, even within cultural groups. Some used generic terms that referred to liver sickness or blood disease (Burke *et al.,* 2011), whilst other participants used specific terms for hepatitis B (Burke *et al.,* 2004; Wallace *et al.,* 2011). Findings from three studies (Burke *et al.,* 2004; Burke *et al.,* 2011; Wallace *et al.,* 2011) highlighted that understanding about hepatitis B among migrant populations was influenced by their cultural beliefs and personal experiences which shaped their perceptions of hepatitis B.

> *"[Hepatitis B may be described as] white blood eats red blood disease." [Cambodian American adult, USA; Burke et al., 2011; pg. 31]*

"I wasn't sure what does it mean hepatitis B… I asked some other people and then they say this mean this kind of thing in our language we say… it means that this skin is yellow." [Afghani male diagnosed with chronic HBV, Australia; Wallace et al., 2011; pg. 3]

Symptoms of hepatitis B were only explicitly discussed in two studies (Chen *et al.,* 2006; Wallace *et al.,* 2011) although there was evidence to suggest that participants in other studies were familiar with the effects and outcomes of hepatitis B (Choe *et al.,* 2006). Participants felt they were able to identify people infected with hepatitis B by their appearance: 'yellow skin', 'yellow eyes' and 'fatigue'. According to Chen *et al.* (2006) the absence of symptoms contributed to a reluctance to get tested for hepatitis B.

"Because it's a waste of time. When there is no reason to go, I won't go. Unless, like when I was coming to Canada and the immigration department demanded such a check up, then I went. Ordinarily, when I am not sick or have no discomfort, I won't go." (North American Chinese adult; Chen et al., 2006; pg. 105)

Three studies identified that people do not always differentiate correctly between the various forms of hepatitis (Wallace *et al.,* 2011; Burke *et al.,* 2011; Buck *et al.,* 2006). There was a misconception of a progressive connection between the different forms, often with hepatitis A being the least virulent and hepatitis C the most (Burke *et al.,* 2011). There was also evidence that some people from migrant groups misunderstood the association between hepatitis B and HIV/AIDS (van der Veen *et al.,* 2009; Burke *et al.,* 2011). Some had the perception that hepatitis B and HIV/AIDS were related to each other or were different stages of the same disease (Burke *et al.,* 2011), perhaps because both are spread through sexual contact (van der Veen *et al.,* 2009).

"Yes, it [hepatitis] progresses from B to C. If we don't wash hands, it could spread hepatitis A. For A, for example, the cook, who makes food for us, goes to the restroom and does not wash his hand or drop his sweat; this would definitely spread hepatitis A. If we do not check up or protect ourselves, later it will develop to B or C. For this disease, once we have A or B, it will develop to C." [Cambodian American male, USA; Burke et al., 2011; pg. 31]

"Three levels - hepatitis A, hepatitis B and hepatitis C with hepatitis C being worse." [Afghani born male, Australia; Wallace et al., 2011; pg. 5]

"I thought there's no cure for AIDS yet and I thought AIDS was part of hepatitis. So, one form of hepatitis I didn't think there's a cure for it." [Cambodian American female, USA; Burke et al., 2011; pg. 31]

Knowledge and understanding of hepatitis B amongst health professionals was explored in two studies (Hwang *et al.,* 2010; Wallace *et al.,* 2011). Physicians demonstrated accurate knowledge about the biological mechanisms of transmission and some healthcare professionals were aware of culturally-specific transmission routes (e.g. nail salons) but both Hwang *et al.* (2010) and Wallace *et al.* (2011) documented a lack of, or gaps in, knowledge about hepatitis B among some providers of healthcare.

"Because Korean custom is we eat together like when you drink wine and we made soup, if bowl soup, we eat together. We don't separate." ['Other' provider, USA; Hwang et al., 2010]

"If you've been diagnosed with chronic hepatitis B, ask your GP for a referral to a specialist… I've noticed that GPs will sit on hepatitis B in their own room for years and years." [Community Worker, Australia; Wallace et al., 2011; pg. 4]

Cultural influences on the causes of hepatitis B *and* hepatitis B *transmission*

A range of contributory causes of hepatitis B were highlighted in four studies (Burke *et al.,* 2004; Choe *et al.,* 2005; Chen *et al.,* 2006; Burke *et al.,* 2011). Participants often considered the causes of hepatitis B to be socio-environmental; for example participants cited inadequate rest, alcohol abuse (Chen *et al.,* 2006), excess hard work and deprivation experienced in prison camps (Burke *et al.,* 2004), poor sanitation and lack of cleanliness (Choe *et al.,* 2005; Burke *et al.,* 2011; Wallace *et al.,* 2011), and the transition to another country (Burke *et al.,* 2011). By far the most common cited cause of hepatitis B, was food related (Chen *et al.,* 2006; Burke *et al.,* 2004; Choe *et al.,* 2005; Buck *et al.,* 2006; Burke *et al.,* 2011), linked to access, contamination or cultural practices. Deleterious food, raw and dirty food (Chen *et al.,* 2006), lack of food (Burke *et al.,* 2004) and consuming non indigenous food (Burke *et al.,* 2011) were all considered putative factors. The cultural practice of communal eating that is common in South Asian countries where food and utensils are shared was seen as the primary cause of the disease and the main mode of transmission (Choe *et al.,* 2005; Chen *et al.,* 2006; Burke *et al.,* 2011). This belief was also evident among some health professionals who participated in the study by Hwang *et al.* (2009).

''It is contagious. You have contact with people with hepatitis, eat the food that they have started eating, touch the things that they have touched. Then it's easy to be infected.''[North American Chinese adult; Chen et al., 2006; pg. 103]

"Lots of Korean families sit together sharing food in the same bowl.… We all share a part of a stew by dipping everybody's spoon, not like in the US — the lack of sanitation causes more hepatitis … through sharing the same utensils." [Korean American female; Choe et al., 2005; pg. 2957]

"… if each person eats separately then there is less transmission. But when a whole family eats together, they stick their chopsticks or spoon right into the common dish. Some people stick their spoon right into the bowl of soup and eat from it. All the saliva passes to each other. In Asia, several generations stay together but in America people live separately. Even with eating, no one touches each other. So that would help decrease germ transmission. But if Vietnamese families start to eat like that it means that that person is being disrespectful." [53 year old Vietnamese American male, USA; Burke et al., 2004; pg. 160]

Inaccuracies in the understanding of hepatitis B transmission were identified in six studies (Burke *et al.,* 2004; Choe *et al.,* 2005; Chen *et al.,* 2006; Buck *et al.,* 2006; van der Veen *et al.,* 2009; Wallace *et al.,* 2011). As previously noted, many people believed that hepatitis B was spread via shared eating and drinking or contamination of food sources. Although common for other forms of hepatitis, such routes are not considered to be significant sources of transmission. Blood transmission, casual contact and sharing hygiene products were recognised as potential routes by men with a history of imprisonment in the study by Buck *et al.* (2006). Sexual contact as a route of transmission was discussed or identified by participants in two studies (van der Veen *et al.,* 2009; Buck *et al.,* 2006), but did not feature as a mode of transmission mentioned by participants born in East and South East Asia. Overall, the evidence suggested that people from migrant groups do not perceive hepatitis B

infection as a sexually transmitted infection (STI), but rather as a liver or blood illness (Choe *et al.,* 2005; van der Veen *et al.,* 2009; Wallace *et al.,* 2011), which had implications for their beliefs about the spread of hepatitis B and the stigmatisation of those with hepatitis B.

> *"I don't know much [about hepatitis B], just that it spreads by sharing a shot-glass and if you drink too much, then you get it…" [36 year old Korean American female, USA; Choe et al., 2005; pg. 2957]*

> *"People just do not know much about this disease. They simply come for a sick-call at home, and do not bother about it." [First generation Turkish Dutch male, The Netherlands; van der Veen et al., 2009; pg. 5]*

> *"It's just called liver sickness... hepatitis B is not seen as a sexually transmitted disease." [Health Worker, Australia; Wallace et al., 2011; pg. 4]*

Vertical transmission (mother to child) was acknowledged in discussions related to the high prevalence within families (Burke *et al.,* 2004). The familial spread of hepatitis B meant that infection was not viewed as an unusual or unique experience. In essence, the inter-generational nature of hepatitis B made it a socially acceptable normative experience (van der Veen *et al.,* 2009; Wallace *et al.,* 2011). Wallace *et al.* (2011) ascertained that vertical transmission could also perpetuate misconceptions about hepatitis B, such as infected individuals perceiving it to be a blood disorder.

> *"I had nothing to hide because it was given to me from birth." (Australian born female with Vietnamese parents, Australia; Wallace et al., 2011; pg. 3)*

> *"The whole family have hep B except for my father… maybe it's a blood thing." [Cambodian born male, Australia; Wallace et al., 2011; pg. 4]*

Stigma

The concept of stigma and hepatitis B was discussed in five studies (Choe *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009; Wallace *et al.,* 2011; Burke *et al.,* 2011). Stigma associated with hepatitis B was seen to restrict disclosure of both testing and infection status (Chang *et al.,* 2008; van der Veen *et al.,* 2009; Wallace *et al.,* 2011). Participants purported that infected individuals may not want to tell other people of their hepatitis B status or intention to seek a test because of a fear of discrimination against themselves and their families (Chang *et al.,* 2008), exclusion (Wallace *et al.,* 2011) and parental rejection or disapproval (van der Veen *et al.,* 2009). Three studies (van der Veen *et al.,* 2009; Wallace *et al.,* 2011; Burke *et al.,* 2011) concluded that the stigma associated with hepatitis B was generally perceived to be less than or different to other STIs or HIV/AIDS. According to health professionals who participated in the study by Wallace *et al.* (2011), one reason for this was the fact that people born in Asian countries consider hepatitis B to be a 'liver sickness' and do not associate it with STIs.

> *"It's just called liver sickness ... hepatitis B is not seen as a sexually transmitted disease, because ... you don't get the genital symptoms, it doesn't have the stigma as syphilis." [Health Worker, Australia; Wallace et al., 2011; pg. 4]*

This was further supported by evidence of the lack of knowledge of sexual contact among participants as a method of transmission (Choe *et al.,* 2006). Notably, van der Veen *et al.* (2009)

concluded that increasing awareness of hepatitis B as an STI could possibly lead to increased social stigma.

Cultural influences on preventive behaviours

General health behaviours

Hepatitis B and liver disease prevention strategies were discussed in four studies (Choe *et al.,* 2005; Chen *et al.,* 2006; van der Veen *et al.,* 2009; Wallace *et al.,* 2011). A range of strategies were proposed but not necessarily practiced by participants (Choe *et al.,* 2005). Some suggestions were generic in nature and addressed health improvement in general. These included living a balanced life, strengthening the body's natural defences (Chen *et al.,* 2006) and the need to modify individual behaviours such as reducing the intake of alcohol (Wallace *et al.,* 2011), moderating diet, increasing exercise, reducing stress and getting sufficient rest (Choe *et al.,* 2005; Chen *et al.,* 2006). Specific ways to prevent hepatitis B were linked to participant's perceptions about transmission and reflected cultural influences on their health behaviour. Strategies included practicing good hand washing and hygiene, altering eating habits to avoid the use of shared utensils, preparing meals carefully to avoid contamination and avoiding contact with infected people (Choe *et al.,* 2005; Chen *et al.,* 2006).

> *''In general, we should pay attention to general hygiene. Say we have to wash hands before eating and after going to washroom. We should start with our own personal hygiene, since we cannot control others. That's why we have to do our part. It can be spread, so you have to be responsible for your own hygiene. If it's cleaner, you can have a protective shield. Others cannot affect you, even if they are dirty.'' [North American Chinese adult, USA and Canada'; Chen et al., 2006; pg.103]*

> *"[To prevent hepatitis B] we need to wash our hands, not eat other people's food. I need to pay closer attention to this… I tend to share foods with other people and pass around the drinking glass." [Korean American male, USA; Choe et al., 2005; pg. 2957]*

Similarly to their beliefs about the causes and prevention of hepatitis B, participants born in East and South East Asia expressed beliefs about prevention that were situated within their understanding and experience of traditional practices. Religious influences on health behaviour were also apparent. Male Turkish-Dutch participants considered the concept of 'cleanliness' embedded in the Islamic doctrine as a possible solution for preventing hepatitis B infection; anyone who abided by the rules set out in the religion, which promotes hygienic cleanliness and prohibits extramarital sex, would not be at risk of infection (van der Veen *et al.,* 2009).

> *"Our prophet says: cleanliness is half of the faith. If someone is not clean, he might not go to heaven. A person who lives according to the rules of our religion will be almost 100% sure of not getting this disease (HBV)." [First generation Turkish Dutch male, The Netherlands; van der Veen et al., 2009; pg. 7]*

Complementary and alternative medicine

Many participants born in East and South East Asia advocated the use of complementary and alternative medicine (CAM) as a way to prevent or treat the early stages of hepatitis B. It was evident that their views about health and illness were influenced by cultural beliefs and rooted in different

medical traditions. Participants born in South Asian countries described the use of traditional balance maintaining practices to restore balance among elements of the body and the environment (Burke *et al.,* 2011), and cited the value of using traditional Vietnamese and Chinese medicine to ease the discomfort of hepatitis B (Burke *et al.,* 2004). Health professionals who participated in the study by Hwang *et al.* (2010) expressed some concerns about the use of CAM but acknowledged its importance among the Asian American community, as well as its accessibility and affordability. Additionally, some providers saw CAM as an opportunity to bridge differences between traditional and Western medical practices.

> *''Anyway, Chinese like those 'ji gu cao' and 'xia ku cao' [Chinese herbal medicine] to prevent hepatitis. Once in a while, make some to drink because here in America people often eat pan-fried and deep-fried foods.'' [North American Chinese adult, USA and Canada; Chen et al., 2006; pg. 104]*

> *"When it is in the initial stage hepatitis can be treated with Chinese medicine or with Eastern medicine. They don't have to die. When it is cured the result is long lasting and good; one is immune. There's nothing to it." [Vietnamese American female, USA; Burke et al., 2004; pg. 159]*

> *"You can read the protocols and most of them will prohibit botanicals and alternative complementary medicine. You know, and that may be a mistake because road blocks saying I reject where you're coming from, therefore you're rejecting them from their very entry, how can you expect to bridge a line with them?" [Liver specialist, USA; Hwang et al., 2010; pg. 224]*

Vaccination

Although immunisation of at-risk groups for hepatitis B was outside the scope of the review, views and experiences on vaccination are presented here for completeness. On the whole, vaccination was not generally considered as a means of hepatitis B prevention among people from migrant groups (Chen *et al.,* 2006). There was evidence to suggest that participants had limited awareness of vaccination and its importance. Four studies highlighted the fact that attitudes toward vaccination were generally positive and that many participants were receptive to being vaccinated (Choe *et al.,* 2005; Buck *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009). Among males with a history of imprisonment, and some people from migrant groups, vaccination was seen as a 'good precautionary measure' that would protect one's health and reduce the worry about infecting others (Buck *et al.,* 2006; van der Veen *et al.,* 2009).

> *''After moving here (Canada), then I got more information about this, possibly through a family doctor ... But would it be that most of the people think wrongly that if one is healthy, the injection has no impact on the person? As I am not a carrier, I don't have hepatitis. I don't need to have the injection ... every minute it is possible [for a healthy person] to get seriously ill. Then how come you have to deal with something that may not happen at all? So, for a lot of people, they think this way. So, for myself, in the past, I had that mentality, too, when I was young. No need to waste money, no need to waste time.'' [North American Chinese Adult, USA & Canada; Chen et al., 2006; pg. 105]*

"If there is a good vaccination for this disease, that is the best action to take!" [First generation Turkish Dutch female, The Netherlands; van der Veen et al., 2009; pg. 5]

"Like I said, I wouldn't want to take a chance. I wouldn't want to be walking around with hepatitis B and not knowing it, and passing it along; and if there's something that I can take to make it better so it doesn't progress, I'd like to do that." [Male with a history of imprisonment, USA; Buck et al., 2006; pg. 17]

Significant confusion and uncertainty about vaccination was noted in three studies (Chen *et al.,* 2006; Buck *et al.,* 2006; Chang *et al.,* 2008). There was a lack of clarity surrounding the purpose of the vaccine; some participants perceived it as testing or treatment rather than a prevention strategy (Buck *et al.,* 2006; Chen *et al.,* 2006). Participants also expressed concerns about potential adverse effects and cited a lack of trust and confidence in the efficacy of vaccination (Chen *et al.,* 2006; Chang *et al.,* 2008; Wallace *et al.,* 2011), which fostered a reluctance to get immunized. Others did not perceive a need for vaccination when living in countries with low prevalence of hepatitis B (Chen *et al.,* 2006) or when they were in good health (Chang *et al.,* 2008). The three shot vaccination series was considered to be a deterrent to getting vaccinated as participants often found it confusing, inconvenient and costly (Chang *et al.,* 2008).

''For instance, sometimes something came up and they said, ''Oh this is hepatitis B and you need three shots,'' something like that, or said something like ''lifelong immunity,'' don't know exactly. We did not understand a whole lot about it...'' [North American Chinese adult, USA and Canada; Chen et al., 2006; pg. 105]

"I wouldn't get it [HBV vaccine] 'cause I ain't got it [HBV]. Why would I get the vaccine if I don't have it?" [Male with a history of imprisonment, USA; Buck et al., 2006; pg. 16]

Evidence statements 1-4: Hepatitis B knowledge and beliefs

1: Understanding and awareness of hepatitis B among people from migrant groups may be strongly influenced by their personal experiences and cultural beliefs.[1]

2: People from migrant groups may confuse the various forms of hepatitis and the relationship between hepatitis and HIV, and they may commonly hold less than accurate beliefs about transmission risks.[2] The lack of, or gaps in, knowledge about hepatitis B identified among some healthcare professionals[3] may compound or contribute to inadequate knowledge about hepatitis B among groups at a high risk of chronic infection.

3: People from migrant groups may commonly cite access to or contamination of food, or cultural practices associated with sharing food and communal eating as the main cause of hepatitis B transmission.[4] Although vertical transmission of hepatitis B was acknowledged in some studies, sexual transmission of hepatitis B was infrequently mentioned; overall, the evidence suggests that groups at a high risk of infection do not perceive hepatitis B as an STI.[5]

4: Similarly to their beliefs about the causes and prevention of hepatitis B, people from migrant groups may express beliefs about prevention that are influenced by their personal experiences and cultural background.[6] Among people born in East and South East Asia, prevention strategies may commonly reflect the practice of traditional medicine and vaccination may not generally be considered as a primary means of prevention.[7] Religious influences on preventive health

strategies may also be apparent, for example, among males who follow the Islamic doctrine.[8]

[1] Burke *et al.,* 2004 [++]; Burke *et al.,* 2011 [+]; Wallace *et al.,* 2011 [++]

[2] Burke *et al.,* 2011 [+]; van der Veen *et al.,* 2009 [++]; Wallace *et al.,* 2011 [++]

[3] Hwang *et al.,* 2010 [++]; Wallace *et al.,* 2011 [++]

[4] Burke *et al.,* 2004 [++]; Burke *et al.,* 2011 [+]; Chen *et al.,* 2006 [++]; Choe *et al.,* 2005 [++]

[5] Choe *et al.,* 2005 [++]; van der Veen *et al.,* 2009 [++]; Wallace *et al.,* 2011 [++]

[6] Choe *et al.,* 2005 [++]; Chen *et al.,* 2006 [++]; van der Veen *et al.,* 2009 [++]; Wallace *et al.,* 2011 [++]

[7] Burke *et al.,* 2004 [++]; Burke *et al.,* 2011 [+]; Chang *et al.,* 2008 [++]; Chen *et al.,* 2006 [++]; Choe *et al.,* 2005 [++]; Hwang *et al.,* 2010 [++]

[8] van der Veen *et al.,* 2009 [++]

4.4.2 Barriers and facilitators to hepatitis B testing

Unexpected experiences and uncertain perceptions of HBV testing

Hepatitis B testing was discussed in six studies (Buck *et al.,* 2006; Chen *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009; Wallace *et al.,* 2011; Buck *et al.,* 2006). Three studies (Chen *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009) reported that most participants were generally in favour of being tested for hepatitis B but some participants were reluctant to visit a clinic just for hepatitis screening (Chen *et al.,* 2006). Some participants had experienced testing as part of the immigration process (Chen *et al.,* 2006; Wallace *et al.,* 2011). The study by Wallace *et al.* (2011) indicated that testing had occurred without the explicit consent of most participants. Compulsory testing was considered by participants from the Turkish Dutch community in the study by van der Veen *et al*. (2009) as a motivating factor for compliance. They were also of the opinion that an invitation to screen would increase uptake of testing as it *'would release [people] from suspicion of the social environment'* (van der Veen *et al.,* 2009: pg. 7).

> *"I didn't ask for it, just through a normal blood test." [Vietnamese born male, Australia; Wallace et al., 2011; pg. 2]*

> *"Well it has a bit to do with taboo, but now we have discussed it, I can go for screening without getting into trouble." (Second generation Turkish-Dutch male; van der Veen et al., 2009; pg. 7)*

Two studies (Chang *et al.,* 2008; van der Veen *et al.,* 2009) explored participants' views and beliefs regarding social support for testing. Chang *et al.* (2008) reported that participants were keen to raise awareness of hepatitis B testing among family and friends. Motivations for this included protection of their own and others' health and a concern for community well-being. Social support for testing was also apparent among female participants from the Turkish Dutch community in the study by van der Veen *et al.* (2009). However, the fact that hepatitis B is spread via sexual contact and the associated stigma and fear of discrimination complicated discussions of testing (Chang *et al.,* 2008; van der Veen *et al.,* 2009).

> *"If it is good for health we should share with our relatives and friends." [Chinese American adult, USA; Chang et al., 2008; pg. 5]*

"In China, there is some discrimination against hepatitis B patients, hepatitis B virus carriers, and people having been cured. Some people are infected and don't want to tell other people they are. Or they don't want to tell other people their family members have been infected." [Chinese American adult, USA; Chang et al., 2008; pg. 5]

"I will ask them [the children] why they want to go for screening. I will just ask, not because I do not trust what they have done. Whatever has happened, if there is a risk for having contracted a disease, of course they should go for a test." [First generation Turkish Dutch female, The Netherland; van der Veen et al., 2009; pg. 5]

Facilitators to HBV testing

Reasons for testing were reported in four studies (Buck *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009; Wallace *et al.,* 2011). Drivers for testing were generally related to concerns for self (self preservation) or concern for others (community well-being), and were underpinned by a sense of personal responsibility for one's health and the health of one's spouse and family (van der Veen *et al.,* 2009). Participants cited *'peace of mind'*, '*fear of an HBV epidemic'*, *'precautionary measures'*, *'concerns about susceptibility through risky behaviours'* and *'avoidance of infecting others'* (Buck *et al.,* 2006; Chang *et al.,* 2008) as primary motivators for testing.

"It is better to check it up, get screened, to see whether my immune ability is like that, so that I can be assured about my health." [American Chinese female, USA; Chang et al., 2008; pg. 4]

"The fact that I was in prison and around lots of men that were infected… I'm not sure how it's passed and then the boot camp, exposed to the guards throwing other peoples' razors all around, and I might have gotten someone else's bar of soap or whatever, toothbrush. Just precautionary for my own good, for my own sake. But I know I didn't have nothing when I got to prison. Get tested when I get out, make sure I didn't get anything when I was in to protect myself and others." [Male with a history of imprisonment, USA; Buck et al., 2006; pg. 16]

Barriers to HBV testing

Five studies alluded to different barriers to hepatitis B testing (Chen *et al.,* 2006; Buck *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009; Wallace *et al.,* 2011). Whilst some barriers to testing were context specific (e.g. cited by participants with a history of imprisonment or from countries with different health care finance systems), many of the obstacles cited were relevant to hepatitis B testing in general. For example, a fear of needles or medical checkups (Buck *et al.,* 2006; Chen *et al.,* 2006), the lack of information and understanding about hepatitis B and the absence of symptoms (Chen *et al.,* 2006) was seen to limit uptake of testing.

''Because it's a waste of time. When there is no reason to go, I won't go. Unless, like when I was coming to Canada and the immigration department demanded such a check up, then I went. Ordinarily, when I am not sick or have no discomfort, I won't go.'' [North American Chinese adult, USA and Canada; Chen et al., 2006; pg. 105]

"Well, you might not want to go for a test, because you just intend to live a healthy life. I am not doing a test, just like that. I will first have a look at myself: where did I go wrong, and

primarily I will correct myself in that (risk) behaviour". [Second generation Turkish Dutch male, The Netherlands; van der Veen et al., 2009; pg. 5]

Practical obstacles such as the inconvenience of seeking out testing facilities, time constraints and the expense of tests were also considered to be possible obstacles to taking a hepatitis B test in several studies (Buck *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009). Insufficient information about the testing and vaccination process led to fear of adverse side effects (Chang *et al.,* 2008; Wallace *et al.,* 2011) and concerns about the accuracy and reliability of the tests themselves may have acted as an obstacle to testing (Chang *et al.,* 2008).

"I heard that sometimes the test is not really reliable, sometimes gives false positives or false negatives… If the test is not accurate, you get emotional, your family gets worried." [English-speaking Chinese-American male; Chang et al., 2008; pg. 4]

Cultural beliefs and social norms also appeared to hinder uptake of hepatitis B testing. According to Chen *et al.* (2006), a reluctance to be tested was attributed to the Chinese belief that going to the hospital was '*bad luck*'. Turkish Dutch participants in the study by van der Veen *et al.* (2009) mentioned shame and suspicion linked to sexual behaviour as reasons not to participate in testing for hepatitis B. Although reputation was viewed by first generation Turkish Dutch males as a facilitator for testing, Turkish Dutch males from disadvantaged communities perceived that hepatitis B testing might tarnish their reputation and have a negative impact on perspective partners (van der Veen *et al.,* 2009). In addition, there were particular sensitivities regarding the links between sexual behaviour and hepatitis B testing among women; however, women in this study expressed that reputation should not be *"a hindrance to get tested"* (van der Veen *et al.,* 2009; pg. 6). Inmates cited distrust of prison and medical staff in relation to fear of restrictions or loss of confidentiality in the prison setting as reasons to avoid blood tests during imprisonment (Buck *et al.,* 2006).

Three studies (Chang *et al.,* 2008; Hwang *et al.,* 2010; van der Veen *et al.,* 2009) identified that participant's experiences of communication with providers were barriers to testing as were provider's perceptions of language and cultural differences among themselves and their patients. Hwang *et al.* (2010) reported that language and cultural barriers discouraged non-Asian physicians from providing outreach to the Asian American community, perceiving a resistance to seeing non-Asian physicians among this community. However, the gender and ethnicity of the medical provider was perceived as a barrier for some female participants from the Turkish Dutch community (van de Veen *et al.,* 2009). Some female participants expressed a preference for a Dutch male doctor above a Turkish male doctor, indicating that cultural factors and gender may intersect to influence patient preferences in this respect.

The cost of hepatitis B testing was considered a deterrent to uptake in several studies (Buck *et al.,* 2006; Chang *et al.,* 2008; van der Veen *et al.,* 2009). Financial constraints posed significant problems not only for uptake of testing but for subsequent care as well, as medical providers were reluctant to diagnose hepatitis B when affordability of care was an issue (Hwang *et al.,* 2010). Medical providers reported implementing cost minimizing strategies and streamlining the screening process to make it faster and more affordable to high risk groups (Hwang *et al.,* 2010). Issues related to the expense of hepatitis B testing pertained specifically to countries like the USA, which have a different health care finance system to the UK, and although not relevant to the UK context, it does highlight the fact that the cost of care can influence decisions on medical practice.

Evidence statements 5-8: Barriers and facilitators to hepatitis B testing

5: Studies showed that people born in countries with intermediate and high endemicity for hepatitis B may express a general motivation for testing and keenness to raise awareness of hepatitis B testing among friends and family.[1] However, there is some evidence among those with experience of testing to indicate that testing may occur without explicit consent being sought.[2] Making testing obligatory was considered as a motivating factor for compliance with testing among Turkish Dutch immigrants.[3]

6: Primary motivating factors for testing among people at a high risk of infection are related to concerns for individual health, concern for others health, and the health of the wider community.[4]

7: Barriers to testing include an absence of clear symptoms of infection, practical obstacles such as inconvenience and time constraints, and language and cultural barriers, which may discourage some people from seeking care and may limit the role that healthcare providers play in providing education and outreach to people from migrant groups.[5]

8: The conception of hepatitis B as a 'liver' or 'blood' illness rather than an STI appears to play an important role in tempering stigma associated with hepatitis B. Increasing awareness of hepatitis B as an STI was viewed by van der Veen *et al.* (2009) as potentially contributing to increased stigma.[6]

[1] Chang *et al.,* 2008 [++]; Chen *et al.,* 2006 [++]; van der Veen *et al.,* 2009 [++]
[2] Wallace *et al.,* 2011 [++]
[3] van der Veen *et al.,* 2009 [++]
[4] Buck *et al.,* 2006 [+]; Chang *et al.,* 2008 [++]; van der Veen *et al.,* 2009 [++]; Wallace *et al.,* 2011 [++]
[5] Chang *et al.,* 2008 [++]; Chen *et al.,* 2006 [++]; van der Veen *et al.,* 2009 [++]; Wallace *et al.,* 2011 [++]
[6] van der Veen *et al.,* 2009 [++]

4.4.3 Experiences of diagnosis and clinical management

Only one study (Wallace *et al.,* 2011) explored the views and experiences of people with a diagnosis of chronic hepatitis B.

Poor experience of diagnosis

Participants reported a lack of pre or post test discussion and noted little recollection of providing consent to test. Wallace *et al.* (2011) purported that this lack of information in conjunction with a lack of understanding of hepatitis B meant that some participants were 'shocked' by their hepatitis B diagnosis and that the impact of the diagnosis led to confusion and fear for the future. The absence of information and understanding of hepatitis B at the point of diagnosis meant that some participants sought information that reflected their "cultural understanding of health".

> *"He was an intelligent, educated young man. But because the GP hadn't told him or started that slow education counselling process, by the time he got to me it was a huge catastrophe, he was going to die, his wife was going to leave him... We need to situate the disease in all the cultural issues." [Health worker, Australia; Wallace et al., 2011; pg. 3]*

Negative views of clinical management

Lack of information and knowledge of hepatitis B at diagnosis was perceived by participants to have impacted negatively on their health, and prevented opportunities for behaviour change that might

have improved or promoted better health (Wallace *et al.,* 2001). Both patients and community workers expressed concerns about a lack of provider knowledge with regards to hepatitis B.

> *"If they told me a few years ago that I wasn't really meant to drink alcohol ... I would have cut down on it." [Cambodian born male, Australia; Wallace et al., 2011; pg. 4]*

> *"I told the doctor that I had an e-antigen test, and he goes 'the result?' and I go 'I don't know, it's not active' or something and it was left there ... he hasn't followed [it] up." [Australian born male, Australia; Wallace et al., 2011; pg. 4]*

Disclosure

The experience of disclosing one's hepatitis B status to family and friends was variable (Wallace *et al.,* 2011). Disclosure was relatively easy if hepatitis B was acquired through vertical transmission. The inter-generational spread of hepatitis B normalized and destigmatised the disease so there was '*nothing to hide*' (Wallace *et al.,* 2011). However, the general lack of knowledge and understanding around hepatitis B, the asymptomatic nature of the disease, the lack of a cure, the fact that hepatitis B is spread via sexual contact, the associated stigma and the fear of rejection and exclusion made disclosure difficult for others (Wallace *et al.,* 2011).

Evidence statement 9: Experiences of diagnosis and clinical management

9: One study reported that people with a diagnosis of chronic hepatitis B, including first and second generation immigrants, had little recollection of providing consent to test and did not receive adequate information at diagnosis. This lack of information and knowledge was perceived as impacting negatively on their health and preventing opportunities for behaviour change. Both patients and community workers expressed concerns about a lack of provider knowledge with regards to hepatitis B.[1]

[1] Wallace *et al.,* 2011 [++]

5 Views, perspectives and experiences of practitioners and groups at an increased risk of hepatitis C infection

5.1 Overview of papers

As shown in Table 3, a total of 48 studies were included that examined the views, perspectives and experiences of practitioners and groups at an increased risk of hepatitis C infection. Full data extraction tables are presented in Table 6 in Appendix 5. Three reviews of qualitative research were identified; two were reviews of English language qualitative peer reviewed papers (Rhodes & Treloar, 2008; Treloar & Rhodes, 2009) and one was a review of research reports (Paterson *et al.,* 2007). Of the primary studies included in the review, 16 were from Australia, 11 were from the USA, ten were from the UK, four were from Canada, two were from Ireland, one presented data from both Australia and New Zealand, and one was from Hungary. Of the 48 studies, 32 studies focussed on populations of IDUs and/or drug treatment clients, including seven that sought the views of health professionals serving these populations; 12 studies focused on groups diagnosed with hepatitis C including IDUs and people with alternative sources of infections (e.g. needle stick injury); and four studies focused on prisoners, including 2 that sought the views of health professionals.

A total of 30 individual research studies were reported across the 45 primary qualitative studies. Twenty nine studies reported using interviews as their method of data collection, one used focus groups (McCreaddie *et al., 2011*), seven used both interviews and focus groups (Astone *et al.,* 2005, Gyarmathy *et al.,* 2006; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a, Munoz-Plaza *et al.,* 2005b, Munoz-Plaza *et al.,* 2008, Munoz-Plaza *et al.,* 2010), two used interviews and observations (Carrier *et al.,* 2005, Southgate *et al.,* 2005), one used interviews and autobiography (Harris, 2009b), two used interviews and document analysis (Fraser, 2004; Fraser, 2010), and three used a survey questionnaire and provided an analysis of qualitative open ended responses (Brener & Treloar, 2009; Cullen *et al.,* 2005; Habib & Adorjany, 2003).

Data was reported on 1,160 current and former IDUs. This included clients of methadone clinics and/or drug treatment programmes (n=498), current or former prisoners (n=72), individuals defined as homeless (n=56) and IDUs from dance music/party scenes (n=31). Nine studies explored the views and experiences of people with a diagnosis of hepatitis C including people with various sources of infection; out of a total of 141 participants, 90 were identified as IDUs. One further study (Fraser & Treloar, 2006) did not state overall how many participants were IDUs, but the status of each participant was reported alongside illustrative quotes. Five studies (Munoz-Plaza *et al.,* 2004; 2005a; 2006; 2008; 2010) reported data from a five-year study of hepatitis C services sited within drug treatment programmes and drew on data from 215 drug treatment clients and 107 drug treatment staff. The views of 76 health professionals were reported across the included studies (including: GP's, n=20; prison staff, n=23; and other health professionals, n=33).

- Ten studies and one review article focussed on the lived experience of hepatitis C among IDUs, knowledge of hepatitis C, injecting practices and risk management (Carrier *et al.,* 2005; Davis *et al.,* 2004; Davis & Rhodes, 2004; Ellard 2006; Fraser 2004; Gyarmathy *et al.,* 2006; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Southgate *et al.,* 2005; Wozniak *et al.,* 2007; Wright *et al.,* 2005). The review article reported the findings of a qualitative synthesis of

research articles on injecting practices and risk behaviours among IDUs (Rhodes & Treloar, 2008). The paper reported findings from 31 English language qualitative peer reviewed articles, representing 24 unique studies.

- Four studies and one review article discussed experiences of stigma and discrimination among hepatitis C positive individuals including IDUs/drug treatment clients and the impact of stigma on access to, and uptake of, hepatitis C services (Brener & Treloar, 2009; Habib & Adorjany, 2003; Harris, 2009b; Paterson *et al.,* 2007; Treloar & Hopwood, 2004). The review article examined 21 published research reports (Paterson *et al.,* 2007).
- Thirteen studies and one review article reported data on the experience of a positive hepatitis C diagnosis, the impact of a positive diagnosis on behaviour and implications for the uptake of hepatitis C services and treatment (Copeland, 2004; Craine *et al.,* 2004; Cullen *et al.,* 2005; Faye & Irurita, 2003; Fraser & Treloar, 2006; Fraser 2010; Harris, 2009a; McCreaddie 2011; Paterson *et al.,* 2006; Roy *et al.,* 2007; Sutton & Treloar, 2007; Temple Smith *et al.,* 2004; Treloar & Rhodes, 2009; Tompkins *et al.,* 2005). The review article reported findings of a qualitative synthesis of research findings on the lived experience of hepatitis C among IDUs and experiences of diagnosis and treatment. The paper reported findings from 25 English language qualitative peer reviewed articles, representing 20 unique studies (Treloar & Rhodes, 2009).
- Seven papers reported factors influencing the uptake of hepatitis C services (i.e. testing and treatment) among IDUs (Coupland *et al.,* 2009; Kinder, 2009; Lilly *et al.,* 2008; Sosman *et al.,* 2005; Swan *et al.,* 2010) and individuals engaged in methadone maintenance/drug treatment (Munoz-Plaza *et al.,* 2008; Treloar & Holt, 2008). Eight papers specifically discussed the role of drug treatment programmes and opiate substitute clinics as sites for the delivery of hepatitis C services (e.g. education, testing, pre and post test counselling, treatment) (Astone *et al.,* 2005; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a; Munoz-Plaza *et al.,* 2006; Munoz-Plaza *et al.,* 2010; Perry and Chew-Graham 2003; Strauss *et al.,* 2008; Treloar *et al.,* 2010). Three studies discussed the provision of hepatitis C services (e.g. education, testing and treatment) in prison (Dyer & Tolliday, 2009; Khaw *et al.,* 2007; Munoz-Plaza *et al.,* 2005b).

Although the papers have been categorised into distinct groups according to their main focus, there was considerable overlap across the papers with regards to their findings and the identified themes. For example, although a paper may have primarily focused on the uptake of testing among IDUs, it may also have provided insight into IDUs' knowledge of hepatitis C, injecting practices and experiences of stigma.

Table 3. Summary of included studies: Hepatitis C

Reference	Country	Participants	Data collection method
Astone *et al.,* 2005 [+]	USA	49 HCV positive IDUs	Interviews and focus groups
Brener & Treloar, 2009 [+]	Australia	120 HCV positive and 120 HCV negative client from a drug and alcohol treatment facility	Survey questionnaire and analysis of open-ended questions
Carrier *et al.,* 2005 [+]	Canada	36 IDUs	Ethnography. Interviews and observations
Copeland, 2004 [++]	UK	16 older IDUs	Semi-structured interviews
Coupland *et al.,* 2009 [++]	Australia	23 IDUs with Cambodian, Lao or Vietnamese cultural backgrounds	Pre and post brief intervention interviews
Craine *et al.,* 2004 [++]	UK	43 IDUs in contact with drug treatment services	Semi-structured interviews
Cullen *et al.,* 2005 [–]	Ireland	25 current and past heroin users attending a general practice	Semi-structured questionnaire and analysis of qualitative data
Davis *et al.,* 2004 [++]	UK	59 IDUs	Interviews
Davis & Rhodes, 2004 [++]	UK	59 IDUs	Interviews
Dyer & Tolliday, 2009 [–]	Australia	37 personnel who held positions of responsibility for HCV prevention and/or treatment in custodial settings	Semi-structured interviews
Ellard, 2007 [++]	Australia	31 individuals from the dance/party scene, 13 had injected drugs	Interviews
Faye & Irurita, 2003 [++]	Australia	24 HCV positive individuals, 13 of which were IDUs. Six informants (spouses of participants, a nurse and other persons working in field of substance abuse)	Interviews
Fraser & Treloar, 2006 [++]	Australia	85 participants, 38 of which were HCV positive. IDUs included in the sample but numbers not specified	Semi-structured interviews
Fraser, 2004 [+]	Australia	IDUs. Numbers not specified	Interviews and analysis of health promotion documents
Fraser, 2010 [–]	Australia	30 IDUs	Interviews and analysis of health promotion documents
Gyarmathy *et al.,* 2006 [+]	Hungary	29 IDUs aged 30 years and under	Semi-structured interviews and focus groups
Habib & Adorjany, 2003 [–]	Australia	274 IDUs	Survey questionnaire with analysis of qualitative data
Harris, 2009a [+]	Australia	40 participants living with chronic hepatitis C; 34 were former IDUs	Semi-structured interviews and reflection on the researchers experience of injecting drugs and being HCV +

Reference	Country	Participants	Data collection method
Harris, 2009b [–]	Australia & New Zealand	40 participants living with chronic hepatitis C; 34 were former IDUs	Semi-structured interviews
Khaw *et al.,* 2007 [+]	UK	30 prisoners with a history of injecting drug use	Semi-structured interviews
Kinder, 2009 [++]	USA	8 HCV positive males, 5 of which were IDUs	Interviews
Lally *et al.,* 2008 [++]	USA	20 female IDUs in drug treatment	Semi-structured interviews
McCreaddie *et al.,* 2011 [++]	UK	16 HCV patients not currently on treatment with one or more co-morbidities. 17 staff working with HCV-infected co-morbid patients in various settings.	Focus groups
Munoz-Plaza *et al.,* 2004 [+]	USA	29 drug treatment clients and 23 staff	Interviews and focus groups
Munoz-Plaza *et al.,* 2005a [+]	USA	51 drug treatment clients	Interviews and focus groups
Munoz-Plaza *et al.,* 2005b [+]	USA	11 male prisoners	Semi-structured interviews and focus groups
Munoz-Plaza *et al.,* 2006 [+]	USA	26 drug treatment staff	Interviews
Munoz-Plaza *et al.,* 2008 [+]	USA	164 drug treatment programme clients	Interviews and focus groups
Munoz-Plaza *et al.,* 2010 [+]	USA	215 drug treatment clients and 165 staff	Interviews and focus groups
Paterson *et al.,* 2006 [++]	Canada	33 HCV positive participants living in British Columbia; including 16 IDUs	In-depth interviews
Paterson *et al.,* 2007 [NR]	Not applicable	English language research reports on stigma and injecting drug use. 21 research reports	Literature review. Approach to synthesis not described.
Perry & Chew-Graham, 2003 [+]	UK	20 GPs from drug services	Semi-structured interviews
Rhodes & Treloar, 2008 [NR]	Not applicable	English-language qualitative empirical studies of HCV risk among IDUs. 31 papers, representing 24 studies among over 1,000 IDUs	Meta-ethnographic approach to qualitative synthesis
Rhodes *et al.,* 2004 [++]	UK	59 IDUs, who had injected drugs in the last four weeks	Interviews
Roy *et al.,* 2007 [++]	Canada	39 street-involved young IDUs (<30 years old), currently injecting drugs or in the process of quitting injection	In-depth interviews
Sosman *et al.,* 2005 [+]	USA	42 ex-prisoners	Interviews
Southgate *et al.,* 2005 [++]	Australia	14 IDUs	In-depth interviews. Observational fieldwork
Strauss *et al.,* 2008 [+]	USA	62 drug treatment clients	Interviews

Reference	Country	Participants	Data collection method
Sutton & Treloar, 2007 [++]	Australia	36 HCV positive individuals, including IDUs (numbers not specified)	Semi-structured interviews
Swan *et al.,* 2010 [++]	Ireland	36 participants current and former IDUs	Semi-structured interviews
Temple-Smith *et al.,* 2004 [+]	Australia	32 HCV+ individuals. 8 were current and 22 past IDUs	Interviews
Tompkins *et al.,* 2005 [++]	UK	17 participants homeless IDUs attending a primary care centre	In-depth interviews
Treloar & Holt, 2008 [++]	Australia	77 clients participating in drug treatment.	Semi-structured interviews
Treloar & Hopwood, 2004 [+]	Australia	19 HCV positive individuals, of which 8 were IDUs	Semi-structured interviews
Treloar & Rhodes, 2009 [NR]	Not applicable	English language papers on lived experience of hepatitis C among IDUs. 25 published articles representing 20 unique studies	Meta-ethnographic approach to qualitative synthesis
Treloar *et al.,* 2010 [++]	Australia	27 OST clients and 22 OST health professionals	Semi-structured interviews
Wozniak *et al.,* 2007 [++]	Canada	30 participants. Half were HCV positive (first sample). 31 participants. Two thirds were HCV positive (second sample)	A secondary analysis of interviews conducted with two samples of IDUs.
Wright *et al.,* 2005 [++]	UK	17 HCV positive homeless IDUs	In-depth interviews
HCV – hepatitis C virus; IDUs – injecting drug users; NR – not rated; OST – opiate substitution treatment			

5.2 Quality assessment

Of 45 primary qualitative research studies, 22 studies were rated high quality (++), 18 were rated medium quality (+) and five were rated low quality (–). The full results of quality assessment are presented in Table 8 in Appendix 6. The studies (Cullen *et al.,* 2005; Dyer & Tolliday, 2009; Fraser, 2010; Habib & Adorjany, 2003; Harris, 2009a) rated low in quality had significant omissions in their reporting, the theoretical approach of the work was unclear or not justified in sufficient detail and reporting omissions meant it was not possible to determine whether there were clear and reasonable justifications for the methods chosen. In addition across these five studies, the systematicity and rigour of the analysis could not be reliably determined from the information available. However, it should be noted that despite concerns about the reliability of these five studies the usefulness of the findings were considered as sufficient for inclusion.

Three of the studies identified were syntheses of qualitative research and therefore the NICE quality assessment tool was not suitable for assessing their quality. Two reviews (Rhodes & Treloar, 2008; Treloar & Rhodes. 2009) were based on a meta-ethnographic approach to synthesis qualitative research and used a combination of search methods (including electronic sources, handsearching, checking of reference lists and citation searching) to identify relevant studies. The quality of the studies included the synthesis were also assessed using an adapted version of the Critical Appraisal Skills Programme (CASP) guidance. The methodology used the review undertaken by Paterson *et al.* (2007) was not described and it was unclear how studies were selected for inclusion in the review.

The 12 studies conducted in the UK (n=10) and Ireland (n=2) were found to be of a generally high standard. These papers discussed injecting practices and hepatitis C knowledge among IDUs (Davis *et al.,* 2004; Davis & Rhodes, 2004; Rhodes *et al.,* 2004; Wright *et al.,* 2005), the impact of a positive diagnosis (Craine *et al.,* 2004; Copeland, 2004; Cullen *et al.,* 2005; McCreaddie *et al.,* 2011; Tompkins *et al.,* 2005), and hepatitis C testing and treatment among IDUs (Khaw *et al.,* 2007; Perry *et al.,* 2003; Swan *et al.,* 2010).

5.3 Key themes

The themes developed from the qualitative synthesis of research on hepatitis C were categorised as follows; 1) Injecting practices, risk behaviour and implications for hepatitis C transmission; 2) Knowledge of hepatitis C among IDUs; 3) Hepatitis C testing and the impact of diagnosis; 4) Barriers and facilitators to hepatitis C treatment among IDUs. Where possible, extracts of data from the articles have been used to exemplify each theme and details on participants' sex and age have been reported when available. Table 4 summarises the identified themes and sub themes.

Table 4. Identified themes and sub themes

Theme	Sub-theme	Number of articles discussing theme
Injecting practices, risk behaviour and implications for hepatitis C transmission	Not applicable	16
Knowledge of hepatitis C among IDUs	Hepatitis C as normalised, ubiquitous and socially accepted among IDUs	15

	Incomplete and limited hepatitis C knowledge	20
	A relative understanding of hepatitis C	15
Hepatitis C testing and impact of diagnosis		33
	Barriers to testing	25
	Experience of testing and reaction to diagnosis	21
	Impact of diagnosis on behaviour	17
Stigma as a barrier to disclosure and hepatitis C services	Not applicable	33
Barriers and facilitators to treatment		17
	In general	11
	Drug treatment and methadone maintenance clinics	5
	Prison setting	1

5.4 Findings

5.4.1 Injecting practices, risk behaviour and implications for hepatitis C transmission

Ten papers discussed injecting practices, risk behaviour and the implications of these practices for the transmission and management of hepatitis C (Carrier *et al.,* 2005; Davis *et al.,* 2004; Ellard 2007; Fraser 2004; Gyarmathy *et al.,* 2006; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Southgate *et al.,* 2005; Wozniak *et al.,* 2007; Wright *et al.,* 2005). Six papers that primarily focussed on testing and the impact of diagnosis also discussed injecting practices among IDUs and transmission of hepatitis C (Coupland *et al.,* 2009; Craine *et al.,* 2004; Dyer & Tolliday, 2009; Harris, 2009a; Roy *et al.,* 2007; Swan *et al.,* 2010).

Safe and responsible injecting practices

Safe and responsible injecting practices were employed by IDUs to avoid the transmission of hepatitis C. Such strategies were regarded as '*common sense*' and knowledge on safe injecting practices was imparted to other injectors (Fraser 2004; Davis *et al.,* 2004; Wright *et al.,* 2005). For example, younger and more inexperienced injectors learnt to inject safely through their peers (Fraser 2004; Davis *et al.,* 2004; Ellard 2007).

> *"Even though I know I'm clean, I won't let anyone touch my fits. You know, if they go here you are give it to me, it's like nuh, you know, that's just being totally stupid. You know." [Female IDU, Australia; Fraser, 2004; pg. 212]*

> *"How to be safe, well, it's little things you might pick up. One day you might chuck a filter in a spoon and then you might be with someone and they go, 'oh' you're not supposed to do it like that' you're supposed to do it like that, cause you can catch this and maybe you'll pick something up." [25 year old male IDU, UK; Davis et al., 2004; pg. 1811]*

> *"It's when I started doing it and everything, he said: ''I want to make sure you do it right you know.'' I just thought it was common sense, just to clean it out. You know, it's just common sense really. I didn't really learn it from anywhere. I didn't read an instruction manual to know what to do. I just thought that sounds more sensible." [19 year old male IDU, UK; Davis et al., 2004; pg. 1812]*

Strategies employed to minimize the transmission of hepatitis C included techniques to reduce the exposure of blood (Fraser, 2004), avoiding sharing needles (Southgate *et al.,* 2005; Wright *et al.,* 2005) through keeping used needles and syringes in reserve in separate and safe places (Rhodes *et al.,* 2004), and marking needles and syringes (Rhodes *et al.,* 2004). Although some studies did show that some IDUs employed safe practices in relation to drug paraphernalia (e.g. cleaning equipment) (Wright *et al.,* 2005), this practice was less common and the sharing and reuse of spoons, filters and drug solutions was not always perceived as risky (Coupland *et al.,* 2009; Rhodes *et al.,* 2004; Wright *et al.,* 2005). IDUs often doubted the effectiveness of such methods (Wright *et al.,* 2005; Davis *et al.,* 2004) and expressed concern over the possibility of unintentional sharing (Rhodes *et al.,* 2004).

> *"I don't want it back after someone else has used it, not when I can get hold of clean needles, do you know what I mean? Cos at the end of the day, I don't know if that person's got anything." [Homeless IDU, UK; Wright et al., 2005; pg. 79]*

> *"The thing I can understand that, okay, when you've got difficulty the chemist shuts at six you've got a works [syringe] indoors, but it's as blunt as hell and you want a new works, but it's too late to get one from the chemist. I would go home and use that blunt works. I wouldn't go to someone else and ask to borrow one of their needles." [35 year old male IDU, UK; Rhodes et al., 2004; pg. 623]*

> *"We keep them separate. Um, we've got a little bag, little black bag, that we keep everything in so...and um, usually mine or his we'll wrap one of them in tissue, um. So say it's mine that is wrapped in tissue we know it's mine…" [27 year old male IDU, UK; Rhodes et al., 2004; pg. 624]*

> *"Um, what I do is I'd mark it like where the marks are on the needle. I would get something and scratch, like, maybe the one or seven most of the time. It was the seven or one that I would scratch off, like, and then I'd know they were mine, plus I would always keep mine separate." [28 year old male IDU, UK; Rhodes et al., 2004; pg. 624]*

Barriers to safe injecting practices

Despite deliberate intentions to minimise the risk of hepatitis C transmission through safe injecting practices, the consistent employment of such strategies was difficult; accidents were common and risks were often taken. There appeared to be a contradiction between the research and practice definition of '*not sharing*' and IDUs own conceptualisation of safe injecting practices. In their study of UK IDUs, Rhodes *et al.* (2004) found that the majority of IDUs (66%; 39/59) indicated that they had never shared others' used needles and syringes. However, the authors highlight a paradox of high hepatitis C transmission among IDUs and accounts of never sharing. Some IDUs regarded themselves as clean or careful injectors, yet reported high risk activities under certain conditions and unintentional and infrequent sharing. Injectors may see sharing as using others' needles and syringes in the same injecting session but not between sessions and constructions of '*I never share*' in user parlance may denote a deliberate act (Craine *et al.,* 2004; Rhodes *et al.,* 2004).

A number of barriers were identified that prohibited safe injecting practices; restricted access to needles and syringes at specific times, the prison setting, trusting injecting relations, withdrawal and more chaotic and uncontrolled drug use, homelessness, policing and gender (Coupland *et al.,* 2009;

Craine *et al.,* 2004; Dyer & Tolliday, 2009; Gyarmathy *et al.,* 2006; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Roy *et al.,* 2007; Southgate *et al.,* 2005; Swan *et al.,* 2010; Wright *et al.,* 2005).

Restricted access to clean equipment

Clean needles and syringes ware regarded as easily accessible by IDUs, which reinforces the perception of safe injecting practices a '*common sense*'. However, risks were taken when clean equipment was not immediately available (Craine *et al.,* 2004; Rhodes *et al.,* 2004; Wright *et al.,* 2005).

> *"When I first started taking drugs you could not get syringes. You could just not get them, that's why a lot of people shared them. I mean, I've seen twenty at a time share one syringe and needle." [Homeless IDU, UK; Wright et al., 2005; pg. 77]*

> *"…there are so many needle exchanges ... that you haven't got no need to share with people." [26 year old male IDU diagnosed with hepatitis C, UK; Rhodes et al., 2004; pg. 624]*

> *"I know I said that I always make sure I never run out, you know what I mean, two or three occasions where I've had to take one out the cinbin. I always wash them out before I put them in the cinbin anyway. I always do that…" [22 year old male IDU, UK; Rhodes et al., 2004; pg. 624]*

Trusting injecting relations

The sharing of needles, syringes and paraphernalia among close friends and intimate partners was regarded as less risky due to trusting relations. For example, hepatitis C disclosure was expected by such individuals who were regarded as clean and perceived as never sharing (Carrier *et al.,* 2005; Davis *et al.,* 2004; Gyarmathy *et al.,* 2006; Rhodes & Treloar 2008; Rhodes *et al.,* 2004; Wozniak *et al.,* 2007). In their review of the literature, Rhodes & Treloar (2008) highlighted the fragility of these trust relations, including reported cases of mistaken trust leading to hepatitis C transmission.

> *"I also know that she doesn't share with anyone." [30 year old female IDU, Serbia; Rhodes & Treloar, 2008; pg. 1598]*

Chaotic/uncontrolled drug use and withdrawal

More chaotic and uncontrolled drug use and the effects of withdrawal also prevented safe injecting practices. A preoccupation with drugs left little space for concern over hepatitis C and coping with the effects of withdrawal tended to override other concerns surrounding potential risks associated with the sharing of injecting equipment (Craine *et al.,* 2004; Harris, 2009a; Roy *et al.,* 2007; Swan *et al.,* 2010; Wright *et al.,* 2005).

> *"When you're having cravings, if you have a quarter [gram] in your hands... Even if you're aware of the risks, your body's obsession makes you do things that your mind wouldn't do normally. It's really because of coke that hepatitis is spreading." [20 year old male IDU, Canada; Roy et al., 2007; pg. 399]*

> *"I think if you've got the bag and you've not had and you're ill. It's not when you're bingeing, it would be more, you'd be more at risk when you're rattling, because if you can't get hold of a clean pin, you know, and there's only like your boyfriend's there, you know, you're going to use it." [30 year old female IDU, UK; Craine et al., 2004; pg. 119]*

"Where you're rattling, where you are desperate for some heroin and you will just not think about that at that moment in time, all you will think about is if you can get some, some, some relief if somebody gives you a few quid's worth of heroin and says, "sort yourself out," you know like, cos you are feeling terrible, and then you will go to any lengths to like find the equipment to do it and if that involves going through a bin, then you will." [Homeless IDU, UK; Wright et al., 2005; pg. 78]

Homelessness and street injecting

Safe injecting practices were restricted among homeless IDUs and street injectors (Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Wright *et al.,* 2005). One UK study (Wright *et al.,* 2005) found that the poverty associated with homeless drug use resulted in a need to share paraphernalia such as filters to prevent liquefied drugs being soaked up. Spoons were also less likely to be cleaned due to the potential 'wasting' of drugs. Filters were rarely discarded due to them holding drug residue which could be used in times of withdrawal. A Canadian study of hepatitis C positive IDUs (Roy *et al.,* 2007) also found that the conditions of street injecting were unsuitable for the implementation of safe injecting practices.

"I live in an apartment, I have four walls, I have all my stuff, I'm clean. But when you're in the streets all you have is a backpack, and what you have, you share 'cause that's all you have. You know?" [25 year old male IDU, Canada; Roy et al., 2009; pg. 399]

The prison setting

An Australian study of health professionals' perceptions of injecting drug use in prison (Dyer & Tolliday, 2009) found that safe injecting practices and risk avoidance were restricted within the prison environment. Similar to prisons in the UK, access to clean needles, syringes, paraphernalia and cleaning equipment was limited. A fear of disclosing oneself as an IDU was also seen as preventing prisoners from requesting clean equipment. Everyday items such as tooth brushes and razors were also found to be commonly shared to reduce costs, which had implications for the transmission of hepatitis C. A UK study of street IDUs (Wright *et al.,* 2005) found that the prison setting contributed to the risky practice of drug users reusing their own needles, sharing needles among large numbers of other inmates and sharpening over used blunted needles on toilet walls or broken glass.

"Syringes have been found that would have been circulating for three to five years… and no cleaning solutions are provided." [Hepatitis C education and support provider within a prison, Australia; Dyer & Tolliday 2009; pg. 39]

"Requesting bleach may identify individuals as injecting drug users and might cause their cells to be raided more often" [Hepatitis C education and support provider within a prison, Australia; Dyer & Tolliday 2009; pg. 39]

"In prison you know if someone gets a needle it can get passed around to about like sort of eight to ten people." [Homeless IDU, UK; Wright et al., 2005; pg. 78]

Policing

In a review of qualitative research papers (Rhodes & Treloar 2008) and a UK study of street injecting (Wright *et al.,* 2005) the policing of IDUs was highlighted as a form of environmental disruption to

risk reduction intention, with fear of interruption or arrest leading to hurried injection and sharing, especially when injecting in public settings.

> *"You had to do it really fast and sometimes you lost, you spilt your gear and that because you were being paranoid you'd heard a noise so you'd put it, you'd do it right quick so you… a copper could have walked around the corner and if he'd have seen you doing that you're arrested straight away for class A drugs, so you're on a straight paranoia while you're doing it outside." [Homeless IDU, UK; Wright et al., 2005; pg. 77]*

Gender

A qualitative synthesis of literature on injecting practices (Rhodes & Treloar, 2008) highlighted injecting risks as highly gendered in nature. The review reported evidence to suggest that female IDUs can enter into various forms of abusive relationships with men, in which oppressive relations and physical, emotional or sexual violence are normalised. In this context, hepatitis C is noted as a gendered risk itself through the logistics of drug preparation and injecting, which are controlled by men. In such circumstances women have less control over their injecting practices and are therefore restricted in the extent to which they can perform safe injecting practices (Bourgois *et al.,* 2004; cited in Rhodes & Treloar, 2008; pg. 1599).

> *"It's the same for everyone out here. The guys like it this way. They like the feeling of having all that control over somebody. I mean it's a really big amount of control. You are controlling how high someone gets; how sick someone gets. It makes the guys feel like the girl won't leave. They are bound into that relationship." [Female IDU, USA; Rhodes & Treloar, 2008;* pg. 1599*]*

Evidence statements 10 & 11: Injecting practices, risk behaviour and implications for hepatitis C transmission

10: There was evidence that safe and responsible injecting practices are employed by IDUs to avoid the transmission of hepatitis C.[1] There was a lack of consensus as to whether safe practices are strictly adhered to in relation to the sharing of drug related paraphernalia.[2]

11: A number of personal and external barriers were identified that may prohibit safe injecting practices. Trusting injecting relations; withdrawal and uncontrolled drug use, restricted access to needles and syringes at specific times, the prison setting, homelessness, policing and gender were found to act as barriers to the use of safe injecting practices.[3]

[1] Davis *et al.,* 2004 [++]; Ellard, 2007 [++]; Fraser, 2004 [+]; Rhodes *et al.,* 2004 [++]; Southgate *et al.,* 2005 [++]; Wright *et al.*, 2005 [++]

[2] Coupland *et al.*, 2009 [++]; Rhodes *et al.*, 2004 [++]; Wright *et al.*, 2005 [++]

[3] Carrier *et al.*, 2005 [+]; Craine *et al.*, 2004 [++]; Davis *et al.*, 2004 [++]; Dyer & Tolliday, 2009 [-]; Gyarmathy *et al.*, 2006 [+]; Harris, 2009a [+]; Rhodes & Treloar, 2008 [NR]; Rhodes *et al.*, 2004 [++]; Roy *et al.*, 2007 [++]; Swan *et al.*, 2010 [++]; Wozniak *et al.*, 2007 [++]; Wright *et al.*, 2005 [++]

5.4.2 IDUs knowledge of hepatitis C

HCV as normal, ubiquitous and socially accepted

A common theme within the research was the social acceptance of hepatitis C among IDUs; but it should be noted that many of the studies considered here were conducted in settings with a high prevalence of hepatitis C. Fifteen papers reported hepatitis C as normalised, ubiquitous and expected among IDUs (Carrier *et al.,* 2005; Copeland, 2004; Davis & Rhodes, 2004; Davis *et al.,* 2004; Ellard 2007; Faye & Irurita 2003; Harris, 2009a; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Roy *et al.,* 2007; Swan *et al.,* 2010; Tompkins *et al.,* 2005; Treloar & Holt, 2009; Treloar & Rhodes, 2009; Wozniak *et al.,* 2007).

A discourse of '*everybody's got it'* has been shown to lead to the perception of hepatitis C as expected, unavoidable and as not constituting a serious health threat. IDUs perceived themselves as never being completely safe from, or in control of hepatitis C transmission despite intentions to reduce risk of transmission (Carrier *et al.,* 2005; Coupland *et al.,* 2009; Davis *et al.,* 2004; Davis & Rhodes, 2004; Ellard 2007; Faye 2003; Fraser 2004; Harris, 2009a; Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Roy *et al.,* 2007; Sutton & Treloar, 2007; Tompkins *et al.,* 2005; Treloar & Holt, 2009; Swan *et al.,* 2010; Wozniak *et al.,* 2007). Studies also showed that having hepatitis C confirmed an IDU identity and provided evidence of belonging to IDU networks and a way of drawing a distinction between those who do and those that don't belong to an IDU community (Rhodes and Treloar 2004; Roy *et al.,* 2007; Wozniak *et al.,* 2007).

> *"And nobody talked about hep C really. I mean you know, in passing, it was just so assumed everybody had it. And nobody saw it as a big deal. No-one was thinking about it. Nobody thought it was anything other than just a complete minor detail that had no bearing on life at all." [43 year old female IDU, Australia; Harris, 2009a; pg. 1032]*
>
> *"It's all over the place, I think everyone has got it" [37 year old male IDU diagnosed with hepatitis C, UK; Rhodes et al., 2004; pg. 628]*
>
> *"I bet you more than half of the intravenous drug users have Hep C" [46 year old male IDU, Canada; Wozniak et al., 2007; pg. 391]*
>
> *"It's almost normal to have hepatitis C for us. It's almost sure that if you're gonna inject, you'll get it one day." [25 year old female IDU, Canada; Roy et al., 2007; pg. 399]*
>
> *"I'd be very surprised if I didn't have it you know? 90% of heroin injectors have got it anyway. A high percentage." [24 year old male IDU, UK; Davis et al., 2004; pg. 1815]*

There were exceptions to the social acceptance of hepatitis C among IDUs. Wozniak *et al.* (2007) noted that the extent to which individuals participate in the 'normalised discourse' of hepatitis C varies, with some IDUs rejecting the notion of hepatitis C as expected and unavoidable. Moreover, the deliberate use of safe injecting practices (Rhodes *et al.,* 2004; Southgate *et al.,* 2005; Wright *et al.,* 2005) previously discussed, and findings showing testing positive for hepatitis C as a highly anxious and distressing experience, (Coupland *et al.,* 2009; Faye & Irurita, 2003; Harris, 2009a; Kinder, 2009; Lally *et al.,* 2008; Munoz-Plaza *et al.,* 2005b; Sutton & Treloar, 2007; Swan *et al.,* 2010;

Tompkins *et al.,* 2005; s*ee Section 5.4.3. Experience of testing and reactions to diagnosis*) suggests there is a disjuncture in the normalisation discourse (Rhodes & Treloar, 2008).

> *"Like, if someone comes with a dirty rig well it's either too bad you better find another rig, or when we're done with it, you can have it, but I wouldn't, I would not give someone like I got a conscience, I wouldn't give someone a dirty can. I wouldn't say here, take it. And people have said to me, I don't care if it's dirty, I'll take it, and I've dumped it out because I said f– you, you're not gettin' the rig. You know, I've had a stupid girlfriend of mine that wanted to get Hep C because I had it. She's like, well I'll use the same one as you and I'm like why? She says, well we're girlfriend boyfriend anyway, and I'm like I don't care, you can't have it, and you know I'm gonna get it anyway, I'm like NO – and I've squished the can because she's so insistent on using it, because she loved me so much she wanted to get Hep C like me. Like you know, that's how bad I've seen it get. Like, that's the stupidity part. When someone says I'll do it because I love you so much?" [45 year old male IDU, Canada; Wozniak et al., 2007; pg. 393]*

IDUs are not a homogenous group and the extent to which sharing and hepatitis C is regarded as normal and as confirming an IDU identity differed depending on the social context of drug use. Contrary to other research, Southgate *et al.* (2005) found that among IDUs in Australia, there was evidence that hepatitis C was not considered attractive, inevitable or a way of signifying the position of a *'real user'*. Ellard (2007) explored injecting practices among drug users in the Australian dance music scene and found that although prevalent, injecting drug use and hepatitis C was not normalised within the scene and that injectors did not regard themselves as problematic drug users. Roy *et al.* (2007) also found that IDUs who were more integrated in mainstream society were more aware of the risks and significance of hepatitis C than those who were integrated in IDU networks.

Incomplete and uncertain knowledge of hepatitis C among IDUs

Twenty papers reported data on IDUs' knowledge of hepatitis C. There was evidence that IDUs have an uncertain and impartial knowledge of hepatitis C in terms of what the disease is, how it differs from other forms of hepatitis, how the infection is transmitted and what symptoms are involved (Carrier *et al.,* 2005; Copeland 2004; Coupland *et al.,* 2009; Davis *et al.,* 2004; Davis & Rhodes, 2004; Ellard 2007; Fraser 2004; Fraser 2010; Gyarmathy *et al.,* 2006; Harris, 2009a; Munoz-Plaza *et al.,* 2004; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Sosman *et al.,* 2005; Southgate *et al.,* 2005; Sutton & Treloar, 2007; Swan *et al.,* 2007; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Wright *et al.,* 2005).

A common finding across research studies was an incomplete and confused understanding of hepatitis C among IDUs to the extent that research participants asked the researcher questions about hepatitis C as a way of gaining information and clarity (Copeland, 2004; Davis *et al.,* 2004; Davis & Rhodes, 2004; Ellard 2007; Fraser 2010; Harris, 2009a; Munoz-Plaza 2004; Rhodes *et al.,* 2004; Southgate *et al.,* 2005; Sutton & Treloar, 2007). Limited knowledge among IDUs was also acknowledged by service providers (Munoz-Plaza *et al.,* 2004) and confusion was reinforced by the perception that expert and scientific knowledge on hepatitis C was shifting and uncertain (Davis *et al.,* 2004; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Tompkins *et al.,* 2005).

> *"How many different types of Hep C are there?" [18 year old female IDU diagnosed with hepatitis C, UK; Davis et al., 2004; pg. 1813]*

"It's a bit of a mystery really, what it does to you as far as I'm concerned. It's to do with your liver isn't it in later life? F–s your liver up a bit?" [24 year old male IDU, UK; Davis & Rhodes, 2004; pg. 126]

IDUs were aware of hepatitis in general, yet often viewed the various forms of hepatitis C as a single entity (Davis & Rhodes, 2004; Ellard, 2007; Gyarmathy *et al.,* 2006; Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Southgate *et al.,* 2005).

"I don't know A, B, C what the difference is, but I've heard about it for years." [35 year old male IDU, UK; Davis et al., 2004; pg. 1813]

Unawareness of the symptoms of hepatitis C was also common among IDUs. Confusion surrounded which organs were affected and yellowness associated with jaundice was often viewed as the main symptom of hepatitis C infection (Davis *et al.,* 2004; Fraser 2004; Harris, 2009a; Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Southgate *et al.,* 2005). Using jaundice as a reliable sign of hepatitis C infection has implications for risks in sharing injecting equipment and can lead to IDUs only seeking testing if they experience jaundice (Harris, 2009a; Southgate *et al.,* 2005; Swan *et al.,* 2005).

"Hepatitis eats at your kidneys doesn't it?" [22 year old male IDU, UK; Davis et al., 2004; pg. 1813]

"It can make you very ill. It's your kidney, your kidney plays up when you've got it, like hurting like. Been told like feels like someone's kicked you in the kidney." [22 year old male IDU, UK; Davis & Rhodes, 2004; pg. 126]

"When I was in Leeds this boy turned yellow and no-one ever said anything but I thought he had it. He said he had taken too many tablets and that's what made him yellow from his kidneys but I felt that maybe that, but I don't know if that's yellow jaundice. Is it or is that the same thing?" [22 year old female IDU, UK; Rhodes et al., 2004; pg. 626]

"Once a week we'd do groups on women, health issues and things like that and this one week was about Hep C. And he (a doctor) said, 'Hands up the people that have got it' and everyone put their hand up except for me and I said, 'Well, I've not been tested...but I can't remember being yellow or anything like that.'...He said 'You don't necessarily go yellow. Can you remember in the last five years having a really bad flu?'." [35 year old female IDU, Australia; Southgate et al., 2005; pg. 4]

There was also a lack of knowledge and confusion over the transmission of hepatitis C (Davis *et al.,* 2004; Rhodes *et al.,* 2004). IDUs tended to view hepatitis C transmission in relation to the sharing of needles and equipment, unhygienic practices and dirt, and exposure to blood via the syringe rather than the area in which injecting took place, hands or swabs (Davis & Rhodes, 2004; Ellard 2007; Fraser 2004; Harris, 2009a; Rhodes & Treloar, 2008; Southgate *et al.,* 2005). As Ellard (2007) noted, people expect to see blood and therefore do not consider blood to be present on equipment, bodies and in the general space if it is not visible. There also appeared to be greater confusion as to whether hepatitis C could be transmitted sexually (Coupland *et al.,* 2009; Ellard 2007; Sosman *et al.,* 2005; Tompkins *et al.,* 2005; Wright *et al.,* 2005) and through the sharing of drug paraphernalia (Davis *et al.,* 2004; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008). An emphasis on transmission through hygiene and dirt led to the misconception among some IDUs that hepatitis C transmission

was possible through the unclean practice of re-use of one's own needle and syringe (Rhodes & Treloar, 2008; Southgate *et al.,* 2005)

> *"I knew you can get AIDS and HIV from using someone else's needle, but I didn't know you could get HIV from a spoon and hep C and all that."* [24 year old male IDU, UK; Davis *et al.,* 2004; pg. 1814]

Despite such gaps in knowledge, there was evidence that some IDUs were reflexive about their quality of knowledge and aware about their limited and partial understandings of hepatitis C. Such awareness was also found to be anxiety provoking (Davis *et al.,* 2004; Davis & Rhodes, 2004; Rhodes *et al.,* 2004).

> *"I know I have been tested for it and it was clear, but I mean until, I was in a bit of a worry. You know, sort of I don't know, I don't really know much about it. I still don't really know much about it. Just sort of like basic stuff, not sharing and stuff like that. But my boyfriend, he hasn't been tested for it, so I don't know. I mean I don't really know." [22 year old IDU, UK; Davis & Rhodes 2004; pg. 126]*

> *'I think from what I've read and everything else it does seem to be more contagious then Hep B. And I know they haven't got a cure for hep B. Is there? But they don't really know a lot about hep C at all and they haven't got any medication to manage it in anyway, have they?' [33 year old IDU, UK; Davis & Rhodes, 2004; pg. 126]*

A relative understanding of HCV among IDUs

A common research finding was how knowledge and understanding of hepatitis C was learnt in relation to HIV; a finding that was reported in 15 studies (Copeland, 2004; Davis & Rhodes, 2004; Davis *et al.,* 2004; Ellard 2007; Faye & Irurita, 2003; Harris 2009a; Munoz-Plaza *et al.,* 2010; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Roy *et al.,* 2007; Southgate *et al.,* 2005; Sutton & Treloar, 2007; Swan *et al.,* 2010; Treloar & Rhodes, 2009; Wozniak *et al.,* 2007).

A consequence of the comparison with HIV was that IDUs held a number of incorrect or misinformed beliefs about hepatitis C and perceived it to be of minimal concern (Davis & Rhodes, 2004; Davis *et al.,* 2004; Ellard 2007; Harris, 2009a; Munoz-Plaza *et al.,* 2010; Roy *et al.,* 2007; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008; Sutton & Treloar, 2007; Southgate *et al.,* 2010; Swan *et al.,* 2010; Wozniak *et al.,* 2007). The perception of hepatitis C as normalised and as less serious than HIV was also a product of joint testing procedures, a bias towards HIV services in practice, the trivialisation of hepatitis C in comparison to HIV by health professionals, family members and peers, and the social importance of popular HIV discourse (e.g. via the media) since the 1980's (Davis & Rhodes, 2004; Harris, 2009a; Khaw *et al.,* 2007; Munoz-Plaza *et al.,* 2010; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008). Consequently, safe injecting practices were often implemented as a strategy to prevent HIV infection as it was perceived as easier to control and more stigmatised than hepatitis C (Coupland *et al.,* 2009; Ellard, 2007; Faye & Irurita, 2003; Harris, 2009a; Davis *et al.,* 2004; Davis & Rhodes, 2004; Munoz-Plaza *et al.,* 2010; Rhodes *et al.,* 2004; Rhodes & Treloar, 2008).

> *"I think that I was really irresponsible, and that yeah it was my fault that I got it, I wasn't very careful, and I'm also kind of glad that that is all I got, I could have easily had AIDS, and I haven't. As much as I resent my hepatitis C sometimes, I feel grateful that that is all I have got." [41 year old female IDU, Australia; Harris, 2009a; pg. 1033]*

"I just didn't realise it was such a sturdy disease ... I thought it was a bit like AIDS, in the air for a couple of seconds, and it's dead." [25 year old IDU diagnosed with hepatitis C, UK; Davis & Rhodes, 2004; pg. 125]

"I know a lot, lot more about AIDS what it is than hepatitis C. I haven't got a clue what it [hepatitis C] is and I haven't got a clue what hepatitis B is at all ... I've no idea why, how you get it, and how you get rid of it, if you can get rid of it ...." [22 year old IDU, UK; Davis & Rhodes, 2004; pg. 127]

"I remember when I actually went back to get the results, the guy says to me: 'You don't have HIV, you don't have AIDS, but you do have hepatitis C'. And I was sat there crying he was going: 'Oh, it doesn't really matter' He didn't tell me anything about it he was just like: 'Here's a leaflet. Bye." [18 year old IDU, UK; Davis & Rhodes, 2004; pg. 127]

The meaning of hepatitis C to IDUs was also understood relative to other problems linked to drug consumption and living conditions, such as the everyday danger of overdose, the need to consume drugs and deal with withdrawal, and material deprivation (Coupland *et al.,* 2009; Faye & Irurita, 2003; Harris, 2009a; Rhodes & Treloar 2008; Roy *et al.,* 2007).

"When you take drugs all the time, you don't really think you'll live long enough to die of hepatitis C, it's something that lasts a long time. (...) I've had 7 overdoses, and I told myself that I would die of that much sooner than I would die of hepatitis C." [24 year old female IDU, Canada; Roy et al., 2007; pg. 400]

Evidence statements 12-15: Knowledge of hepatitis C

12: Despite strong evidence of hepatitis C as normal and ubiquitous among IDUs,[1] the extent to which individuals participate in the social acceptance of hepatitis C varies and some IDUs may reject the notion of hepatitis C as expected and unavoidable.[2] The deliberate use of safe injecting practices and research showing that testing positive for hepatitis C is a highly anxious and distressing experience suggests there is a disjuncture in the normalisation of hepatitis C among IDUs.[3]

13: There was conflicting evidence as to whether having hepatitis C confirms an IDU identity. Some studies have shown that hepatitis C can provide evidence of belonging to IDU communities.[4] Two studies and one review found that hepatitis C was not considered attractive, inevitable or a way of signifying an IDU identity.[5]

14: There was strong evidence that IDUs have an uncertain and incomplete knowledge of hepatitis C. Studies showed that IDUs are confused over what the disease is, how it differs from other forms of hepatitis, how the infection is transmitted and what symptoms are involved.[6] Knowledge confusion was also reinforced by the perception that expert and scientific knowledge on hepatitis C is shifting and uncertain.[7] There was evidence that some IDUs are aware of their limited knowledge on hepatitis C.[8]

15: Hepatitis C is often understood in relation to HIV, which trivialises the seriousness of contracting hepatitis C and may have implications for the use of safe injecting practices and the uptake of hepatitis C services.[9]

[1] Carrier *et al.*, 2005 [+]; Copeland, 2004 [++]; Davis & Rhodes, 2004 [++]; Davis *et al.*, 2004 [++]; Ellard, 2007 [++]; Faye &

Irurita, 2003 [++]; Harris, 2009a [+]; Rhodes *et al.*, 2004 [++]; Roy *et al.*, 2007 [++]; Rhodes & Treloar, 2008 [NR]; Swan *et al.*, 2010 [++]; Tompkins *et al.*, 2005 [++]; Treloar & Rhodes, 2008 [NR]; Treloar & Holt, 2009 [++]; Wozniak *et al.*, 2007 [++]

[2] Wozniak *et al.*, 2007 [++]

[3] Coupland *et al.*, 2009 [++]; Faye & Irurita, 2003 [++]; Harris, 2009a [+]; Kinder, 2009 [++]; Lally *et al.*, 2008 [++]; Munoz-Plaza *et al.*, 2005b [+]; Rhodes *et al.*, 2004 [++]; Southgate *et al.*, 2005 [++]; Sutton & Treloar, 2007 [++]; Swan *et al.*, 2010 [++]; Tompkins *et al.*, 2005 [++]; Wright *et al.*, 2005 [++]

[4] Rhodes & Treloar, 2008 [NR]; Roy *et al.*, 2007 [++]; Wozniak *et al.*, 2007 [++]

[5] Ellard, 2007 [++]; Southgate *et al.*, 2005 [++]; Rhodes & Treloar, 2008 [NR]

[6] Copeland, 2004 [++]; Coupland *et al.*, 2009 [++]; Davis & Rhodes, 2004 [++]; Davis *et al.*, 2004 [++]; Ellard, 2007 [++]; Fraser, 2004 [+]; Fraser, 2010 [-]; Gyarmathy *et al.*, 2006 [+]; Harris, 2009a [+]; Munoz-Plaza *et al.*, 2004 [+]; Rhodes & Treloar, 2008 [NR]; Rhodes *et al.*, 2004 [++]; Sosman *et al.*, 2005 [+]; Southgate *et al.*, 2005 [++]; Sutton & Treloar, 2007 [++]; Swan *et al.*, 2010 [++]; Tompkins *et al.*, 2005 [++]; Wright *et al.*, 2005 [++];

[7] Davis *et al.*, 2004 [++]; Rhodes *et al.*, 2004 [++]; Rhodes & Treloar, 2008 [NR]; Tompkins *et al.*, 2005 [++]

[8] Davis *et al.*, 2004 [++]; Davis & Rhodes, 2004 [++]; Rhodes *et al.*, 2004 [++]

[9] Copeland, 2004 [++]; Davis & Rhodes, 2004 [++]; Davis *et al.*, 2004 [++]; Ellard, 2007 [++]; Faye & Irurita, 2003 [++]; Harris 2009a [+]; Munoz-Plaza *et al.,* 2010 [+]; Rhodes *et al.*, 2004 [++]; Rhodes & Treloar, 2008 [NR]; Roy *et al.*, 2007 [++]; Southgate *et al.*, 2005 [++]; Sutton & Treloar, 2007 [++]; Swan *et al.*, 2010 [++]; Treloar & Rhodes, 2008 [NR]; Wozniak *et al.*, 2007 [++]

5.4.3 Testing and the impact of diagnosis

Thirty three papers reported data on barriers to testing, experience of testing, reactions to diagnosis and the impact of diagnosis on behaviour and the uptake of hepatitis C services and treatment (Carrier *et al.,* 2005; Copeland *et al.,* 2004; Craine *et al.,* 2004; Cullen *et al.,* 2005; Davis *et al.,* 2004; Dyer & Tolliday, 2009; Faye & Irurita, 2003; Fraser & Treloar, 2006; Fraser, 2004; Fraser, 2010; Gyarmathy *et al.,* 2008; Harris, 2009a; Khaw *et al.,* 2007; Kinder, 2009; Lally *et al.,* 2008; McCreaddie *et al.,* 2011; Munoz-Plaza *et al.,* 2005a; Munoz-Plaza *et al.,* 2004; Paterson *et al.,* 2006; Perry *et al.,* 2003; Roy *et al.,* 2007; Rhodes *et al.,* 2004; Rhodes and Treloar 2008; Southgate *et al.,* 2005; Sosman *et al.,* 2003; Strauss *et al.,* 2008; Sutton & Treloar, 2007; Swan *et al.,* 2010; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Wright *et al.,* 2005; Wozniak *et al.,* 2007).

Barriers and facilitators to testing

Twenty five studies reported findings relating to barriers and facilitators to hepatitis C testing (Craine *et al.,* 2004; Davis *et al.,* 2004; Dyer & Tolliday, 2009; Fraser 2004; Fraser, 2010; Gyarmathy *et al.,* 2006; Harris, 2009a; Khaw *et al.,* 2007; Kinder, 2009; Lally *et al.,* 2008; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a; Munoz-Plaza *et al.,* 2005b; Perry *et al.,* 2003; Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Roy *et al.,* 2007; Sosman *et al.,* 2005; Southgate *et al.,* 2005; Sutton & Treloar, 2007; Swan *et al.,* 2010; Strauss *et al.,* 2008; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Wozniak *et al.,* 2007). A number of barriers and facilitators to testing were identified; a lack of visible symptoms; perceived low risk of infection; fear of a positive diagnosis, needles and disclosure; convenient and opportunistic testing concern over hepatitis C infection and proactive testing; and staff support and encouragement.

Lack of visible symptoms of hepatitis C infection

The lack of visible symptoms was found to prevent proactive testing among IDUs. Many IDUs did not initiate testing until they experienced symptoms (Fraser, 2010; Swan *et al.,* 2010; Temple-Smith *et al.,* 2004) and the misconception of jaundice as a defining feature of hepatitis C infection

contributed towards delays in testing (Davis *et al.,* 2004; Fraser, 2004; Harris, 2009a; Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Southgate *et al.,* 2005; Strauss *et al.,* 2008; Sutton & Treloar, 2007).

> *"I went to the GP and said I thought my eyes looked a bit yellow. And he took some blood and I went back and he said, 'You've got non-A, non-B hepatitis'…I remember getting very little information about it… at that point he was treating it like an acute, he thought it was going to be like hep B" [43 year old female IDU who received a diagnosis in 1983, Australia; Harris, 2009a; pg. 1031]*

> *''Once a week we'd do groups on women, health issues and things like that and this one week was about Hep C. And he (a doctor) said, 'Hands up the people that have got it' and everyone put their hand up except for me and I said, 'Well, I've not been tested... but I can't remember being yellow or anything like that."...He said 'You don't necessarily go yellow. Can you remember in the last five years having a really bad flu?'." [35 year old female IDU, Australia; Southgate et al., 2005; pg. 4]*

Perceived low risk of infection

Despite hepatitis C being normalised among IDUs (Carrier *et al.,* 2005; Copeland, 2004; Davis & Rhodes, 2004; Davis *et al.,* 2004; Ellard, 2007; Faye & Irurita, 2003; Harris, 2009a; Rhodes *et al.,* 2004; Roy *et al.,* 2007; Rhodes & Treloar, 2008; Strauss et a 2008; Swan *et al.,* 2010; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Treloar & Holt, 2009; Wozniak *et al.,* 2007; *see Section 5.4.2. HCV as normal, ubiquitous and socially accepted*), there was evidence that some IDUs perceived themselves to be at low risk of hepatitis C infection and as such did not actively seek testing (Craine *et al.,* 2004; Gyarmathy *et al.,* 2006; Lally *et al.,* 2008; Sosman *et al.,* 2005 Strauss *et al.,* 2008). In a UK study (Perry *et al.,* 2003) of GP's experiences of hepatitis C testing in methadone clinics, IDUs denial of possible hepatitis C infection was viewed as a barrier to the informed consent process and therefore testing.

> *"I know many who are infected with 'hepa', but I don't feel at risk of getting infected. I know that they would tell me, and they would never let me use the needle." [19 year old male IDU, Hungary; Gyarmathy et al., 2006; pg. S67]*

> *"See, and I thought I was one of the few ones that didn't have it. And come to find out I did have it… because I hadn't had any trouble with my liver or nothing." [27 year old OST client, USA; Strauss et al., 2008; pg. 1168]*

> *"Either they understand that they're going to address their lifestyle, or they don't understand and it will make no difference..." [GP, UK; Perry et al., 2003; pg. 542]*

Fear of a positive diagnosis, needles and hepatitis C status disclosure

Apprehension and fear of a positive test result (Craine *et al.,* 2004; Khaw *et al.,* 2007; Sosman *et al.,* 2005; Strauss *et al.,* 2008), fear of the physical process of testing and the use of needles (Craine *et al.,* 2004; Sosman *et al.,* 2005; Strauss *et al.,* 2008) and fear of disclosure¸ a lack of privacy and confidentiality in the testing process (Sosman *et al.,* 2005; Strauss *et al.,* 2008; Swan *et al.,* 2010) acted as a barrier to testing among IDUs.

> *"A lot of people are scared to go get tested. Because a lot of people think that if they have it, it's the end of the world. A lot of people think that with a lot of diseases. Even though we've*

been educated on it, they still think like, 'Oh, my God.' It's just scary." [20 year old female IDU, USA; Strauss et al., 2008; pg. 1169]

"It sounds weird, but I hate needles. Although I used them... I used 'em, for so long. So, it's hard for me to, you know, like have blood drawn and needles and stuff." [19 year old female former IDU, USA; Strauss et al., 2008; pg. 1170]

"People are frightened to get the test ye na [you know], thinking that it could be a killer not knowing what, not knowing what it actually is, what it actually does to you, I mean?" [Male prisoner, UK; Khaw et al., 2007; pg. 3]

Convenient and opportunistic testing

Convenient and opportunistic testing was an important facilitator of hepatitis C testing. When testing was not convenient and opportunistic, IDUs were less likely to engage with the testing process (Gyarmathy *et al.,* 2006; Sosman *et al.,* 2005; Swan *et al.,* 2010). Distance from the testing site and access to transport also encouraged testing (Swan *et al.,* 2010; Lally *et al.,* 2008). A 'one-stop shop' for all hepatitis C services was regarded as a convenient approach among IDUs (Swan *et al.,* 2010; Roy *et al.,* 2007), with drug treatment programme sites and methadone clinics being perceived as suitable locations for such services, including testing (Gyarmathy *et al.,* 200, Munoz-Plaza *et al.,* 2004; Roy *et al.,* 2007; Strauss *et al.,* 2008). In an American study of hepatitis C services in drug treatment centres, both clients and staff perceived drug treatment programmes as an appropriate and feasible site for hepatitis C-related education and services including testing (Munoz-Plaza *et al.,* 2004). Some IDUs preferred testing to be conducted in a general practice setting as they perceived this setting as offering opportunities to raise concerns and ask questions (Temple-Smith *et al.,* 2004). A UK study of GP's experiences of hepatitis C testing (Perry *et al.,* 2007) found that there was a clear divide between GPs who preferred to respond to an IDU's request to test, and those who were proactive in encouraging testing. Those with reactive attitudes felt there was limited value of interventions. In UK (Swan *et al.,* 2010) and Australian (Temple-Smooth *et al.,* 2004) studies, the opportunity to engage in testing was also found to be gendered, with men being screened when entering prison, hospital and drug treatment and women when receiving other routine tests (e.g. a smear test) and appointments made during pregnancy.

"Transportation… would help a heck of a lot because people are out here catching buses and they're [drug] sick. Who wants to go out there in the snow, rain, sleet, or whatever, even when they're not sick? Let alone when you are sick… You won't go to an appointment for that. I don't have a car... I haven't been making my appointments because I don't have a ride out there. And I'm not going to get on no bus and all that s– when I don't feel good" [43 year old Cape Verdian female diagnosed with hepatitis C, USA; Lally et al., 2008; pg. 58]

"He (GP) was…willing to go over it with me, but I was quite shocked and I just left it at that and pretended that it didn't happen." [Female diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 49]

When IDUs were unlikely to deliberately seek testing to confirm their hepatitis C status, opportunistic testing was an important facilitator for testing uptake (Rhodes *et al.,* 2004; Temple-Smith *et al.,* 2004). Concern over informed consent to testing was noted by a number of authors (Perry *et al.,* 2005; Rhodes *et al.,* 2004; Tompkins *et al.,* 2005; Munoz-Plaza *et al.,* 2005a). Studies

showed that IDUs were often unaware that they have been tested for hepatitis C (Munoz-Plaza *et al.,* 2005a; Tompkins *et al.,* 2005). In an American study (Munoz-Plaza *et al.,* 2005a), some IDUs and health professionals did not perceive this as problematic in that it increased testing compliance, whilst others raised concerns that it restricted patient choice. When health professionals saw informed consent as an important feature of the testing process, time restrictions in confirming informed consent acted as a barrier to testing (Perry *et al.,* 2003).

> *"It was just routine, just routine. They was doing these tests at the doctors, 'cause I was a drug user. They said do you want to get tested for, like, everything, AIDS, hep C, the lot. I said yeah go on, crack on... I'll get a negative everything and will be happy. It just so happens I picked the results up the day before my birthday and it turned out I had hep C. I was f–ing fuming." [23 year old male IDU diagnosed with hepatitis C, UK; Rhodes et al., 2004; pg. 627]*

> *"From fasting blood sugar to lipids, Hep B, Hep C, Hep A, rubella... So, they're explained what everything is... And we don't do HIV unless it is requested, obviously... But the Hep C is just done... It's a done deal." [Registered Nurse at a drug treatment programme, USA; Munoz-Plaza et al., 2005a; pg. 664]*

Concern over hepatitis C infection and proactive testing

There was evidence that IDUs actively sought testing due to concerns that they may have contracted hepatitis C through injecting behaviour and the belief that hepatitis C was expected when injecting drugs (Kinder, 2009; Khaw *et al.,* 2007; Roy *et al.,* 2007; Swan *et al.,* 2007; Temple-Smith *et al.,* 2004; Wozniak *et al.,* 2007). A study of IDUs in Australia (Temple-Smith *et al.,* 2004) found that women were more likely to actively seek testing due to concern and suspicion of hepatitis C infection, whereas men were found to be dismissive of their risk taking and potential hepatitis C infection. As such, women appeared to be less surprised when diagnosed as hepatitis C positive, whilst men were shocked and expressed disbelief over their hepatitis C status (Temple-Smith *et al.,* 2004). Concern over HIV also provided the opportunity for hepatitis C testing through the joint testing process (Swan *et al.,* 2010; Rhodes *et al.,* 2004).

> *"I usually go the doctor every month for a blood test... because a friend stabbed me with one of her fits, dirty fits." [Female IDU diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg 51.]*

> *"I've not been, yeah, I've been to the doctor not once … I don't want to know what's going on." [Male diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 51]*

> *"The only reason I did decide to get tested for Hep was because I was an IV drug abuser, and that was the only reason. I was never symptomatic." [Male former IDU, Canada; Wozniak et al., 2007; pg. 392]*

> *"I went for an HIV test 'cause an ex girlfriend told me that she had HIV. But she was lying... So I thought I might as well get tested. We had split up by then. But it come back I had hepatitis C." [26 year old male IDU diagnosed with hepatitis C, UK; Davis & Rhodes, 2004; pg. 127]*

Proactive testing was also influenced by the nature of drug use and the extent to which IDUs were engaged with mainstream society (Harris, 2009a; Lally *et al.,* 2008; Roy *et al.,* 2007). In an American

study (Lally *et al.,* 2008) testing was found to be of little concern to IDUs due to a pre-occupation with obtaining drugs. In Canadian (Roy *et al.,* 2007) and Australian (Harris, 2009a) studies, IDUs whose drug use was more controlled took steps to get tested and integration in mainstream society and disengaging from IDU communities was found to encourage testing.

> *"When you're using [drugs] you just don't have time for really anything… Your basic human concerns become getting money and getting off… Not your children, not bathing… [not] updating your wardrobe, not replacing something that's lost, not eating, not sleeping, not taking care of bills, not being responsible. It basically consists of money and using. And worrying how to contact your connections. And trying not to get arrested in the process… Users have a 25 hour a day job." [33 year old homeless female, USA; Lally et al., 2008; pg. 56]*

> *"For the first time in my life what it meant to have this virus in the mainstream world. Because I'd never been part of the mainstream world. It was absolutely devastating to realise that I could be rejected as an entire human being because of this thing." [43 year old female former IDU, Australia; Harris, 2009a; pg. 1033]*

> *"I seen friends of mine getting sick and turning yellow and I says, I better get treatment." [Current or former IDU, Ireland; Swan et al., 2010; pg. 756]*

Staff support and encouragement

Trust and rapport with health professionals and drug treatment staff, and support and encouragement, also acted as a motivator to testing (Munoz-Plaza *et al.,* 2004; Sosman *et al.,* 2005; Strauss *et al.,* 2008). In a UK study (Perry *et al.,* 2003) of GP's experience of hepatitis C testing, drug treatment staff were perceived as an important management filter that moderated drug users' demands and increased drug users' understanding of testing.

> *"I mean they [are] very discrete about what information they let out, you know what I'm saying? The way they informed me about it [the HCV testing] I was willing. When they talk to me there were no risks involved and it's for your own protection." [48 year old male drug user, USA; Strauss et al., 2008; pg. 1171]*

> *"They really push us to get, when we first come in here, to get tested if we haven't been tested. They'll ask, like they asked me, 'Have you been tested?' And I think I had been, but they give you the number to call and you can set up, it's free for us." [20 year old female drug user, USA; Strauss et al., 2008; pg. 1172]*

The prison setting

Three studies reported barriers to testing within the prison settings (Dyer & Tolliday, 2009; Khaw *et al.,* 2007; Munoz-Plaza *et al.,* 2005b). A number of additional barriers to testing specific to the prison setting were reported in a UK study (Khaw *et al.,* 2007). Prisoners believed that administration and bureaucracy prevented the efficient uptake of testing due to long waiting times. A lack of information provision on hepatitis C and testing, prioritising detoxification and withdrawal and movement between prisons were also regarded as preventing the opportunity for, and uptake of, testing in prison. An Australian study (Dyer & Tolliday, 2009) also reported limited time and a lack of staff training acted as a barrier to the provision of adequate pre and post test counselling. An American study (Munoz-Plaza *et al.,* 2005b) evaluated the acceptability of peer education within

prison in relation to the uptake of hepatitis C services, including testing. The study found that prisoners preferred peer educators to prison staff and perceived peer educators as more credible and easily accessible. However, stigma acted as a barrier to accessing peer education. Prisoners felt that prison staff supported peer education as it could free up staff time, yet they also felt that there was a certain degree of resistance to peer education among staff. The prisoners perceived that due to funding constraints, the staff had concerns over the increased demand for testing that had occurred as a result of peer education.

> *"That's the thing when you have to put all these applications in, (Ah ha) it puts you off.... It's because you, everything you do you've got, it's always put an application in, put an app. [application] in, and people are like "What, I have to put an app. in just to get to see if I've got a disease?" Do you know what I mean, that's the way people think. When you've got to put an app. in it's like I'll do it later, do you know what I mean? .... And it just, it's a nightmare, them apps. are definitely." [Female prisoner, UK; Khaw et al., 2007; pg. 4]*

Experience of testing and reactions to diagnosis

Twenty one papers reported findings on the experience of testing and reactions to diagnosis (Craine *et al.,* 2004; Copeland, 2004; Cullen *et al.,* 2005; Faye & Irurita, 2003; Fraser 2010; Harris, 2009a; Kinder, 2009; Lally *et al.,* 2008; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a; Perry *et al.,* 2007; Rhodes *et al.,* 2004; Rhodes and Treloar 2008; Roy *et al.,* 2007; Strauss *et al.,* 2008; Southgate *et al.,* 2005; Sutton & Treloar, 2007; Swan *et al.,* 2010; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005, Wright *et al*., 2005).

Despite evidence of hepatitis C as socially accepted among IDUs (Carrier *et al.,* 2005; Copeland, 2004; Davis & Rhodes, 2004; Davis *et al.,* 2004; Ellard 2007; Faye & Irurita, 2003; Harris, 2009a; Rhodes *et al.,* 2004; Roy *et al.,* 2007; Rhodes & Treloar, 2008; Swan *et al.,* 2010; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Treloar & Holt, 2009; Wozniak *et al.,* 2007; *see section 5.4.2. HCV as normal, ubiquitous and socially accepted*), being diagnosed as hepatitis C positive caused anxiety, shock and depression (Copeland, 2004; Faye & Irurita, 2003; Harris, 2009a; Kinder, 2009; Lally *et al.,* 2008; Munoz-Plaza *et al.,* 2005a; Sutton & Treloar, 2007; Swan *et al.,* 2010; Tompkins *et al.,* 2005). Although the routine nature of testing encouraged opportunistic testing, learning about their hepatitis C antibody status unexpectedly exacerbated anxiety and confusion (Rhodes *et al.,* 2004). Studies also reported that IDUs recommended counselling to help people come to terms with a positive diagnosis for hepatitis C (Southgate *et al.,* 2005; Swan *et al.,* 2010; Strauss *et al.,* 2008).

> *"I couldn't believe it, you know my head was in a jumble and for about a week after. I didn't talk to the nurses or that. I didn't want any visitors or anything. I was just sat in the corner of my room." [Homeless male IDU, UK; Tompkins et al., 2005; pg. 265]*

> *"A bit worried and upset because I didn't know what it was... getting told that you had something..." [Male current/past IDU diagnosed with hepatitis C, UK; Copeland, 2004; pg. 141]*

Studies also demonstrated that IDUs were anxious and concerned over the impact of a positive hepatitis C diagnosis on their chances of finding a long term partner, sexual relations, starting a family and the possibility of transmitting hepatitis C to their intimate partners, children and unborn children (Carrier *et al.,* 2005; Harris, 2009a; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Wright

et al., 2005). Such concerns encouraged disclosure of hepatitis C status (Harris, 2009a; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005).

> *"It stops me going out and getting a girlfriend and stuff like that. It bothers me in ways like that, having hepatitis C." [Homeless male IDU, UK; Tompkins et al., 2005; pg. 266]*

> *"In the past I've anticipated that there could be problems with it [HCV], mainly through things like sexual partners, things like that. I think that's always probably been a main concern." [Current IDU, Australia; Faye & Irurita, 2003; pg. 96]*

> *"It depresses me now. It sort of puts the lid on having a family now and that's the bad, the bad depressive side of it, I can't sort of make my own family now." [Homeless male IDU, UK; Tompkins et al., 2005; pg. 266]*

> *"The last thing I would do, would be to put my daughter in jeopardy… one of the first things that I did when I found out that I had hep C was to find out where I stood where my daughter was concerned…on her getting [it].." [Female current/past IDU diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 49]*

> *"I'm a bit worried… you know if she falls pregnant, you know, the baby's gonna catch the hep C virus." [Male current/past IDU diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 50]*

Other reactions to a positive diagnosis included being unaware, indifferent and '*not bothered*'. This may have been a reflection of the social acceptance and ubiquity of hepatitis C among IDUs previously discussed (Craine *et al.,* 2004; Copeland, 2004; Fraser 2010; Harris, 2009a; Sutton & Treloar, 2007; Tompkins *et al.,* 2005). For example, an Australian study (Faye & Irurita, 2003) found that individuals with a history of injecting drug use were less shocked than individuals contracting the infection through other means. Another common reaction to a positive diagnosis was denial (e.g. '*blocking it out*' or '*pushing it aside*'), which sometimes led to delaying further investigations and treatment (Faye & Irurita, 2003; Swan *et al.,* 2010). Australian research (Temple-Smith *et al.,* 2004) found that women tended to actively seek support in coping with a positive diagnosis, whilst men tended to deny their diagnosis and keep concerns and anxiety to themselves.

> *"Not bothered because I didn't know what it was." [Female current/past IDU diagnosed with hepatitis C, UK; Copeland, 2004; pg. 140]*

> *"Pretty indifferent . . . I don't value my life at all." [Male current/past IDU diagnosed with hepatitis C, UK; Copeland, 2004; pg. 140]*

> *"I like to pretend that I haven't got it, that's basically what I do, yeah." [Male current/past IDU diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 52]*

> *"I did a (hep C) telephone counselling course… just initially selfishly, because I wanted more information, I wanted to… have access to news reports… and stuff that had all been telexed so that you can read them and [find out] what's going on [and] what does it (hep C) mean for us." [Female current/past IDU diagnosed with hepatitis C, Australia; Temple-Smith et al., 2004; pg. 52]*

Confusion over the meaning diagnosis and a lack of information provision

Studies showed that whilst some IDUs recalled good testing practice, experience of being informed on the outcome of their diagnosis was highly confusing. Many IDUs were confused over the meaning of diagnosis and reported limited and inadequate information provision by health professionals, leading to substantial gaps in knowledge (Copeland, 2004; Cullen *et al.,* 2005; Faye & Irurita, 2003; Khaw *et al.,* 2007; Kinder, 2009; Lally *et al.,* 2008; McCreaddie *et al*., 2011Rhodes & Treloar, 2008; Rhodes *et al.,* 2004; Southgate *et al.,* 2005; Strauss *et al.,* 2008; Sutton & Treloar, 2007; Swan *et al.,* 2010; Tompkins *et al.,* 2005). Such confusion was reinforced by the routine and unexpected nature of hepatitis C testing (Rhodes *et al.,* 2004). Experiences of inaccurate diagnoses and misinformation also led to mistrust and little confidence in health professionals' hepatitis C-related knowledge (Carrier *et al.,* 2004; Sutton & Treloar, 2007). Studies have shown that information provision is valued by IDUs and is important in the take up of investigations and treatment, these experiences may have discouraged further engagement in hepatitis C services (Munoz-Plaza *et al.,* 2004; Strauss *et al.,* 2008; Sutton & Treloar, 2007; Swan *et al.,* 2010). The extent to which IDUs paid attention to information provided pre and post testing was also dependent on the nature of their drug use. In a Canadian study (Roy *et al.,* 2007), IDUs whose drug use was more controlled were found to pay more attention to the information they were given by healthcare providers post diagnosis. In a UK study of GP's experience of testing (Perry *et al.,* 2003), it was felt that the testing process was easier with IDUs engaged in an informed IDU network compared to more transient populations where sharing a diagnosis was perceived to be more difficult. The study also noted additional factors that may have influenced IDUs experience of diagnosis. Workload pressures and impersonal relations between GP's and IDUs were felt to lead to shortcomings in hepatitis C provision.

> *"The doctor came in and he said, 'Oh I've got your results here and I'm sorry to say that you've got hepatitis C' and left." [Homeless IDU, UK; Tompkins et al., 2005; pg. 265]*

> *"One thing that I know about hepatitis B and C is that there is just no information. I went to the library; I can't find good information. I can't get it from a doctor… There is not enough education… I don't know signs, symptoms. I don't know how to make myself well." [40 year old female IDU, USA; Lally et al., 2008; pg. 57]*

> *"The doctor, he just said... 'hepatitis C and blah blah blah.' I didn't understand what that meant." [Current/past IDU, Ireland; Swan et al., 2008; pg. 758]*

> *"I was never told nothing. What did they find, or everything, and so I just assumed that everything was all right. And then when I asked [the doctor], is everything all right? I've been tested. Oh, yeah, everything's all right. If it wasn't, we would tell you. …I didn't like that. I want to know. I mean, you're gonna take blood and you're gonna do a physical. Sit down with me and talk to me and tell me what's going on... You got to explain it to me. I want to know. I want to know what it affects. If it affects my liver or kidneys, or what it's gonna do in the long run. I'd love to be told this, but they don't have the time. That's what they say. I don't know if it's just that they don't, or that they're not interested." [37 year old male drug user, USA; Strauss et al., 2008; pg. 1171]*

> *"The doctor just walked in and said I was HIV and Hep C positive - and walked back out. He said he would get a counsellor and send them up... but no-one came." [Drug user, Ireland; Cullen et al., 2005; pg. 74]*

The impact of HCV testing on behaviour

Seventeen articles reported findings in relation to the impact of hepatitis C testing on IDUs' behaviour. There appeared to be conflicting evidence as to whether an awareness of hepatitis C status could lead to behaviour change (Copeland, 2004; Coupland *et al* 2009; Cullen *et al.,* 2005; Craine *et al.,* 2004; Faye & Irurita, 2003; Fraser, 2004; Gyarmathy *et al.,* 2006; Khaw *et al.,* 2007; Paterson *et al.,* 2006; Roy *et al.,* 2007; Sutton & Treloar, 2007; Swan *et al.,* 2010; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Treloar & Hopwood, 2004; Wozniak *et al.,* 2007; Wright *et al.,* 2005).

Behaviour change and disclosure

A number of studies (Faye & Irurita, 2003; Gyarmathy *et al.,* 2006; Tompkins *et al.,* 2005; Treloar & Hopwood, 2004; Wozniak *et al.,* 2007; Wright *et al.,* 2005) reported that IDUs perceived disclosing a positive hepatitis C diagnosis to others (e.g. other injectors, friends, family, sexual partners health professionals) to avoid transmission as responsible and an obligation. There was evidence that hepatitis C positive IDUs took care to prevent transmission, such as not sharing needles and equipment, distributing spare and unused equipment, not letting people near their spilt blood, covering cuts or open wounds, using separate crockery and cutlery, keeping their personal toiletry items separate to prevent accidental transmission and cleaning equipment before letting others use it (Fraser, 2004; Wright *et al.,* 2005). However, IDUs reported that you could never be certain whether other IDUs had disclosed their hepatitis C status and as such trust in the person was important (Wright *et al.,* 2005). Safe injecting practices may also be employed to prevent contracting other infections (Wright *et al.,* 2005). An Australian study (Temple-Smith *et al.,* 2004) found gender differences in strategies to avoid transmission, with women expressing more concern and taking more action to reduce the risk of infecting others.

> *"I'm careful. When I cut myself, I'm really careful! I'm a little paranoid about that, like, when I cut myself, I'm really careful about what I touch, I go wash my hands, put on a band aid, it's a matter of principle." [20 year old male IDU, Canada; Roy et al., 2007; pg. 400]*

> *"I'm obliged to tell them… You don't expect someone to treat you where there are dangers involved without disclosing those sorts of things." [Female diagnosed with hepatitis C, Australia; Treloar & Hopwood, 2004; pg. 186]*

> *"It is an unwritten law. If you are infected with something, you have to tell others. You have to have a backbone [i.e., you have to be truthful]." [26 year old male IDU, Hungary; Gyarmathy et al., 2006; pg. S67]*

> *"If you say, 'have you got AIDS or hepatitis have you, or anything' and if they say 'no', then you've got to trust them haven't you?" [Homeless IDU, UK; Wright et al., 2005; pg. 79]*

Leading a healthy lifestyle

A common change in behaviour resulting from a positive diagnosis was leading a healthier lifestyle, such as eating more healthily (Faye & Irurita 2003; Khaw *et al.,* 2007; Paterson *et al.,* 2006; Roy *et al.,* 2007; Sutton & Treloar, 2007; Wright *et al.,* 2005; Wozniak *et al.,* 2007) and reducing alcohol (Coupland *et al.,* 2009; Cullen *et al.,* 2005; Wright *et al.,* 2005; Wozniak *et al.,* 2007) and drug use (Copeland, 2004; Sutton & Treloar, 2007; Wright *et al.,* 2005). Being diagnosed as hepatitis C positive also led to IDUs re-evaluating their lives and making the first steps towards a more stable life and moving on from drug addiction (Roy *et al.,* 2007; Sutton & Treloar, 2007; Swan *et al.,* 2010).

"Hep C, if you don't eat properly, keep using and all that it can make your liver weak. But if you just look after yourself fit can still stabilise it for a long time." [25 year old Vietnamese-Australian female IDU, Australia; Coupland et al., 2009; pg. 237]

"['You tested positive for Hep C...'] and I started drinking more. But at the same time I was reading more about it, and I was modifying my diet a bit, eating a little less red meat and some other things I was doing, but I was drinking a lot, a lot." [30 year old male IDU, Canada; Wozniak et al., 2007; pg. 392]

"I try to eat a proper diet, you know, stay away from fatty foods, spicy foods. Obviously I know all about the foods and stuff you are meant to eat and not eat." [Homeless IDU, UK; Wright et al., 2005; pg. 80]

"'I was sick of it [...], I was sick, I found out I had hepatitis C, I had to stop using [drugs]. It didn't make sense anymore." [Female; 26 years, Roy et al., 2007; pg. 402]

However, a number of studies found that some IDUs resorted to alcohol (Wright *et al.,* 2005; Wozniak *et al.,* 2007), and drug use (Cullen *et al.,* 2005) to block out and cope with a positive hepatitis C diagnosis.

"It helps me escape. For just that one time I can forget about it [hepatitis C] you know what I mean and then I can hack thinking about it for another week or whatever before it gets too much when I need to go out again and forget about it." [Homeless IDU, UK; Wright et al., 2005; pg. 81]

"I'm not spending as much [money] on drugs, and I'm not thinking in the morning about how much money I have to score, so I drink more!" [Drug user, Ireland; Cullen et al., 2005; pg. 74]

Reinforcing existing behaviour and non-discloser

Testing positive for hepatitis C was also shown to reinforce existing risk behaviour and some IDUs took a careless attitude to their behaviour and risk-taking (Sutton & Treloar, 2007). One UK study (Craine *et al.,* 2004) found limited evidence of a direct reduction in risk behaviour. Both IDUs and drug workers suggested that a negative test result could initially lead to more cautious behaviour, whereas knowledge of a positive test produced more ambivalent responses. Another UK study (Wright *et al.,* 2005) found that a positive diagnosis actually led to an increase in injecting in order to deal with depressive feeling and the denial of infection as a coping mechanism, which had implications for hepatitis C status disclosure. A Canadian study (Wozniak *et al.,* 2007) reported an example of one IDU not disclosing their positive status due to fear of being perceived as immature and to avoid ridicule among the IDU group. In their UK study, Craine *et al.* (2004) found that IDUs may report being 'clean' despite being diagnosed as positive or not knowing their official hepatitis C status.

"They know that there are these risks, they're just in denial, they won't admit it to their selves, you know what I mean, put themselves at risk, they don't want to think about it, they choose not to think about it, they choose not to talk about' it." [Homeless IDU, UK; Wright et al., 2005; pg. 80]

"I look at it like this. I'm sick already, what else can they do to me? Like it can happen, I can get a lot worse than what I am and I can catch a lot more things than what I have. But it doesn't worry me." [39 year old male former IDU diagnosed with hepatitis C, Australia; Fraser & Treloar, 2006; pg. 105]

"I just got Hep C, but (inaudible) I just, after (inaudible), cause I, I grew up rough, like, so that (inaudible), and then (inaudible) I just said, "F– it." It just, I don't care, I'll just keep, keep going the way I am, you know? Understand? And just, when you get put down, it just, your self-esteem goes down, you know? And then you just don't give a f–. You know, all you wanna do is just get more high. And just wanna, you just wanna do it." [Male IDU, Canada; Wozniak et al., 2007; pg. 392]

Testing negative for hepatitis C could also reinforce engagement in risky behaviour, as some IDUs assumed a 'natural' immunity to hepatitis C following a negative diagnosis and perceived their previous engagement in such risky behaviour as careful and responsible (Carrier *et al.,* 2005). Although safe injecting practices were employed to reduce transmission to others, knowing that they were hepatitis C positive led to careless and continued reuse of their own needles when injecting alone (Wright *et al.,* 2005). Wright *et al.* (2005) and Roy *et al.* (2007) also found that when IDUs disclosed their positive hepatitis C diagnosis to other injectors, the responsibility over whether to share was perceived as shifting to the other user.

"... I have shared, one that I shared about f–in' four, 5 months ago, it was, and I was like, all the time it was on my mind, 'F–in' hell, I've like been given that second chance off God, you know, with being negative, and what am I doing', but you sort of like try and justify it by thinking, you know, 'well I've cleaned it out with sterilised water'." [31 year old female IDU; Craine et al., 2004; pg. 119]

"If you ask anyone if they've had the Hep C test they tell you that they've had it and they're clean... I've said it myself..." [27 year old male IDU diagnosed with hepatitis C, UK; Craine et al., 2004; pg. 118]

"I can't be fairer than tell them and if they still want to go ahead and do it that's their problem." [Homeless IDU, UK; Wright et al., 2005; pg. 80]

"…He was using my old [syringe] he knew the risks. I didn't take the responsibility. He knows what he's getting into..." [20 year old male IDU, Canada; Roy et al., 2007; pg. 400]

Stigma as a barrier to disclosure and HCV services

A total of 33 studies referred to stigma. Five papers specifically focussed upon stigma and discrimination among hepatitis C positive individuals including IDUs and drug treatment clients, and the impact of stigma on the uptake of hepatitis C services (Brener & Treloar, 2009; Habib & Adorjany, 2003; Harris, 2009b; Paterson *et al.,* 2007, Treloar and Hopwood 2004). Of the five studies, one was a review of 21 published research reports (Paterson *et al.,* 2007). A further 28 articles discussed stigma associated with hepatitis C and injecting drug use as main findings (Astone *et al.,* 2005; Carrier *et al.,* 2005; Copeland, 2004; Coupland *et al.,* 2009; Craine *et al.,* 2004; Davis *et al.,* 2004; Ellard, 2007; Faye & Irurita, 2003; Fraser, 2004; Fraser & Treloar, 2006; Fraser, 2010; Khaw *et al.,* 2007; Lally *et al.,* 2008; McCreaddie *et al.,* 2011; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a;

Munoz-Plaza 2005b; Paterson *et al.,* 2006; Perry *et al.,* 2003; Roy *et al.,* 2007; Strauss *et al.,* 2008; Sutton & Treloar, 2007; Swan *et al.,* 2007; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Treloar *et al.,* 2010; Wright *et al.,* 2005).

Stigma was perceived to be an outcome of hepatitis C being associated with injecting drug use (Coupland *et al.,* 2009; Copeland, 2004; Davis *et al.,* 2004; Faye & Irurita, 2003; Fraser & Treloar, 2006; Fraser, 2010; Harris, 2009b; McCreaddie *et al.,* 2011; Paterson *et al.,* 2006; Paterson *et al.,* 2007; Swan *et al.,* 2010; Temple-Smith *et al.,* 2004; Treloar & Rhodes, 2009; Tompkins *et al.,* 2005) and infection (Faye & Irurita, 2003; Harris, 2009b; McCreaddie *et al.,* 2011; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009). As noted by Paterson *et al.* (2007) in a review of research reports on stigma among hepatitis C positive IDUs, hepatitis C-related stigma is multifaceted and can be confounded and exacerbated by other attributes that are assigned negative labels, such as illicit drug use, poverty, ethnicity, homelessness, and prostitution.

> *"There's the stigma involved about taking drugs, and it's infectious." [Person diagnosed with hepatitis C, Australia; Faye & Irurita, 2003; pg. 97]*

> *"People who got it through blood transfusions, people have sympathy for them but because when you're using drugs it's self-inflicted, people aren't going to have sympathy for ya and they basically don't care." [Current/former IDU, Ireland; Swan et al., 2010; pg. 756]*

> *"I went into the hospital, because at that time, there was so much stigma attached to it. You were treated like a leper when you went into hospital, although I was in for something else. Because I had the hepatitis C, right away they think, drug addict …. You know, I'd be stuck in a room and on the front of the door, it'd have "do not enter, infectious" and things like that you know. And you're eating off of plastic plates and plastic knife and staff. They really weren't very nice when you were in the hospital. It was horrible." [61 year old female former IDU diagnosed with hepatitis C for more than 15 years, UK; McCreaddie et al., 2011; pg. 53]*

Studies showed that hepatitis C positive IDUs experienced stigma from other injectors (Tompkins *et al.,* 2005) within the wider community (Craine *et al.,* 2004; Habib & Adorjany, 2003; Harris, 2009b; McCreaddie *et al.,* 2011; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009), from health professionals and also as a result of what were perceived to be inappropriate precautions to infection in health care settings (Astone *et al.,* 2005; Carrier *et al.,* 2005; Fraser and Treloar 2006; Fraser 2004; McCreaddie *et al.,* 2011; Paterson *et al.,* 2006; Paterson *et al.,* 2007; Roy *et al.,* 2008; Strauss *et al.,* 2008; Temple-Smith *et al.,* 2004; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009). The experience of stigma prevented IDUs from seeking hepatitis C testing due to fear of disclosure (Khaw *et al.,* 2007; Lally *et al.,* 2008; Strauss *et al.,* 2008; Sosman 2008), prevented disclosing a positive hepatitis C status to others due to fear of a negative reaction, isolation and social exclusion (Craine *et al.,* 2004; Ellard 2007; Harris, 2009b; McCreaddie *et al.,* 2011; Roy *et al.,* 2007; Sutton & Treloar, 2007; Tompkins *et al.,* 2005; Treloar & Rhodes, 2009; Wright *et al.,* 2005), prevented engagement with further prevention education, investigations and treatment (Coupland *et al.,* 2009; Lally *et al.,* 2008; McCreaddie *et al.,* 2011; Munoz-Plaza 2004; Munoz-Plaza *et al.,* 2005b; Perry *et al.,* 2003; Roy *et al.,* 2007; Swan *et al.,* 2010; Temple- Smith *et al.,* 2004; Treloar & Hopwood, 2004; Treloar *et al.,* 2010) and resulted in IDUs receiving inadequate and judgemental health care by health professionals (Brener & Treloar 2009, Carrier *et al.,* 2005; Habib & Adorjany, 2003; Faye & Irurita, 2003; Strauss *et al.,* 2008; Temple-Smith *et al.,* 2004; Treloar & Rhodes, 2009; Paterson *et al.,* 2007). In a study of Indo-Chinese IDUs living in

Australia, Coupland *et al.* (2009) found that being labelled as an IDU through hepatitis C disclosure could lead to profound social consequences such as limiting marriage options. As such, IDUs were unlikely to disclose their status and undergo treatment. In a review of the literature on stigma among hepatitis C positive IDUs (Paterson *et al.,* 2007), stigma by health professionals was found to be reinforced by lack of staff knowledge on hepatitis C and injecting drug use, past negative experiences between IDUs and staff, lack of privacy of care within health care settings and a general institutionalisation of hepatitis C-related stigma as a product of official policies.

> *"I know how I answer [the doctor's] question is going to determine how I'm going to get treated in this town. I could lie and get treated well, or I could tell the truth and get treated like s–…I said 'through intravenous drugs'. And his whole demeanour towards me completely changed." [Female current/former IDU, Australia; Temple-Smith et al., 2004; pg. 53]*

> *"We have two waiting rooms — to isolate them from the main general practice crowd." [GP, UK; Perry et al., 2007; pg. 542]*

> *"I am treated like a contagious leper in hospitals by doctors and dentists. They are ok till I tell them my hep C status." [47 year male IDU diagnosed with hepatitis C, Australia; Habib & Adorjany, 2003; pg. 259]*

Evidence statements 16-22: Testing and the impact of diagnosis

16: A number of barriers to hepatitis C testing among IDUs were identified. Perceiving themselves to be at low risk of hepatitis C infection, a lack of visible symptoms of hepatitis C infection, fear of a positive test result, the use of needles and fear of disclosure were found to prevent the uptake of hepatitis C testing among IDUs.[1] Three studies reported barriers to testing specific to the prison setting including long waiting times, lack of information provision, prioritisation of detoxification and withdrawal, and movement between prisons.[2]

17: Hepatitis C positive IDUs experience stigma from other injectors, within the wider community and from health professionals.[3] Stigma is perceived to be an outcome of the association between hepatitis C and injecting drug use and hepatitis C as infectious,[4] and may prevent IDUs from seeking hepatitis C testing due to fear of disclosure.[5] IDUs may not disclose a positive hepatitis C status due to fear of a negative reaction, isolation and social exclusion.[6]

18: Convenient and opportunistic testing and a 'one-stop shop' approach for all hepatitis C services was regarded as a convenient approach among IDUs.[7] There was evidence that some IDUs were unaware that they had been tested for hepatitis C and concern over informed consent to testing was noted by a number of authors.[8] Although an opportunistic approach can increase testing compliance, a lack of informed consent may also contribute towards uncertain knowledge of hepatitis C among IDUs and limit the impact of testing on behaviour.

19: There was evidence that IDUs may actively seek testing due to concerns that they may have contracted hepatitis C through their injecting behaviour.[9] Although a comparison with HIV can lead to a trivialisation of hepatitis C, concern over HIV also provided the opportunity for testing through the joint testing process.[10] Proactive testing was influenced by the nature of drug use and the extent to which IDUs were engaged with mainstream society; IDUs whose drug use was more controlled had a greater tendency to get tested and integration in mainstream society also encouraged testing.[11]

20: Trust and rapport with health professionals and drug treatment staff acted as motivators to testing. Support and encouragement from health professionals also facilitated engagement with testing among IDUs.[12]

21: Studies showed that the experience of being informed about the outcome of hepatitis C testing can be highly confusing. Limited and inadequate information provision by health professionals can lead to confusion over the meaning of a positive diagnosis and substantial gaps in knowledge.[13]

22: There is conflicting evidence as to whether an awareness of hepatitis C status can lead to behaviour change. A positive hepatitis C diagnosis can lead to IDUs adopting healthier lifestyles, such as eating more healthily and reducing alcohol and drug use.[14] Studies have also shown that alcohol and drugs are used as a means of coping with a positive diagnosis.[15] There is evidence that IDUs take care to prevent hepatitis C transmission and disclose a positive hepatitis C diagnosis to avoid transmission.[16] Testing positive for hepatitis C can also reinforce existing risk behaviour and one UK study found limited evidence of a direct reduction in risk behaviour.[17] Another UK study[18] indicated that there is evidence that a positive diagnosis may actually lead to an increase in injecting in order to deal with depressive feelings and denial. Testing negative for hepatitis C can also reinforce risky behaviour in that some IDUs assume previous injecting practice to be safe following a negative diagnosis.[19]

[1] Craine *et al.*, 2004 [++]; Davis *et al.*, 2004 [++]; Fraser, 2004 [+]; Fraser, 2010 [-]; Gyarmathy *et al.,* 2006 [+]; Harris, 2009a [+]; Khaw *et al.*, 2007 [+]; Lally *et al.*, 2008 [++]; Perry *et al.*, 2003 [+]; Rhodes & Treloar, 2008 [NR]; Rhodes *et al.*, 2004 [++]; Temple-Smith *et al.*, 2004 [+]; Sosman *et al.*, 2005 [+]; Southgate *et al.*, 2005 [++]; Strauss *et al.*, 2008 [+]; Sutton & Treloar, 2007 [++]; Swan *et al.*, 2010 [++]

[2] Dyer & Tolliday, 2009 [-]; Khaw *et al.*, 2007 [+]; Munoz-Plaza *et al.*, 2005b [+]

[3] Astone *et al.*, 2005 [+]; Carrier *et al.*, 2005 [+]; Craine *et al.*, 2004 [++]; Fraser, 2004 [+]; Fraser & Treloar, 2006 [++]; Habib & Adorjany, 2003 [-]; Harris, 2009b [-]; McCreaddie *et al.*, 2011 [++]; Paterson *et al.*, 2006 [++]; Paterson *et al.*, 2007 [NR]; Roy *et al.*, 2007 [++]; Strauss *et al.*, 2008 [+]; Temple-Smith *et al.*, 2004 [+]; Tompkins *et al.*, 2005 [++]; Treloar & Rhodes, 2008 [NR]

[4] Copeland, 2004 [++]; Coupland *et al.*, 2009 [++]; Davis *et al.*, 2004 [++]; Faye & Irurita, 2003 [++]; Fraser, 2010 [-]; Fraser & Treloar, 2006 [++]; Harris, 2009b [-]; McCreaddie *et al.*, 2011 [++]; Paterson *et al.*, 2006 [++]; Paterson *et al.*, 2007 [NR]; Swan *et al.*, 2010 [++]; Temple-Smith *et al.*, 2004 [+]; Tompkins *et al.*, 2005 [++]; Treloar & Rhodes, 2008 [NR]

[5] Khaw *et al.*, 2007 [+]; Lally *et al.*, 2008 [++];Sosman *et al.*, 2005 [+]; Strauss *et al.*, 2008 [+]

[6] Craine *et al.*, 2004 [++]; Ellard, 2007 [++]; Harris, 2009b [-]; McCreaddie *et al.*, 2011 [++]; Roy *et al.*, 2007 [++]; Sutton & Treloar, 2007 [++]; Tompkins *et al.*, 2005 [++]; Treloar & Rhodes, 2008 [NR]; Wright *et al.*, 2005 [++]

[7] Gyarmathy *et al.*, 2006 [+];Munoz-Plaza *et al.*, 2004 [+]; Rhodes *et al.*, 2004 [++];Roy *et al.*, 2007 [++]; Sosman *et al.*, 2005 [+]; Swan *et al.*, 2010 [++];Strauss *et al.*, 2008 [+]; Temple-Smith *et al.*, 2004 [+]

[8] Munoz-Plaza *et al.*, 2005b [+]; Perry & Chew-Graham, 2003 [+]; Rhodes *et al.*, 2004 [++]; Tompkins *et al.*, 2005 [++];

[9] Khaw *et al.*, 2007 [+]; Kinder, 2009 [++]; Roy *et al.*, 2007 [++]; Swan *et al.,* 2010 [++]; Temple-Smith *et al.,* 2004 [+]; Wozniak *et al.,* 2007 [++]

[10] Rhodes *et al.*, 2004 [++]; Swan *et al.*, 2010 [++]

[11] Harris, 2009a [+]; Lally *et al.*, 2008 [++]; Roy *et al.*, 2007 [++]

[12] Munoz-Plaza *et al.*, 2004 [+]; Perry *et al.*, 2003 [+]; Sosman *et al.*, 2005 [+]; Strauss *et al.*, 2008 [+]

[13] Copeland, 2004 [++]; Cullen *et al.,* 2005 [-]; Faye & Irurita, 2003 [++]; Khaw *et al.*, 2007 [+]; Kinder, 2009 [++]; Lally *et al.*, 2008 [++]; Rhodes & Treloar, 2008 [NR]; Rhodes *et al.*, 2004 [++]; Southgate *et al.*, 2005 [++]; Strauss *et al.*, 2008 [+]; Sutton & Treloar, 2007 [++]; Swan *et al.*, 2010 [++]; Tompkins *et al.*, 2005 [++]

[14] Copeland, 2004 [++]; Coupland *et al.*, 2009 [++]; Cullen et al., 2005 [-]; Faye & Irurita, 2003 [++]; Khaw *et al.*, 2007 [+]; Paterson *et al.,* 2006 [++]; Roy *et al.*, 2007 [++]; Sutton & Treloar, 2007 [++]; Wright *et al.*, 2005 [++]; Wozniak *et al.*, 2007 [++]

[15] Cullen et al., 2005 [-];Wozniak *et al.*, 2007 [++]; Wright *et al.*, 2005 [++]

[16] Faye & Irurita, 2003 [++]; Fraser, 2004 [+]; Gyarmathy *et al.*, 2006 [+]; Tompkins *et al.*, 2005 [++]; Treloar & Hopwood, 2004 [+]; Wright *et al.*, 2005 [++]; Wozniak *et al.,* 2007 [++]

[17] Craine *et al.*, 2004 [++]; Sutton & Treloar, 2007 [++]

[18] Wright *et al.*, 2005 [++]

[19] Carrier *et al.*, 2005 [+]; Wright *et al.*, 2005 [++]

5.4.4 Barrier and facilitators to subsequent care and treatment

Sixteen studies discussed barriers and facilitators to treatment for hepatitis C among IDUs (Coupland *et al.,* 2009; Cullen *et al.,* 2005; Dyer & Tolliday, 2009; Faye & Irurita, 2003; Fraser, 2010; Kinder, 2009; Lally *et al.,* 2008; McCreaddie *et al.,* 2011; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2006; Munoz-Plaza *et al.,* 2008; Roy *et al.,* 2007; Strauss *et al.,* 2008; Swan *et al.,* 2010; Treloar *et al.,* 2010; Treloar & Holt, 2008).

Knowledge of side effects and treatment efficacy

Fear of treatment side effects prevented IDUs from engaging with hepatitis C treatment. Such fear was exacerbated by the circulation of 'horror stories' among peers about liver biopsies and treatment (Cullen *et al.,* 2005; Fraser, 2010; Kinder, 2009; Munoz-Plaza *et al.,* 2008; Swan *et al.,* 2010; Treloar & Holt, 2008). A UK study (Swan *et al.,* 2010) on barriers and facilitators to hepatitis C testing and treatment found that such stories appear to emphasise severe side-effects, such as depression, mood swings, hair loss, weight loss, and experiences similar to heroin withdrawal (Swan *et al.,* 2010). In one study, the structural layout and lack of discretion at a hospital outpatient clinic also meant that treatment 'horror stories' recalled by health professionals had often been overheard by IDUs (Swan *et al.,* 2010). Studies also showed that questioning the efficacy of hepatitis C treatment and the possibility of non-response to treatment acted as a barrier to treatment uptake (Kinder, 2009; Lally *et al.,* 2008; Treloar *et al.,* 2010). Lack of information provision on treatment was also found to add to feelings of uncertainty about the treatment process and associated side effects (Kinder, 2009). As previously discussed (see *Section 5.4.3. 'Experience of testing and reactions to diagnosis'*) fear and anxiety over the implications of being hepatitis C positive also led to IDUs delaying treatment (Fraser, 2010; Swan *et al.,* 2010).

> *'… [I]f [HCV treatment] didn't work I'd be pretty upset. If I went through it, had done it all properly, and it didn't work, I'd be oh, what a f–ing waste doing that was, you know what I mean. Going through all that and I've still got hepatitis, like.' [27 year old male OST client, Australia; Treloar et al., 2010; pg. 841]*

> *''[F]rom what I was hearing on the street, it wasn't really helping and then when treatment was finished, people were feeling a lot worse ...and one or two people died.'' [Current/former IDU, Ireland; Swan et al., 2010; pg. 756]*

> *''[S]he let air or something get in when she was taking the biopsy and the chap ended up in hospital.'' [Current/former IDU, Ireland; Swan et al., 2010; pg. 756]*

> *"[O]ne of the nurses was telling the other one... that some guy who had been on the hepatitis C treatment... had been told in another hospital that because he was on the interferon-ribavirin treatment, that his cholesterol had gone sky high and he had a heart attack... They*

were discussing that loudly, so that everyone around could hear... [I]t gripped fear into the people who were going down that road." [Current/former IDU, Ireland; Swan et al., 2010; pg. 757]

A fear of needles was common among IDUs after giving up injecting drug use and using needles during the treatment process was a challenge to overcome when considering treatment (Kinder, 2009; Swan *et al.,* 2010).

"[E]very week I'm in (hospital outpatient clinic) since last June and I still can't get the knack of giving blood. I'm petrified. I hate it ...I'll get a ball of tissue and it'll be shredded to pieces by the time I'm finished." [Current/former IDU, Ireland; Swan et al., 2010]

"That was kind of hard to begin to inject my body again with needles, what I used to do 15 to 20 years ago. So that was the process that would be very hard for me." [Male former IDU, USA; Kinder, 2009; pg. 406]

In contrast, a number of studies showed that anxiety over hepatitis C and witnessing peers suffer from symptoms hepatitis C infection encouraged treatment uptake (Kinder, 2009; Swan *et al.,* 2010). Hearing stories of successful treatment cases among peers also encouraged treatment and counterbalance negative stories of treatment (Munoz-Plaza *et al.,* 2004).

"I decided I needed to pursue treatment. Not taking treatment was never an option for me." [Male former IDU and substance abuse counsellor, USA; Kinder, 2009; pg. 405]

"I seen friends of mine getting sick and turning yellow and I says, I better get treatment." [Current/former IDU, Ireland; Swan et al., 2010; pg. 756]

"Yeah, most of [what people say about the medications is] negative. But the positive thing is that, obviously, it's there; because it works on some people... or you wouldn't go through the torture of going through it." [Female OST client, USA; Munoz-Plaza et al., 2008; pg. 75]

"There was a fella actually in the States that was on the interferon ...and it worked for him. And I knew he was very sick and he went through it... [T]hen I met him and he said 'It's gone outta me blood, totally gone.' So that's when I said I need to do something about it." [Current/former IDU, Ireland; Swan et al., 2010; pg. 757]

Competing priorities and structural constraints

A preoccupation with drug use, chaotic lifestyles, long waiting times between appointments and employment led to IDUs missing and forgetting treatment appointments, thus increasing the possibility of treatment drop out (Coupland *et al.,* 2009; Lally *et al.,* 2008; Swan *et al.,* 2010). Socio-economic and family circumstances also meant that treatment was de-prioritised among IDUs. Some IDUs viewed factors such as a lack of stable housing, homelessness, parental responsibilities, lack of transport and access to childcare, and the need to continue employment as preventing their eligibility for treatment (Coupland *et al.,* 2009; Fraser, 2010; Swan *et al.,* 2010; Treloar *et al.,* 2010). Concerns over having to give up employment or change occupation also prevented treatment uptake among IDUs (Faye & Irurita, 2003; Wright *et al.,* 2005).

"I don't want to risk it. Especially when I'm a sole parent at the moment." [26 year old Lao-Australian female IDU, Australia; Coupland et al., 2009; pg. 238].

'The reason I wouldn't go on the Interferon was because I've just had a baby. And there was no way I was gonna get depressed and look after a baby… I still wouldn't because the kids, I wouldn't like to get depressed with looking after children. I've got a five year old, a 12 year old and a 24 year old. The two little ones still need me. And they can't have a depressed mother.' [42 year old female OST client, Australia; Treloar et al., 2010; pg. 841].

"It does make [HCV treatment] hard because you're sleeping on the streets and you're getting up at night, and you're waking up at all hours of the night, so you're not getting much sleep. And you get a bit aggravated and you get told that you can't sleep here, you can't sleep there, you can't go here." [40 year old homeless male OST client, Australia; Treloar et al., 2010; pg. 841]

Abstinence

Hepatitis C treatment was regarded as inaccessible by some IDUs due to the perceived requirement of abstinence from alcohol and drug use (Coupland *et al.,* 2009; Lally *et al.,* 2008; Swan *et al.,* 2010). As previously discussed, (see *Section 5.4.3. The impact of HCV testing on behaviour, leading an healthy lifestyle*), although some IDUs reduced their alcohol and drug use after being diagnosed with hepatitis C (Coupland *et al.,* 2009; Cullen *et al.,* 2005; Sutton & Treloar, 2007; Wright *et al.,* 2005; Wozniak *et al.,* 2007), some found reducing alcohol intake difficult and resorted to alcohol and drugs as a way of coping (Cullen *et al.,* 2005; Wright *et al.,* 2005; Wozniak *et al.,* 2007). Continued substance use therefore acted as a barrier to treatment (Roy *et al.,* 2007; Wright *et al.,* 2005).

"She [nurse] say it's better to quit to get a better result. She said I couldn't have the treatment 'cause I'm on the heroin but the way that she say it is 'cause my dose [dependence] is too high." [Indo-Chinese IDU, Australia; Coupland et al., 2009; pg. 239]

"(Hepatologist) said he'd help me with the interferon but I had to stop drinking. So I just stopped drinking." [Current/former IDU, Ireland; Swan et al., 2010; pg. 759]

"I never really wanted to do the treatments because I found out you had to stop drinking for 6 months, and then for a year, and then you had to wait another 6 months before maybe seeing any results. So you have to stop living for two years." [23 year old female IDU, Canada; Roy et al., 2007; pg. 402]

Lack of hepatitis C symptoms

A number of studies found that IDUs did not consider treatment as they did not perceive hepatitis C as impacting on their health due to not experiencing symptoms and thus feeling well (Coupland *et al.,* 2009; Munoz-Plaza *et al.,* 2008; Treloar and Holt 2008; Swan *et al.,* 2010). When health problems were experienced, IDUs were more likely to access hepatitis C care and treatment (Fraser & Irurita, 2003; Munoz-Plaza *et al.,* 2008; Swan *et al.,* 2010; Treloar & Rhodes, 2009).

"I was just thinking like, well I'm grand, I don't feel sick ...[S]o why do I need to go (to hepatology clinic)?" [Current/former IDU, Ireland; Swan et al., 2010; pg. 756]

''I woke up ...and the bottom part of my legs had swollen. Like they were bigger than my head ...So ...I tried to link back in (with hepatology clinic).'' [Current/former IDU, Ireland; Swan et al., 2010; pg. 759]

The prison setting

One Australian study of health professionals' experiences of hepatitis C service provision in prisons (Dyer & Tolliday, 2009) reported additional barriers specific to the uptake of hepatitis C treatment in prison. The transportation of prisoners between prisons and length of sentence were viewed as interfering with the treatment process, whilst follow up within the community was regarded as difficult. Funding restraints were also seen as limiting the number of prisoners who could participate in treatment. Within this competitive environment, a prisoners psychiatric history and risk of re-infection would be considered when deciding whether to provide treatment. However, some staff did view the prison setting as more suitable for hepatitis C treatment due to the structured environment and peer support during treatment was regarded as beneficial.

"Transportation is the primary barrier. Funding and time restraints are also a problem." [Health professional, Australia; Dyer & Tolliday, 2009; pg. 40]

"Undergoing treatment is easier in custodial settings than in the community from a risk perspective… the structured environment makes adherence easier." [Health professional, Australia; Dyer & Tolliday, 2009; pg. 40]

Significant others

Receiving support from the family, partners and peers, starting family life and concerns over the impact of hepatitis C on significant others (e.g. partners and children) motivated IDUs to engage with hepatitis C treatment (Faye & Irurita, 2003; Kinder, 2009; Swan *et al.,* 2010). In a UK study, (Swan *et al.,* 2010) perceiving hepatitis C as potentially impacting on the family through shortened life span and poor health encouraged the uptake of treatment.

"[S]ee, I hadn't any kids (at diagnosis) ...It was only in later years, now that when I have children an' all, ya tend to look at it, ya know, look after yourself, if anything happens me there's nothing to look after them." [Current/former IDU, Ireland; Swan et al., 2010; pg. 759]

Information provision, increased knowledge on HCV and staff support and encouragement

A lack of opportunity to access treatment and a lack of information on treatment options were reported as barriers to treatment among IDUs in one UK (Swan *et al.,* 2010) and one Australian study (Treloar *et al.,* 2010). Swan *et al.* (2010) found that trust and confidence in health care providers, perceived concern for service-users by health professionals, and continuity of care, influenced access and engagement with investigations and treatment. A lack of information on treatment options was also reported and some IDUs expressed a lack of confidence in health care providers' knowledge and expertise in hepatitis C.

'I ...actually chased my doctor (GP) ...I'd ring him ''Any news, any news?'' He said ''No news.'' So I rang ...(hospital) here and I said like ''What's the situation like? I put in for this, now I need it. What's happening?'' So I got more motivated because me son and me wife but I had to chase it." [Current/former IDU, Ireland; Swan et al., 2010; pg. 759]

"Nobody seems to feel the need to ask me if I want to be treated. So I say, in saying that, I don't feel like I need any of the treatment that they've got either. That's what I think." [54 year old male OST client, Australia; Treloar et al., 2010; pg. 841]

Increasing knowledge on hepatitis C through the provision of information by health professionals encouraged IDUs to consider their treatment options (Cullen *et al.,* 2005; Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2008; Swan *et al.,* 2010). However, information provided on treatment could be conflicting and a lack of understanding and incorrect interpretations have implications for treatment engagement (Coupland *et al.,* 2009).

Perceiving health care professionals to be supporting, concerned and caring, and being encouraged to undertake treatment by health professionals was found to motivate IDUs to engage in treatment (Kinder, 2009; Fraser 2010; Coupland *et al.,* 2009; McCreaddie *et al.,* 2011; Munoz-Plaza *et al.,* 2004; Swan *et al.,* 2010). Drug treatment settings (including methadone treatment settings) were also noted as preferred sites for hepatitis C treatment due to established rapport with staff (Coupland *et al.,* 2004).

"(Nurse) was always here (hospital outpatient clinic) any time I'd come up. She was the one gave me bloods. She gives me the needles (interferon injections) in me belly ...I think it's a connection. Like I'd sooner quicker (Nurse) stick the needle into me than me partner and I'm with him 14 years." [Current/former IDU, Ireland; Swan et al., 2010; pg. 758]

"I ended up going and getting the biopsy because of the (GPs) here telling me about it and that it's not barbaric, the syringes they use these days are a lot smaller. He pinched me arm and says like 'That's more than what you'd feel actually when you're getting your biopsy'." [Current/former IDU, Ireland; Swan et al., 2010; pg. 757]

"[E]very time I've come (to hospital outpatient clinic), it's been great. (Nurse) walked through the side-effects, me liver stuff, asked me how everything is. She's been there on the phone. She's called me ...That's what the best part of it is. Cos when ya feel like your world's turned upside down and there's someone there that's actually caring about ya, it makes it a lot easier." [Current/former IDU, Ireland; Swan et al., 2010; pg. 757]

Drug treatment settings and a 'one stop shop' approach

A number of studies found that IDUs preferred hepatitis C services, including treatment, to be situated in one setting such as drug treatment programmes and methadone substitution settings (Swan *et al.,* 2010; Munoz-Plaza *et al.,* 2004; Treloar *et al.,* 2010). In an American study, both clients and staff felt that opioid substitution treatment settings were suitable sites for hepatitis C services and treatment. Reasons include easy access and also established relationships with drug treatment staff. In an American study, drug treatment programmes were also viewed as suitable sites for the provision of hepatitis C information with the aim of encouraging participation in testing and treatment (Munoz-Plaza *et al.,* 2004; Munoz-Plaza *et al.,* 2005a; Munoz-Plaza *et al.,* 2006). In a UK study (Swan *et al.,* 2010) IDUs suggested mainstreaming information about risk factors, health implications, and treatment for hepatitis C infection and education of service-users in addiction clinics.

"That'd be a lot better. Then instead of going to two places to do two things you're going to one place by the time rather than going to two different places, which takes a very long time and running around here, and there …" [40 year old male OST client, Australia; Treloar et al., 2010; pg. 841].

"I think it works really well because we have the people coming in for their opiate substitution therapy. So they're sort of like a captive audience. And it seems to work well for the clients if they've got the one contact point. They form good relationships with the doctor and the nurse and then, you know, if they've got any questions that are coming up about their hep C treatment, they can always contact us when they're coming in on that daily basis." [Registered Nurse in a drug treatment programme, Australia; Treloar et al., 2010; pg. 842]

Evidence statements 23-30: Barriers and facilitators to hepatitis C treatment

23: Fear of the side effects associated with hepatitis C treatment and the circulation of 'horror stories' and unsuccessful treatment cases among peers prevented IDUs from engaging with treatment.[1] A fear of needles was also common and using needles during the treatment process was a challenge to overcome when considering treatment.[2] In contrast, anxiety over hepatitis C, witnessing peers suffer from symptoms of hepatitis C infection and hearing stories of successful treatment cases among peers encouraged treatment uptake.[3]

24: Socio-economic and family circumstances can lead to treatment being de-prioritised among IDUs.[4] Studies have shown that a preoccupation with drug use, chaotic lifestyles, long waiting times between appointments and employment contributed towards IDUs missing and forgetting treatment appointments, thus increasing the possibility of treatment drop out.[5] The assumption of abstinence as a requirement for hepatitis C treatment and continued substance use among IDUs acted as a barrier to treatment.[6]

25: Receiving support from the family, partners and peers, starting family life and concerns over the impact of hepatitis C on significant others (e.g. partners and children) motivated IDUs to engage with hepatitis C treatment.[7]

26: There was evidence that not experiencing symptoms was a barrier to treatment as IDUs did not perceive hepatitis C as impacting on their health and as such did not feel treatment was required.[8] When health problems were experienced, IDUs were more likely to access hepatitis C care and treatment.[9]

27: One study[10] found that imprisonment was viewed by health professionals as both a barrier and a facilitator for hepatitis C treatment; transportation of prisoners between prisons and length of sentence were viewed as interfering with the treatment process whereas the structured environment of prison and availability of peer support during treatment were regarded as beneficial.

28: Two studies found that a lack of opportunity to access treatment and a lack of information on treatment options act as barriers to hepatitis C treatment.[11] Increasing knowledge on hepatitis C through the provision of information by health professionals encouraged IDUs to consider their treatment options.[12]

29: The experience of stigma prevented IDUs from seeking hepatitis C testing due to fear of disclosure and prevented IDUs from disclosing a positive hepatitis C status due to fear of a negative reaction, isolation and social exclusion.[13] Stigma also prevented engagement with further prevention education, investigations and treatment and resulted in IDUs receiving inadequate and

judgemental health care by health professionals.[14]

30: Perceiving health care professionals to be supportive, concerned and caring, and being encouraged to undertake treatment by health professionals was found to motivate IDUs to engage in hepatitis C treatment.[15] There was evidence across a number of studies that IDUs preferred hepatitis C services, including treatment, to be situated in one setting such as drug treatment programmes and methadone substitution settings.[16] These services were also seen as useful in providing information of hepatitis C treatment.[17]

[1] Cullen et al., 2005 [-]; Fraser, 2010 [-]; Kinder, 2009 [++]; Munoz-Plaza *et al.,* 2008 [+]; Swan *et al.*, 2010 [++]; Treloar & Holt, 2008 [++]

[2] Kinder, 2009 [++]; Strauss *et al.*, 2008 [+]; Swan *et al.*, 2010 [++]

[3] Kinder, 2009 [++]; Munoz-Plaza *et al.*, 2004 [+]; Swan *et al.*, 2010 [++]

[4] Coupland *et al.*, 2009 [++]; Fraser, 2010; Swan *et al.*, 2010 [++]; Treloar *et al.,* 2010 [++]

[5] Coupland *et al.*, 2009 [++]; Lally *et al.*, 2008 [++]; Swan *et al.*, 2010 [++]

[6] Coupland *et al.*, 2009 [++]; Cullen et al., 2005 [-]; Lally *et al.*, 2008 [++]; Roy *et al.*, 2007 [++]; Swan *et al.*, 2010 [++]; Wozniak *et al.*, 2007 [++]; Wright *et al.*, 2005 [++]

[7] Faye & Irurita, 2003 [++]; Kinder, 2009 [++]; Swan *et al.*, 2010 [++]

[8] Coupland *et al.*, 2009 [++]; Munoz-Plaza *et al.,* 2008 [+]; Treloar & Holt, 2008 [++]; Swan *et al.*, 2010 [++]

[9] Faye & Irurita, 2003 [++]; Munoz-Plaza *et al.,* 2008 [+]; Swan *et al.*, 2010 [++]; Treloar & Rhodes, 2008 [NR]

[10] Dyer & Tolliday, 2009 [-]

[11] Swan *et al.*, 2010 [++]; Treloar *et al.,* 2010 [++]

[12] Cullen et al., 2005 [-]; Munoz-Plaza *et al.*, 2004 [+]; Munoz-Plaza *et al.,* 2008 [+]; Swan *et al.*, 2010 [++]

[13] Craine *et al.*, 2004 [++]; Ellard, 2007 [++]; Harris, 2009b [-]; Khaw *et al.*, 2007 [+]; Lally *et al.*, 2008 [++]; McCreaddie *et al.*, 2011 [++]; Roy *et al.*, 2007 [++]; Sosman *et al.*, 2005 [+]; Strauss *et al.*, 2008 [+]; Sutton & Treloar, 2007 [++]; Tompkins *et al.*, 2005 [++]; Treloar & Rhodes, 2008 [NR]; Wright *et al.*, 2005 [++]

[14] Carrier *et al.*, 2005 [+]; Coupland *et al.*, 2009 [++]; Faye & Irurita, 2003 [++]; Habib & Adorjany, 2003 [-]; Lally *et al.*, 2008 [++]; McCreaddie *et al.*, 2011 [++]; Munoz-Plaza et al 2004 [+]; Paterson *et al.*, 2007 [NR]; Perry *et al.*, 2003 [+]; Roy *et al.*, 2007 [++]; Strauss *et al.*, 2008 [+]; Swan *et al.*, 2010 [++]; Temple-Smith *et al.*, 2004 [+]; Treloar & Hopwood, 2004 [+]; Treloar & Rhodes, 2008 [NR]; Treloar *et al.,* 2010 [++]

[15] Fraser, 2010 [-]; Coupland *et al.*, 2009 [++]; Kinder, 2009 [++]; McCreaddie *et al.*, 2011 [++]; Munoz-Plaza *et al.*, 2004 [+]; Swan *et al.*, 2010 [++]

[16] Munoz-Plaza *et al.*, 2004 [+]; Swan *et al.*, 2010 [++]; Treloar *et al.,* 2010 [++]

[17] Munoz-Plaza *et al.*, 2004 [+]; Munoz-Plaza *et al.,* 2005a [+]; Munoz-Plaza *et al.,* 2006 [+]; Swan *et al.,* 2010 [++]

6 Discussion

The purpose of the synthesis of qualitative research was to provide a context for, and give meaning to, evidence of the effectiveness of interventions aimed at raising awareness and engaging with groups who are at an increased risk of hepatitis B and C infection.

6.1 Overview of papers

A total of 57 qualitative studies were identified for inclusion in this review, covering a range of groups at risk of or diagnosed with hepatitis B and/or C. The majority of the included studies focused on groups at risk of or diagnosed with hepatitis C, in particular IDUs. Just under a quarter of the studies were conducted with at-risk groups in the UK and Ireland, but despite this we did not identify any evidence originating from the UK regarding groups at risk of or diagnosed with hepatitis B. The vast majority of qualitative studies that examined the views and perspectives of people from countries of intermediate and high endemicity were conducted in North America, with populations of relevance to the USA and Canada.

Overall, the quality of the included studies was high. All of the included studies were peer-reviewed journal articles and had therefore been subject to critical assessment prior to inclusion in this review. Studies that were judged to be of low quality had significant reporting omissions that meant it was not possible to have confidence in their reliability. However, quality assessment was not used as a basis for excluding studies from synthesis. The usefulness of all of the included studies was considered to be adequate and the vast majority of studies reported rich, detailed and convincing findings and conclusions. It should be noted that there is currently little consensus as to what are the essential criteria for a judging a qualitative study to be of high quality (Ring *et al.,* 2010) and it is important to add that due to word restrictions in many of the journals (particularly journals that primarily focus on quantitative data) the amount of information an author is able to report may be restricted. This can explain why some of the articles did not provide information on the role of the researcher, data storage, triangulation, analysis techniques and ethics, for example, most papers provided a limited discussion of ethics, but often limited discussion to a statement that ethics approval had been granted.

6.2 Summary of findings

In order to interpret the findings from the qualitative synthesis of research we used the descriptive themes that emerged to answer each of the review questions developed according the SPICE framework.

6.2.1 Among people from high-risk groups identified to be at a high risk of hepatitis B and C infection, their close contacts, and practitioners, what are their knowledge, beliefs and practices in relation to hepatitis B and C?

Knowledge, beliefs and practices in relation to hepatitis B

Understanding and awareness of hepatitis B among people born in countries with intermediate and high endemicity may be influenced by their personal experiences and cultural background. People from migrant groups may not always recognise or understand biomedical concepts of hepatitis and liver disease described according to the Western medical model. Consequently people from high risk

groups may confuse the various forms of hepatitis and the relationship between hepatitis and HIV, and they may commonly hold less than accurate beliefs about transmission risks. A lack of, or incomplete, knowledge about hepatitis B among providers of healthcare services to people from migrant groups has also been documented and health professionals may encounter difficulties in translating medical terms associated with hepatitis B to their patients.

Among people from migrant groups, the causes of hepatitis B may commonly be considered to be socio-environmental, and people born in East and South East Asia may commonly perceive access to or contamination of food, or cultural practices associated with sharing food and communal eating as the main route of hepatitis B transmission. Although common for other forms of hepatitis, such routes are not considered to be significant sources of hepatitis B transmission. Although vertical transmission of hepatitis B was acknowledged in some studies, sexual transmission of hepatitis B was infrequently mentioned; overall, the evidence suggests that groups at a high risk of infection do not perceive hepatitis B as an STI.

Similarly to their beliefs about the causes and prevention of hepatitis B, people from high risk groups may express beliefs about prevention that are strongly influenced by their personal experiences and cultural background. Among people born in East and South East Asia, prevention strategies may commonly reflect the practice of traditional medicine with an emphasis on living a balanced life, strengthening the body's nature defences, and modifying individual health behaviours. Vaccination may not generally be considered as a primary means of hepatitis B prevention among groups at a high risk of infection. Despite generally positive attitudes towards vaccination, some studies indicated that there is significant confusion and uncertainty surrounding the purpose of vaccination among these groups. Among people from migrant groups, traditional medicine (CAM) was widely advocated as a way of preventing or treating the early stages of hepatitis B. Religious influences on preventive health strategies may also be apparent, for example in one study, males perceived that following the concepts of the Islamic doctrine reduced their risk of infection.

Knowledge, beliefs and practices in relation to hepatitis C

There was evidence that IDUs have an uncertain and impartial knowledge of hepatitis C in terms of what the disease is, how it differs from other forms of hepatitis, how the infection is transmitted and what symptoms are involved. IDUs commonly have an incomplete and confused understanding of hepatitis C, are unaware of the symptoms of hepatitis C infection and demonstrate a lack of knowledge and confusion over the transmission of hepatitis C. There is evidence that some IDUs are reflexive about their quality of knowledge and are aware about their limited and partial understandings of hepatitis C, however such awareness is found to be anxiety provoking. Knowledge and understanding of hepatitis C is frequently learnt in relation to HIV and consequently IDUs may hold a number of incorrect or misinformed beliefs about hepatitis C and perceive it to be of minimal concern. A common theme within the research was the social acceptance of hepatitis C among IDUs. IDUs perceive themselves as never being completely safe from, or in control of hepatitis C transmission despite intentions to reduce risk of transmission. However, there are exceptions to the social acceptance of hepatitis C. Some IDUs may reject the notion of hepatitis C as expected and unavoidable, suggesting that there is a disjuncture in the normalisation discourse. IDUs that are more integrated in mainstream society are more aware of the significance of hepatitis C than those who are integrated in IDU networks. Studies showed that safe and responsible injecting practices are employed by IDUs to avoid the transmission of hepatitis C. However, despite deliberate intentions to

minimise the risk of hepatitis C transmission through safe injecting practices, the consistent employment of such strategies is difficult. A number of barriers have been identified that may prohibit safe injecting practices including restricted access to needles and syringes at specific times, the prison setting, trusting injecting relations, withdrawal and more chaotic and uncontrolled drug use, homelessness, policing and gender.

6.2.2 What are the views, experiences and attitudes of people from high-risk groups of case finding and testing and communication of test results for hepatitis B and C infection?

Case finding and testing, and communication of test results

Evidence suggests that people born in countries with an intermediate or high endemicity for hepatitis B may express a general motivation for testing and keenness to raise awareness of hepatitis B testing among friends and family. However, one study found that among people with a diagnosis of chronic hepatitis B infection testing had frequently occurred without their explicit consent being given and that they commonly lacked adequate information about their diagnosis. This lack of information in conjunction with a lack of understanding of hepatitis B meant that some participants were 'shocked' by their diagnosis leading to confusion and fear for the future.

There was evidence that IDUs may actively seek hepatitis C testing due to concerns that they have contracted hepatitis C through injecting behaviour and the belief that hepatitis C is expected when injecting drugs. However, whether testing is proactively sought was shown to be influenced by the nature of drug use and the extent to which IDUs were engaged with mainstream society. IDUs whose drug use was more controlled took steps to get tested, and integration in mainstream society and disengaging from IDU communities was found to encourage testing. Despite evidence of hepatitis C as socially accepted among IDUs, being diagnosed as hepatitis C positive can cause anxiety, shock and depression. In addition, although the routine or unexpected nature of hepatitis C testing may be perceived to encourage opportunistic testing, learning of a positive diagnosis unexpectedly may exacerbate anxiety and confusion among IDUs. Evidence suggest that IDUs may be anxious and concerned over the impact of a positive diagnosis on their chances of finding a long term partner, sexual relations, starting a family and the possibility of transmitting hepatitis C. However, other reactions to a positive diagnosis include being unaware or indifferent, and commonly, denial. Studies have shown that whilst some IDUs recall good testing practice, experience of being informed on the outcome of hepatitis C diagnosis is generally, highly confusing. Evidence indicated that many IDUs may be confused over the meaning of diagnosis and that they may receive limited or inadequate information provision by health professionals, leading to substantial gaps in knowledge. Such confusion may be reinforced when hepatitis C testing is routine or unexpected. There was conflicting evidence as to whether an awareness of hepatitis C status can lead to behaviour change. A common change in behaviour resulting from a positive hepatitis C diagnosis is adopting a healthier lifestyle, such as eating more healthily and reducing alcohol and drug use. However, alcohol and drug use may also be used as a means of coping with a positive diagnosis. Studies showed that some IDUs perceive disclosing a positive hepatitis C diagnosis to others to avoid transmission as responsible and an obligation, and there was evidence that hepatitis C positive IDUs take care to prevent hepatitis C transmission. However, testing positive for hepatitis C was also shown to reinforce existing risk behaviour and one UK study (Craine *et al.,* 2004) found limited evidence of a direct reduction in risk

behaviour. Testing negative for hepatitis C was also shown to reinforce engagement in risky behaviour, as some IDUs may assume a 'natural' immunity to hepatitis C and assume previous injecting practice to be safe following a negative diagnosis

Stigma

Studies showed that stigma associated with hepatitis B may restrict disclosure of an intention to seek testing and/or infection status due to fear of discrimination against the person seeking testing and their families, exclusion and parental rejection or disapproval. Evidence suggests that stigma associated with hepatitis B may generally be perceived to be less than or different to other STIs or HIV/AIDS, largely because people from migrant groups may not associate hepatitis B with sexual transmission.

Hepatitis C positive IDUs may experience stigma from other injectors, within the wider community, from health professionals and also as a result of what they perceive to be inappropriate precautions to infection in health care settings. This experience of stigma may prevent IDUs from seeking hepatitis C testing due to fear of disclosure. Stigma may also prevent disclosure of a positive hepatitis C status to others due to fear of a negative reaction, isolation and social exclusion, prevented engagement with further prevention education, investigations and treatment and resulted in IDUs receiving inadequate and judgemental health care from health professionals.

6.2.3 What are experiences of people from high-risk groups and practitioners of barriers and facilitators to case finding and testing and subsequent care and treatment?

Barriers and facilitators to case finding and testing

Evidence suggests that the primary motivating factors for testing among people at a high risk of hepatitis B infection are generally related to concerns for individual health, concern for others health, including the health of family and friends, and also the health of the wider community. Barriers to testing are frequently context specific, for example, studies conducted in North America identified financial concerns among patients and healthcare providers as a major barrier to testing. More general concerns may relate to fears or concerns about testing arising from individual and culturally influenced beliefs. The absence of clear symptoms of infection is a key barrier identified across various groups. Among some people born in East and South East Asia, for example, a reliance on visual cues as a marker for hepatitis B, such as yellow skin or eyes, potentially poses a barrier to testing given that many people with hepatitis B may not display significant symptoms during infection. Practical obstacles such as the inconvenience of seeking out testing facilities and time constraints are also barriers to taking a test. The conception of hepatitis B among people born in East and South East Asia as a 'liver' or 'blood' illness rather than an STI appears to play an important role in tempering stigma associated with hepatitis B. Van der Veen *et al.* (2009) noted that increasing awareness of hepatitis B as an STI could potentially lead to an increase in social stigma and subsequently increase the importance of stigma as a barrier to testing. Language and cultural barriers are also prominent, they may discourage some people born in countries of intermediate and high endemicity from seeking care and may limit the role that healthcare professionals play in providing education and outreach to people from migrant groups.

A number of barriers and facilitators to testing have been identified among groups at a high risk of acquiring hepatitis C infection. Based on the finding that many IDUs do not initiate testing until they experience symptoms, evidence suggests that a lack of visible symptoms of infection may prevent proactive testing. In addition, there is evidence that some IDUs may perceive themselves to be at low risk of infection and as such do not actively seek testing. Apprehension and fear of a positive test result, fear of the physical process of testing and the use of needles and fear of disclosure, a lack of privacy and confidentiality in the testing process may also act as barriers to testing. Convenient and opportunistic testing is an important facilitator of hepatitis C testing, and a 'one-stop shop' approach for all hepatitis C services is regarded as a convenient approach among IDUs, with drug treatment programme sites and methadone clinics being perceived as suitable locations for such services. Studies have shown that IDUs may also express a preference for testing to be conducted in a general practice setting as they perceive this setting as offering opportunities to raise concerns and ask questions. When IDUs are unlikely to deliberately seek testing to confirm their hepatitis C status, opportunistic testing has been shown to be an important facilitator for testing uptake. Concerns over informed consent to testing have been noted by a number of authors; IDUs are often unaware that they have been tested for hepatitis C and although this may be perceived by some IDUs and health professionals as increasing testing compliance, concerns have been raised that it restricts patient choice. Trust and rapport with health professionals and drug treatment staff, and support and encouragement, have also been shown to act as motivators for testing. Additional barriers to testing specific to the prison setting have been identified and include long waiting times, lack of information provision, prioritisation of detoxification and withdrawal, and movement between prisons.

Barriers and facilitators to subsequent care and treatment

None of the included studies examined views and experiences of treatment among people at a high risk of hepatitis B infection.

A fear of the side effects associated with hepatitis C treatment may prevent IDUs from engaging with treatment, and such fears may be exacerbated by the circulation of 'horror stories' among peers about liver biopsies and side effects of treatment. A fear of needles is common among former IDUs and the use of needles during the treatment process may pose a challenge to IDUs considering treatment. In contrast, anxiety over hepatitis C, witnessing peers suffer from symptoms of infection and hearing stories of successful treatment cases among peers may encourage treatment uptake. A preoccupation with drug use, chaotic lifestyles, long waiting times between appointments and employment can lead to IDUs missing and forgetting treatment appointments, thus increasing the possibility of treatment drop out. Adverse socio-economic and family circumstances also mean that treatment may be de-prioritised among IDUs and they may view these factors as preventing their eligibility for treatment. Evidence suggests that some IDUs regard hepatitis C treatment as inaccessible due to the perceived requirement of abstinence from alcohol and drug use; continued substance use may therefore act as a barrier to treatment. There was evidence that not experiencing symptoms and thus feeling well is a barrier to treatment as IDUs may not perceive hepatitis C as impacting on their health. Health professionals may view imprisonment as both a barrier and a facilitator for hepatitis C treatment; in one study, transportation of prisoners between prisons and length of sentence were viewed as interfering with the treatment process whereas the structured environment of prison and availability of peer support during treatment were regarded as beneficial. Receiving support from the family, partners and peers, starting family life and concerns over the

impact of hepatitis C on significant others (e.g. partners and children) can motivate IDUs to engage with treatment. A lack of opportunity to access treatment and a lack of information on treatment options have also been reported as barriers to treatment.

6.2.4 What are people from high risk groups and practitioners' views and perspectives on opportunities for changing behaviour in relation to hepatitis B and C testing and subsequent care and treatment?

Hepatitis B and C testing

Views and perspectives on opportunities for changing behaviour in relation to hepatitis B testing were not generally sought from people from high risk groups in the included studies. However, making testing obligatory was considered as a motivating factor for compliance with testing among Turkish Dutch migrants. Among health professionals serving people from Asian migrant groups, some saw traditional medicine (CAM) as an opportunity to bridge differences between traditional and Western medical practices and had prioritised the role of Asian health professionals in delivering education and outreach to these communities.

Evidence suggests that convenient and opportunistic testing is an important facilitator of hepatitis C testing among IDUs, and a 'one-stop shop' approach for all services is regarded by IDUs as a convenient approach, with drug treatment programme sites and methadone clinics being perceived as suitable locations for such services. Studies have shown that IDUs may also express a preference for testing to be conducted in a general practice setting as they perceive this setting as offering opportunities to raise concerns and ask questions. Trust and rapport between IDUs and health professionals and drug treatment staff, and support and encouragement, have also been shown to act as key motivators for testing uptake.

Subsequent care and treatment

One study showed that lack of information and knowledge at the time of diagnosis of hepatitis B infection is perceived as impacting negatively on health and may prevent opportunities for behaviour change. Both patients and community workers have expressed concerns about a lack of provider knowledge with regards to hepatitis B.

Increasing knowledge of hepatitis C through the provision of information by health professionals may encourage hepatitis C positive IDUs to consider their treatment options. However, some studies show that IDUs may have a lack of confidence in health care providers' knowledge and expertise in hepatitis C. Perceiving health care professionals to be supporting, concerned and caring, and being encouraged to undertake treatment by health professionals has been found to motivate IDUs to engage in treatment. In particular, drug treatment settings (including methadone treatment settings) have been noted as preferred sites for hepatitis C treatment due to established rapport with staff. In addition, there was evidence across a number of studies that IDUs prefer hepatitis C services, including treatment, to be situated in one setting such as drug treatment programmes and methadone substitution settings.

6.3 Contextual factors and applicability of the research evidence

Various contextual factors may influence the findings of this synthesis. However, within the time frame for the review it was not possible to systematically explore the influence of such factors on our findings. Important factors are discussed below.

The majority of chronic hepatitis B infections in England arise from the immigration of hepatitis B carriers from countries where the prevalence of hepatitis B infection is intermediate or high. People emigrating from such countries are not a homogenous group and a range of individual experiences and socio-cultural beliefs will influence their knowledge and beliefs relating to hepatitis B, and their motivation to seek testing and subsequent care and treatment. Across the included studies that examined the views and experiences of people at a high risk of hepatitis B infection, Asian American communities were most commonly the focus of these studies. As Asian Americans have been identified as the racial and ethnic group with the highest rates of chronic hepatitis B in the USA, the focus on this group was unsurprising. In a UK context, important groups at a high risk of being affected by chronic hepatitis B infection[3] include people born in South Asia, sub-Saharan African (e.g. Nigeria, Kenya), countries of the former Soviet Union and the Philippines (Pendleton & Wilson-Webb, 2007). However, none of these groups were represented in the qualitative research identified and therefore the findings of this review may have limited applicability to groups at greatest risk of becoming chronically infected with hepatitis B in the UK. A review of qualitative research that examined barriers and facilitators to the uptake of HIV testing among African communities in England (Fakoya at al., 2011) found that fear of HIV-related stigma was commonly cited as a barrier to seeking or accepting an HIV test. Low perception of personal risk for HIV infection also acted as a barrier to HIV testing, as did structural factors, differences in cultural norms and the impact of the migration process. In common with the literature identified for inclusion in this review, personal experiences and cultural practices influenced the uptake of testing services. For example, Burns *et al.* (2007) highlight that the philosophy of health promotion and preventive medicine are not well established in most African communities meaning that *"a society where you might just go to hospital feeling completely well and walk in and take an HIV test is not necessarily what people think of as standard behaviour"* (Burns *et al.,* 2007; pg. 105). This echoed the findings of this review that an absence of clear symptoms of infection represented a major barrier to hepatitis B testing among migrant populations. These findings suggest that although the findings of this review may have limited applicability, the themes identified may concur with other qualitative insights into barriers to infectious disease testing among migrant populations.

In England, as elsewhere in the UK, injecting drug use is the major risk factor for acquiring hepatitis C infection. An increase in the provision of hepatitis B vaccination in prisons has provided an important route for accessing IDUs and consequently the last decade has been a decline in its prevalence among this population. The literature identified for inclusion in this review focused on IDU's views and experiences of hepatitis C and there were relatively few studies that examined experiences related to hepatitis B infection in these populations. One fifth of the studies included in the review were conducted with IDU populations in the UK and therefore the findings of the review appear to be largely applicable to groups at an increased risk of hepatitis C infection in England. However, a number of caveats should be borne in mind in interpreting the findings of this review. As noted, IDUs

[3] Countries that were identified as contributing a high estimated number of people with chronic hepatitis B infection (>10,000) to the overall UK total.

are not a homogenous group and the included studies drew on the views and experiences of diverse populations across a range of settings and contexts. The applicability of the analytical themes arising from the thematic synthesis therefore need to be considered and verified according to the setting and context of IDU populations in England. IDU populations may differ according to the social and demographic patterns of injecting drug use in different countries, by the characteristics of their drug use and according to the availability and reach of harm reduction programmes. For example, injectors of non-opioid drugs (e.g. amphetamine, cocaine/crack) may be less likely to be in with contact services or reluctant to approach heroin-orientated services (Hartnoll *et al.,* 2010) and this has implications for the interpretation of the findings from this review; such as that drug treatment programme sites and methadone clinics were perceived as suitable locations for providing 'one-stop shop' services for hepatitis C.

6.4 Strengths and weaknesses of the review

There is the possibility that relevant literature was missed during the searches conducted for this review. However a comprehensive search protocol was prepared for the review that incorporated searching of a range of electronic sources, web-based searches and hand searching. In addition, a relatively small number of studies were identified that examined views and experiences relating to hepatitis B testing, and relevant research undertaken in the UK was not identified. However, as a range of literature sources were searched, it is unlikely that key studies were missed and we have therefore concluded that there is a lack of research regarding the views and perspectives of groups affected by hepatitis B in the UK. The literature identified was also limited in that there appear to be very few studies that have examined views and experiences relating to hepatitis B among people from African migrant groups and Asian migrant groups outside of China, Korea, Vietnam and Cambodia. There was also a lack of studies among high risk groups that explored experiences of receiving a diagnosis of hepatitis B, or perspectives on subsequent care and treatment for hepatitis B.

This review focused on the findings of qualitative research studies. A large number of quantitative research studies using closed-ended questions were excluded during the review process and these studies may potentially have provided further data on barriers and facilitators to testing among groups at a high risk of acquiring hepatitis B and/or C infection.

A particular strength of this review is that it included literature examining views and experiences along the patient pathway of care for hepatitis B and C. By drawing on literature relating to knowledge and beliefs on prevention and transmission, for example, we were able to extract themes on the socio-cultural factors that may influence people's views and experiences of illness and disease which have a direct impact on testing and treatment uptake. By focussing the review only on studies that examined hepatitis B and/or C testing we would have excluded a rich set of data.

7 Conclusions and recommendations

7.1 Conclusions

This review of qualitative research on the views, perspectives and experiences of hepatitis B and C testing among practitioners and people at greatest risk of infection identified a number of strong themes in the literature. Although the two groups of particular relevance to this review, current and former IDUs and people from migrant groups, are two very distinct groups, we identified a considerable degree of overlap and consistency in the findings and themes identified within and across the groupings that we applied to the included studies. However, because of a lack of UK studies, the findings of this review may have limited applicability to groups at greatest risk of becoming chronically infected with hepatitis B in the UK.

7.1.1 Knowledge and awareness

The evidence identified for this review suggests that people from high risk groups may hold concepts of illness and disease that differ from biomedical understandings. Consequently people from high risk groups may have an incomplete or confused understanding of the various forms of hepatitis and the relationship between hepatitis and HIV. These beliefs appear to play a key role in how people from high risk groups perceive and manage their risk of acquiring hepatitis B and C. Among people from migrant groups, the causes of hepatitis B may commonly be considered to be socio-environmental, giving rise to the perception that risk may be managed by living a balanced life, strengthening the body's nature defences, and modifying individual health behaviours rather than by seeking testing or vaccination. IDUs may perceive themselves as never being completely safe from, or in control of hepatitis C transmission and although steps may be taken to minimise risk through safe injecting practices, the consistent employment of such strategies is difficult.

7.1.2 Testing

People from high risk groups hold complex views about testing; although they may express a motivation to, or actively, seek testing this review indicates that testing may cause shock and anxiety. In particular, routine or unexpected testing, in which consent for hepatitis B and/or C testing is not explicitly sought, can exacerbate anxiety and confusion among people from high risk groups. In instances where limited or inadequate information is provided by health professionals, incomplete or confused understandings of hepatitis B and C infection can persist after testing.

This review finds that among people from migrant groups and IDUs, a lack of visible symptoms or 'feeling well' is a key barrier to testing uptake. Concerns about stigma may also discourage testing uptake due to fear of discrimination and exclusion. IDUs additionally may experience stigma from health professionals. Language and cultural barriers prevent some people from migrant groups from seeking testing and can limit the role that healthcare professionals play in providing education and outreach to migrant communities. Additional barriers to testing specific to the prison setting include long waiting times, lack of information provision, prioritisation of detoxification and withdrawal, and movement between prisons. Few studies described motivators for testing uptake among people from migrant groups, but taking personal responsibility for their individual health and for the health of others appears to be a key factor for seeking testing. Key motivators for testing among IDUs

identified in this review are convenient and opportunistic testing, and a good relationship with health professionals build on trust and rapport.

7.1.3 Subsequent care and treatment

Few studies examined views and experiences of subsequent care and treatment among people at a high risk of hepatitis B infection. Lack of information and knowledge at the time of diagnosis of hepatitis B infection is perceived as impacting negatively on health and may prevent opportunities for behaviour change.

A number of factors may serve to discourage IDUs from accessing subsequent care and treatment for hepatitis C. This review indicates that fear of treatment (relating to side effects or a fear of needles), adverse social circumstances, a perceived requirement of abstinence from alcohol and drug use, lack of opportunities to access treatment, lack of information on treatment options and structural factors such as long waiting times between appointments may limit uptake. Receiving support from family, partners and peers, starting family life and concerns over the impact of hepatitis C on significant others (e.g. partners and children), however, can motivate IDUs to engage with treatment. Similar to motivators for testing, perceiving health care professionals to be supporting, concerned and caring, and being encouraged to undertake treatment by health professionals can motivate IDUs to engage in treatment.

7.2 Recommendations for practice

The evidence identified through this review of qualitative research suggests that there are modifiable factors among groups at a high risk of acquiring hepatitis B and/or C that could be addressed through interventions that aim to encourage uptake of testing.

Appropriate interventions are required to improve knowledge and awareness of hepatitis B and C infection among high risk groups. In particular, it appears that much could be done to improve the quality and level of information available to high risk groups before and after testing. Development of intervention materials should take into consideration how biomedical information can be tailored to incorporate meaning relevant to the socio-cultural context of high risk groups, but without contributing to stigma or increasing fear and confusion. Efforts should also be extended to address knowledge and information gaps among healthcare professionals and other providers of healthcare that may be accessed by people from high risk groups (e.g. practitioners of CAM).

Due to the stigma associated with hepatitis B and C infection, interventions that aim to increase uptake of testing need to consider how the positive outcomes of testing can be exploited, for example, by promoting the benefits of taking responsibility for not only individual health, but also the health of family and friends, and the wider community.

Structural factors that discourage uptake of testing and subsequent care and treatment should be addressed by increasing opportunities for people from high risk groups to access testing and other services. In particular, convenient and opportunistic testing appears to be an important facilitator of hepatitis C testing among IDUs. Interventions should also focus on building trust and rapport between people from high risk groups and health professionals, for example by addressing cultural and linguistic barriers to care or by targeting stigmatised attitudes to particular high risk groups.

7.3 Recommendations for research

Research is lacking on the views and experiences of groups in the UK who at greatest risk of becoming chronically infected with hepatitis B. In the wider literature, there is a lack of research that has explored the views and experiences of people from high risk groups who have been diagnosed with chronic hepatitis B.

With regards to groups at a high risk of acquiring hepatitis C or becoming chronically infected with hepatitis B, research is lacking on what people from high risk groups think could be done to increase uptake of testing. There is therefore a need for research that engages with people from high risk groups to identify interventions, strategies and approaches that they consider suitable. It is imperative that views are sought from a diverse range of populations and that particular efforts are made to explore the views of migrant and vulnerable populations.

8 References

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Appendix 1. Example search strategy

Ovid MEDLINE(R) 1948 to March Week 1 2011 / Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations March 09, 2011

#	Searches	Results
1	exp Hepatitis C/	38337
2	exp Hepatitis B/	39640
3	((hepatitis or hep) adj (B or C)).ti,ab.	81496
4	(HBV or HCV).ti,ab.	46381
5	or/1-4	101579
6	qualitative research/	10161
7	interview/	21650
8	Focus Groups/	11237
9	Interviews as Topic/	30225
10	Nursing Methodology Research/	13800
11	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or experience$).ti,ab.	803326
12	(life adj3 (history or stor$)).ti,ab.	8151
13	(verbal interaction$ or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab.	14439
14	((discourse or discurs$ or narrative) adj3 analys?s).ti,ab.	1333
15	exp Attitude to Health/	234519
16	attitude/	35660
17	"Attitude of Health Personnel"/	77670
18	(attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or incentive$ or reason$).ti,ab.	651089
19	or/6-18	1539705
20	Substance Abuse, Intravenous/	10549
21	Drug users/	406
22	((substance$1 or drug$1 or stimulant$) adj3 (abuse or misuse or dependen$ or use$2 or usage or addict$ or inject$ or intravenous$)).ti,ab.	150084
23	((opiod$ or morphine or heroin or opiate or cocaine or steroid$ or PIED$ or (performance adj3 enhancing) or methadone) adj3 (abuse or misuse or dependen$ or use$2 or usage or addict$ or inject$ or intravenous$)).ti,ab.	39822
24	Heroin Dependence/	7216
25	Morphine Dependence/	2903
26	Substance-Related Disorders/	67850
27	Street Drugs/	6288
28	Opioid-Related Disorders/	6566
29	Cocaine-Related Disorders/	4893
30	Anabolic agents/	5109
31	Needle sharing/	1144
32	((needle$ or syringe$ or inject$ or paraphernalia or equipment) adj3 (behaviour$ or behavior$ or practic$ or pattern$ or sharing or share$1 or reusing or reuse$ or abuse$ or abusing or misus$ or exchange$ or suppl$ or provide$ or distrib$ or provision or access$ or dispens$ or sharer$1)).ti,ab.	12350
33	Needle-Exchange Programs/	1105

34	(NSP or NEP or NSEP or NSPs or NEPs or NSEPs).ti,ab.	3106
35	((needle$ or syringe$ or inject$ or paraphernalia or equipment) adj3 (program$ or service$ or centre$ or scheme$ or center$ or site$1 or facilities or facility or scheme$ or area$ or pharmacy or pharmacies or unit or units or steril$ or equipment or bleach$ or disinfectant$ or disinfect$1 or citric acid$)).ti,ab.	66358
36	((drug$ or crack) adj3 (den or dens or house$)).ti,ab.	487
37	shooting galler$.ti,ab.	137
38	"Emigration and Immigration"/	21229
39	"Emigrants and Immigrants"/	2609
40	"Transients and Migrants"/	7149
41	refugees/	5724
42	(immigrant$ or migrant$ or asylum or refugee$ or undocumented).ti,ab.	25742
43	Vulnerable populations/	3861
44	((hard$ adj2 reach) or (hard$ adj2 locate) or (hard$ adj2 find) or (hard$ adj2 treat) or (difficult adj2 locate) or (difficult adj2 engage) or (difficult$ adj2 reach) or (difficult$ adj2 find) or (difficult$ adj2 treat)).ti,ab.	8803
45	((vulnerable or disadvantaged or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient$ or inaccessible or underserved or inequitable or low$ or poor$ or at risk or high risk) adj4 (people or population$ or communit$ or neighbourhood$ or neighborhood$ or group$ or area or areas or demograph$ or patient$ or social$ or socio economic$ or socioeconomic$ or status$ or education$ or societ$)).ti,ab.	411927
46	patient satisfaction/	46455
47	"patient acceptance of health care"/ or patient compliance/ or treatment refusal/	71888
48	health services accessibility/	39198
49	Access to Information/	2426
50	health education/ or consumer health information/ or patient education as topic/ or sex education/	113498
51	Health Promotion/	40767
52	Preventive Health Services/ or Community Health Services/	32808
53	exp Sexual Behavior/	66030
54	risk reduction behavior/ or risk-taking/	18468
55	(health$ adj3 (educat$ or aware$ or opportunit$ or attitude$ or access$ or inform$ or promot$ or prevent$ or behavio?r$)).ti,ab.	109057
56	(sex$ adj2 (behavio?r$ or educat$)).ti,ab.	23891
57	(risk$ adj3 (taking or factor$ or behavio?r$ or educat$ or reduc$)).ti,ab.	325749
58	(patient$ adj3 (satisfaction or educat$ or behavio?r$ or compliance or comply or complie$)).ti,ab.	57098
59	"Marketing of Health Services"/	13210
60	social marketing/	1470
61	(marketing or advertis$ or publicis$ or publiciz$).ti,ab.	23432
62	exp Culture/	93159
63	Language/ or linguistics/ or communication barriers/	28677
64	(culture$ or cultural$).ti,ab.	709704
65	((language$ or linguistic$ or communicat$) adj3 problem$).ti,ab.	2946
66	(illiteracy or illiterate$).ti,ab.	2828
67	Politics/ or Public Policy/ or Health Policy/	95397
68	exp Social Behavior/	129574

69	prejudice/ or psychosocial deprivation/ or social values/	37101
70	Socioeconomic Factors/	89383
71	social class/	26385
72	exp poverty/	24361
73	"Discrimination (Psychology)"/	13632
74	(prejudice or discriminat$ or "social value$" or poverty or depriv$).ti,ab.	181466
75	(social$ adj1 (inclusion or include$ or exclude$ or exclusion)).ti,ab.	1230
76	shame/	1269
77	(stigma$ or shame$).ti,ab.	14644
78	Motivation/	41398
79	(barrier$ or facilitat$ or hinder$ or block$ or obstacle$ or restrict$ or restrain$ or obstruct$ or inhibit$ or impede$ or delay$ or constrain$ or hindrance).ti,ab.	2681630
80	or/20-79	4783448
81	5 and 19 and 80	4366
82	animals/ not humans/	3464943
83	81 not 82	4336
84	limit 83 to yr="1990 -Current"	4152

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Non-systematic review/Commentary (n=6)

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Appendix 4. References to studies not available in the time frame for the review

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Appendix 5. Data extraction tables

Table 5. Summary of study characteristics: Hepatitis B

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Buck et al., 2006 Title: Hepatitis B Vaccination in Prison: The Perspectives of Formerly Incarcerated Men Country: USA Quality score: +	Research questions: Assessed inmates' knowledge, attitudes, and perceptions of HBV and of HBV testing and vaccination to examine how the perspectives relate to potential vaccination programmes for males with a history of incarceration. Theoretical approach: Not reported Data collection: Biological sub-study (collection of biological specimens), semi structured interviews	Source: Incarcerated males scheduled for release from state prisons in California, Mississippi, Rhode Island, and Wisconsin; mean 24 years (SD 3 years); 59% African American, 27% Caucasian; 10% Hispanic; 3% other; mean 3 years of imprisonment (SD 3 years). Recruitment: Males due to be released within 30 to 60 days were identified and those who met the criteria were selected using nonbiased sampling procedures Sample size: 42 males with a history of imprisonment	Analysis: Data summaries were examined to identify primary coding categories and theme within each category and categories were recorded in a formal coding table. Data summaries were content coded and quotes were extracted (and second reviewed/coded) Key themes: Knowledge and beliefs; barriers and motivators; prevention strategies	Limitations Author: Sample included a relatively small number of participants and this may not be representative of all young males being released from state prisons. Potential reporting bias to illegal and stigmatising behaviour. Reviewer: Context not clearly described; some lack of detail and context regarding data meaning that richness of data was inadequate. Funding: Centers for Disease Control and Prevention (CDC)

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Burke et al., 2004 Title: Honoring tradition, accepting new ways': Development of a Hepatitis B control intervention for Vietnamese immigrants Country: USA Quality score: ++	Research questions: To identify cultural factors influencing hepatitis B knowledge, including knowledge of one's own status, understanding of transmission, and barriers and facilitators to testing. Theoretical approach: Not reported Data collection: 25 open-ended interviews and six focus groups. Conducted in Vietnamese by bilingual research assistants. Taped interviews and focus groups were transcribed in Vietnamese and transcripts were then translated into English for coding and analysis.	Source: Vietnamese-Americans living in the Seattle area; born in Vietnam; mean 53 years (21-74 years); mean length of time in USA 7 years (1-26 years); mean education level 8 years (1-16 years); self-reported English proficiency ranged from none (14%) to fair/good (53%). Recruitment: Convenience sample recruited through community sites. Sample size: 47 participants	Analysis: Thematic analysis. Iterative data review, multiple coders, and 'member checking' Key themes: Knowledge and beliefs; CAM	Limitations Author: Pilot intervention ongoing therefore the author is unable to report on results. Small sample size. Reviewer: None identified Funding: National Cancer Institute
Burke et al., 2011 Title: Chumnguh Thleum: Understanding liver illness and hepatitis B Among Cambodian immigrants Country: USA Quality score: +	Research questions: To identify unanticipated concerns and understandings about hepatitis B illness, testing, and vaccination. Theoretical approach: Not reported Data collection: Eight group interviews segregated by age (20– 39 and 40–64) and gender. Interviews were conducted in English, Khmer or a mixture of both languages.	Source: Cambodian males and females from the Cambodian community in the Seattle-Tacoma metropolitan area of Washington State; born in Cambodia (90%), Vietnam/Thailand (5%) or USA (5%); aged 20-60 years; years in USA ranged from <10 (36%) to >20 (49%) English proficiency ranged from none/not good (30%) to very good/fluent (22%) Recruitment: Convenience sample recruited through community coalition members' and research assistants' social networks Sample size: 97 participants	Analysis: Iterative data review, multiple coders, and ''member checking''. Key themes: Knowledge and beliefs, CAM	Limitations Author: Due to the sample, the results are not generalisable. Reviewer: Focus on intervention development meant that a lack of detail may have been present in the data. Funding: Not stated

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Chang et al., 2008 Title: Attitudes toward hepatitis B and liver cancer prevention among Chinese Americans in the San Francisco Bay Area, California Country: USA Quality score: ++	Research questions: To identify motivations for and deterrents from taking preventive action against chronic hepatitis B and liver cancer. Theoretical approach: Not reported Data collection: Six focus groups separated according to language (Cantonese, Mandarin, or English) and gender (male or female).	Source: Chinese or Chinese-American adults without a family history of liver cancer or other liver disease from the San Francisco Bay Area; aged 18 to 74 years; born in China (78%), Hong Kong (13%), Indonesia/Taiwan/Vietnam (7%), USA (2%); years lived in USA ranged from <4 (18%) to >20 (15%). Recruitment: In person by bilingual interviewers and through bilingual flyers posted at community sites. Sample size: 47 participants	Analysis: Three steps, content analysis, coding of data and verification of findings. Key themes: Barriers and facilitators to testing	Limitations Author: Participants were self selected volunteers and are not a representative sample. There were socioeconomic differences which may be attributed to the incentive provided for participating. Some viewpoints may have been more reflective of a traditional Chinese culture, rather than a Chinese American culture. Coding and data analysis of the focus group transcripts were based on subjective decisions and interpretations may be influenced by the researcher's preconceptions. Focus groups provide a limited view of beliefs and practices and do not offer a broad assessment of cultural context. Reviewer: None identified. Funding: Stanford Comprehensive Cancer Center

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Chen et al., 2006 Title: Lay beliefs about hepatitis among North American Chinese: Implications for hepatitis prevention Country: USA Quality score: ++	Research questions: To learn about the hepatitis prevention behaviour of relatively unacculturated North American Chinese adults, along with their knowledge, beliefs, and perceptions with regard to hepatitis, screening, and vaccination. Theoretical approach: Not reported Data collection: Semi-structured, in-depth interviews. Interviews were conducted in Mandarin or Cantonese and translated into English.	Source: North American Chinese, aged 19–62 years, who spoke Cantonese, Mandarin, or English; born in China (45%), Hong Kong (35%) and Taiwan (20%); years in USA ranged from <5 (35%) to >10 (38%); English proficiency ranged from none/poor (33%) to good/fluent (30%). Recruitment: Recruited by Chinese-speaking staff members of local community health clinics and service organizations through their social networks in neighbourhoods with a high proportion of Chinese immigrants in Seattle and Vancouver Sample size: 40 participants	Analysis: Transcripts were coded and analysed using open coding, axial coding, and constant comparative methods. Key themes: Knowledge and beliefs; barriers to testing	Limitations Author: the conclusions cannot be generalised because a high proportion of participants were highly educated and results may not be applicable to a less educated population. The study identifies a broad range of cultural factors; therefore no conclusions can be made regarding alternate hypotheses. Reviewer: None identified Funding: National Cancer Institute
Choe et al., 2005 Title: Hepatitis B and liver cancer beliefs among Korean immigrants in Western Washington Country: USA Quality score: ++	Research questions: To elicit information about hepatitis B and liver cancer beliefs and behaviour according to the linguistic and cultural framework of the target population Theoretical approach: Not reported Data collection: semi-structured interviews. Interviews began with open-ended questions, which were followed by directed probes to elicit further details about particular responses. Interviews were conducted in Korean and translated into English. Two focus groups were conducted to clarify several themes and concepts that emerged in preliminary interview analysis.	Source: First-generation Korean immigrants aged 18 to 64 years; median years in the USA ranged from 4-36; 58% reported poor/fair English Recruitment: Individuals identified by churches and community-based organisations that provided social services to Korean immigrants in western Washington. Sample size: 30 interview participants and 18 focus group participants	Analysis: Content codes were used to thematically group together similar interview text. Key themes: Knowledge and beliefs	Limitations Author: Not reported Reviewer: None identified Funding: National Cancer Institute. Additional support through the University of Washington Biobehavioral Cancer Prevention and Control Training Program

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Hwang et al., 2009 Title: Medical care of hepatitis B among Asian American populations: Perspectives from three provider groups Country: USA Quality score: ++	Research questions: To better understand and elucidate the hepatitis B beliefs, attitudes and practice patterns of medical providers serving Asian American communities and the barriers to appropriate medical care and outreach. Theoretical approach: Grounded theory Data collection: Focus groups using a guide created for use in qualitative research in hepatitis among Korean American adapted for medical providers. Focus group sessions were conducted in English, audiotaped and transcribed. Transcripts were validated against the recordings to ensure accuracy.	Source: Physicians serving the Asian American community, stratified into three specialty groupings (primary care physicians, liver specialists and other providers) Recruitment: Purposive sample compiled from community resources Sample size: 23 participants	Analysis: Constant comparison method Key themes: Barriers to testing	Limitations Author: the study is local and has a small sample size and therefore the conclusions cannot be generalised. Reviewer: Context not clearly reported; role of 'other providers' is not clear and therefore lack insight into their experiences Funding: Gilead, Inc.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
van der Veen et al., 2009 Title: Hepatitis B screening in the Turkish-Dutch population in Rotterdam, the Netherlands; qualitative assessment of socio-cultural determinants Country: The Netherlands Quality score: ++	Research questions: To investigate behavioural and socio-cultural determinants associated with hepatitis B screening in the Turkish population in the Netherlands Theoretical approach: Not reported Data collection: Seven single sex group discussions (first generation migrants who emigrated before the age of 21, or emigrated at or after the age of 21). Discussions were led by male and female Turkish discussion leaders in Dutch or Turkish using a guide.	Source: First and second generation Turkish migrants; aged 17-76 years; 33% emigrated before age 21; 26% emigrated at or after age 21; 22% born in the Netherlands, having at least one parent born in Turkey. Recruitment: Assisted by a local umbrella organisation for Islamic organisations. Sample size: 54 participants	Analysis: Producing verbatim transcriptions, clarifying the transcripts by discussion, giving thematic labels to relevant sections, and summarizing the information Key themes: Knowledge and beliefs; stigma; barriers and facilitators to testing;	Limitations Author: The focus groups may present a picture of what is perceived as socially acceptable in a community, rather than what is happening in the community. Recruitment was carried out by an Islamic organisation and may have caused selection bias. Results are not representative of the whole community due to differences between group (demographics and education levels). Focus groups were not all conducted by the same researcher, group 2 focus groups were led by a Dutch researcher and all other groups were led by Turkish discussion leaders, this may have influenced level of openness and social desirability. Due to capacity Dutch transcripts of the Turkish discussions were not back-translated which may have caused translation related bias. Reviewer: None identified Funding: ZonMW, organisation for health research and development.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Wallace et al., 2011 Title: Managing chronic hepatitis B: A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia Country: Australia Quality score: ++	Research questions: To identify how people with chronic hepatitis B respond to their infection. Theoretical approach: Grounded theory Data collection: Face-to-face semi-structured interviews, guided by a pilot tested interview schedule. All but one interview was conducted in English. Four focus group discussions informed by the outcomes from interviews with individuals.	Source: People with chronic hepatitis B and health and community workers. Interview participants were born in Vietnam (n=6), China (n=5), Cambodia (n=3), Afghanistan (n=2), Australia (n=1), North America (n=1), Greece (n=1) and Turkey (n=1). Majority diagnosed in Australia, time since diagnosis ranged from 20 years to 6 weeks. Recruitment: Purposive sampling through various community sites and professional networks. Sample size: 20 interviews participants; 40 staff and volunteers of non-government organisations providing health and social support services to the communities most at risk of chronic hepatitis B infection participated in the focus groups.	Analysis: Conducted using grounded theory by organising data into codes from which main themes were identified as interviews progressed. Key themes: Impact of diagnosis; knowledge and beliefs; stigma	Limitations Author: Due to sampling limitations, the findings have limited generalisability (the limitations are not reported) Reviewer: None identified Funding: Bristol Myers Squibb

Table 6. Summary of study characteristics: Hepatitis C

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Astone et al., 2005 Title: Providing Support to Drug Users infected with Hepatitis C: The role of methadone maintenance treatment staff Country: USA Quality score: +	Research questions: To identify reasons for clients' lack of hepatitis C service utilization and staff strategies that influence clients' perceptions of support in using these services. Theoretical approach: Not reported Data collection: Interviews and focus groups	Source: Four methadone maintenance treatment programmes in Texas, Washington, Arizona and New York Recruitment: A main contact person worked at each programme to recruit participants Sample: 49 participants (58% male, 42% female)	Analysis: Transcripts analysed for emerging themes in ATLASti. Key themes: Stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Findings are not representative of the views of clients at all methadone maintenance treatment programmes. Participants may have provided socially desirable answers. Reviewer: Little justification for theoretical approach provided; reliability and rigour of analysis difficult to judge. Funding: National Institute on Drug Abuse
Brener & Treloar, 2009 Title: Alcohol and other drug treatment experiences of hepatitis C positive and negative clients: Implications for hepatitis C Country: Australia Quality score: +	Research questions: To assess whether hepatitis C positive clients perceive that alcohol and other drugs staff discriminate against them. Theoretical approach: Not reported Data collection: Survey conducted with open- and closed-ended questions.	Source: Drug and alcohol treatment clients with and without hepatitis C Recruitment: Recruited through health care sites that catered to a large number of hepatitis C positive clients. Sample: 240 participants. 68 of the hepatitis C positive participants were male and 52 were female, mean age 38 years. 69 of the hepatitis C negative participants were male and 51 female, mean age 39 years. Hepatitis C negative participants had a higher level of education and were more likely to be employed than hepatitis C positive participants.	Analysis: Not reported Key themes: Stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: attitudes of participants towards their health care providers may have been influenced by the context in which they were collected (at the treatment facility). Findings may not be representative of other areas. Reviewer: Rationale not clear for qualitative approach; lack of reporting of study and data collection methods Funding: Lead author funded by a NHMR postgraduate scholarship.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Carrier et al., 2005 Title: Exploring the contingent reality of biomedicine: Injecting drug users, hepatitis C virus and risk. Country: Canada. Quality score: +	Research questions: To understand IDUs motives for willingness or refusal to participate in possible hepatitis C vaccine trials Theoretical approach: Not reported Data collection: interviews and observations	Source: Interviewees selected from prospective study cohort of active IDUs Recruitment: via drug services (a needle exchange facility and a drop-in resource), on the streets and in public parks Sample: 36 participants (27 males and 9 females)	Analysis: All interviews were recorded and transcribed to identify emerging themes Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; Incomplete and uncertain knowledge of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: Theoretical approach clear but lack of detail available to determine rigour and reliability of methods Funding: Not reported
Copeland, 2004 Title: The drug user's identity and how it relates to being hepatitis C antibody positive: a qualitative study. Country: Australia. Quality score: ++	Research questions: To examine how IDUs construct their identity and their knowledge and feelings about their hepatitis C status. Theoretical approach: Grounded theory Data collection: Semi-structured interviews	Source: Current or past IDUs with a hepatitis C antibody positive test attending the Muirhouse Medical Practice Recruitment: A purposive sampling was used by accessing the Edinburgh Drug Addiction Study (ongoing cohort study, for clients who have injected) Sample: 16 participants. 9 were male and 7 female. Mean age for males 36 years. Mean age for females 41 years. All	Analysis: A mix of categorised, content and narrative analysis was used in order to analyse the data. Key themes: Hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to Diagnosis; the impact of hepatitis C testing on behaviour.	Limitations Author: Findings cannot be generalised due to focus on current/past IDUs with hepatitis C from a socially disadvantaged general practice population. Reviewer: None identified. Funding: Lothian Primary Care NHS Trust.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Coupland et al., 2009 Title: Promoting equitable access to hepatitis C treatment for Indo-Chinese IDUs. Country: Australia. Quality score: ++	Research questions: To explore barriers to treatment uptake among a culturally diverse groups of IDUs. Theoretical approach: Grounded theory. Data collection: Interviews conducted before and after participants received a brief intervention about hepatitis C treatment and an offer of facilitated referral to a tertiary liver clinic. Interviews were conducted in English.	Source: Current IDUs with Cambodian, Lao or Vietnamese cultural backgrounds (parents born in these countries), aged 18 years or over. Recruitment: Recruited through fieldwork contacts, street and social networks using a targeted sampling frame. Sample. 23 participants. 5 were Cambodian, 8 Lao and 10 Vietnamese. Median age 28 years. 6 female, 18 male. 22 were unemployed.	Analysis: Data analysis was inductive. Field notes and interview transcripts were analysed using a grounded theory approach, also known as the constant comparative method. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normalised, ubiquitous and socially accepted among IDUs; a relative understanding of hepatitis C among IDUs; incomplete and limited hepatitis C knowledge; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barrier and facilitators to subsequent care and treatment.	Limitations Author: Small sample size, difficulties recruiting Cambodian and female participants. Reviewer: None identified Funding: Authors were supported by the National Health and Medical Research Council (NHMRC) Public Health Postgraduate Scholarship, an NHMRC Postdoctoral Research Fellowship a NHMRC Senior Research Fellowship.
Craine et al., 2004 Title: Hepatitis C testing and injecting risk behaviour: the results of a UK based pilot study. Country: UK Quality score: ++	Research questions: To investigate the impact of testing IDUs for hepatitis C on injecting risk behaviour. Theoretical approach: Not reported Data collection: Semi structured interviews, focus groups	Source: IDUs in contact with treatment services (from three population groups – hepatitis C positive test, hepatitis C negative test and never tested) Recruitment: via the drug treatment programmes Sample: 43 IDUs, 24 had been tested for hepatitis C	Analysis: Data analysed using inductive framework approach. Focus on 'emergent' data. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; Stigma as a barrier to disclosure and hepatitis C services	Limitations Author: the interviews and analysis were undertaken by one individual therefore the study may have been exposed to unintentional bias. Reviewer: Details lacking to verify the 'trustiworthiness' of the study Funding: funded by UK Department of Health.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Cullen et al., 2005 Title: Experience of hepatitis C among current or former heroin users attending general practice. Country: Ireland. Quality score: -	Research questions: To document existing knowledge among current or former heroin users attending general practice regarding hepatitis C infection, and to describe their experience of the infection, related diagnostic and therapeutic interventions. Theoretical approach: Not reported Data collection: Semi-structured questionnaire.	Source: Current and past heroin users attending a general practice. Recruitment: Patients presenting to the practice over a six-week period were invited to participate. Sample: 25 participants (56% male). Mean age 32 years. 88% (n=22) were hepatitis C positive.	Analysis: A category code was applied to each section of meaningful text, appropriate indexing used to identify common themes, and the process repeated by two researchers independently. Key themes: Experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; barrier and facilitators to subsequent care and treatment.	Limitations Author: findings cannot be generalised for all heroin users or general practices in Ireland. The sample may have included patients with a drug problem not known to the practice and self reported behaviour may have underestimated some activities. The patients receiving methadone maintenance had all been assessed at a specialist addiction treatment service and therefore had been exposed to health promotion messages. Reviewer: Shortness of transcript meant that full appraisal of reliability and rigour of methods was not possible. Funding: Support from HRB (Research Project Grant and Summer Student Research Grant), ICGP (Research and Education Foundation) and the South Western Area Health Board ('HIV in Primary Care Research Project').

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Davis & Rhodes, 2004 Title: Beyond prevention? IDU narratives about hepatitis C Country: UK Quality score:++	Research questions: To explore how younger injectors spoke about hepatitis C risk reduction. Theoretical approach: Not reported Data collection: Interviews	Source: People who had injected drugs in the previous 4 weeks. Recruitment: Combination of drug user networks, community-based drug services and snowballing. Sample size: 59 participants. 40 were male and 19 female. Mean age 29.8 years. 19 were hepatitis C positive.	Analysis: Analysis was interpretive. Interviews were transcribed and content and themes were identified in a process of exploring regularity and disjunction of the various personal experience narratives, catalogued in NVIVO Key themes: Hepatitis C as normal, ubiquitous and socially accepted; Incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs.	Limitations Author: Not reported Reviewer: None identified Funding: supported by the Policy Research Programme of the Department of Health
Davis et al., 2004 Title: Preventing hepatitis C: 'Common sense', 'the bug' and other perspectives from the risk narratives of people who inject drugs. Country: UK Quality score: ++	Research questions: to address the prevention of hepatitis C using interviews with people who inject drugs Theoretical approach: Not reported Data collection: Interviews.	Source: People who had injected drugs in the previous 4 weeks. Recruitment: Combination of drug user networks, community-based drug services and snowballing. Sample: 59 participants. 40 were male and 19 female. Mean age 29.8 years. 19 were hepatitis C positive.	Analysis: All interviews were transcribed and the content catalogued using computer software and based on a framework of themes generated from the interviews. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services	Limitations Author: Not reported Reviewer: None identified Funding: supported by the Policy Research Programme of the Department of Health.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Dyer & Tolliday, 2009 Title: Hepatitis C education and support in Australian prisons: preliminary findings of a nationwide survey. Country: Australia. Quality score: -	Research questions: to explore the efficiency of hepatitis C education and support services available in custodial settings, from the perspective of health educators and policy makers. Theoretical approach: Not reported Data collection: Semi structured telephone interviews	Source: Personnel who held positions of responsibility for hepatitis C prevention and/or treatment in custodial settings. Recruitment: snowballing (every state and territory in Australia) Sample: 37 participants (18 females and five men)	Analysis: Thematic analysis Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; barriers and facilitators to testing; barrier and facilitators to subsequent care and treatment.	Limitations Author: Not reported Reviewer: Rationale and justification for qualitative approach not clear Funding: Not reported
Ellard, 2007 Title: 'There is no profile it is just everyone': The challenge of targeting hepatitis C education and prevention messages to the diversity of current and future IDUs. Country: Australia. Quality score: ++	Research questions: To investigate drug use, knowledge of hepatitis C, and risk minimisation amongst participants of the Sydney inner city dance party/club scene. Theoretical approach: Not reported Data collection: Semi structured interviews	Source: Individuals from the dance/party scene. Recruitment: advertisements in free community newspapers distributed via cafes, clubs and bookshops, flyers distributed in dance clubs and through snowballing. Sample: 31 participants (age 20 to 39). 13 IDUs	Analysis: Interviews were transcribed and used to identify patterns, inconsistencies and themes. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; stigma as a barrier to disclosure and hepatitis C services	Limitations Author: Findings cannot be generalised to the dance/party scene that the participants were recruited from or the wider community. Reviewer: None identified Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Faye & Irurita, 2003 Title: Balancing perspective: the response to feelings of being condemned with the hepatitis C virus. Country: Australia. Quality score: ++	Research questions: to explore the social and psychological processes, interactions, and perceptions of individuals in Western Australia with hepatitis C. Theoretical approach: Grounded theory Data collection: Interviews	Source: Clients and staff working in the substance use field Recruitment: Media promotion Sample: 85 participants, 38 were hepatitis C positive (Age 21 to 73). IDUs included in the sample but numbers not specified.	Analysis: Constant comparative analysis Key themes: Hepatitis C as normal, ubiquitous and socially accepted; Incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment.	Limitations Author: Not reported Reviewer: None identified Funding: Not reported.
Fraser, 2004 Title: 'It's your life!': injecting drug users, individual responsibility and hepatitis C prevention. Country: Australia. Quality score: +	Research questions: Examines interview data gathered from injecting drug users, to consider the ways in which the notion of individual responsibility functions within them Theoretical approach: Not reported Data collection: In-depth, semi-structured interviews	Source: Current or ex-injecting drug users Recruitment: NA Sample: 30 participants; 15 male and 15 female	Analysis: Not reported, analysed for dominant themes Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; incomplete and uncertain knowledge of hepatitis C among IDUs; barriers and facilitators to testing; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: Lack of details available regarding rigour and reliability of methods. Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Fraser & Treloar, 2006 Title: 'Spoiled identity' in hepatitis c infection: the binary logic of despair. Country: Australia. Quality score:++	Research questions: To look at one response to diagnosis with hepatitis C: a sense of despair and absolute contamination, leading to a belief that contraction of other blood-borne viruses is of no consequence Theoretical approach: Not reported Data collection: Semi-structured interviews.	Source: Not clear Recruitment: An advertisement was inserted in an issue of the quarterly publication of the Hepatitis C Review. A mail out in Sydney. Flyers were left on waiting rooms at a GP practice. GPs and NSP staff could also make referrals. Sample: 85 participants, 38 of which were hepatitis C positive. IDUs included in the sample but numbers not specified.	Analysis: Transcripts were coded by individual researchers. Codes were entered into the qualitative data-analysis programme NVivo Key themes: Barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services	Limitations Author: Not reported Reviewer: None identified Funding: funded by the National Health and Medical Research Council of Australia.
Fraser, 2010 Title: Hepatitis C and the limits of medicalisation and biological citizenship for people who inject drugs. Country: Australia. Quality score: -	Research questions: To explore complexities of individual reactions to the injunction to care for the health via continuous self-education and medical engagement, and to look at the dynamics of change in these reactions. Theoretical approach: Not reported Data collection: Interviews and analysis of health promotion documents.	Source: Individuals with hepatitis C living in Melbourne, Australia. Recruitment: via services including Hepatitis C Victoria, VIVAIDS, and the primary health services Next Door and Health Works. Flyers advertising the study were supplied to these services, and an advertisement was also used in Hepatitis C Victoria's magazine Sample: 30 individuals with hepatitis C.	Analysis: Interviews were transcribed verbatim and then coded using NVivo. Key themes: Incomplete and uncertain knowledge of hepatitis C among IDUs; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment.	Limitations Author: Not reported Reviewer: Structure of article made it difficult to assess the richness of the data presented. Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Gyarmathy et al., 2006 Title: Strong HIV and hepatitis disclosure norms and frequent risk behaviors among Hungarian drug injectors. Country: Hungary Quality score: +	Research questions: to assess the knowledge, risk perceptions, norms, risk behaviours, and risk networks related to HIV/HBV/ hepatitis C Theoretical approach: Not reported Data collection: Interviews	Source: IDUs Recruitment: Targeted sampling using non treatment settings (street outreach and chain referral methods) Sample: 29 IDUs aged 30 and under	Analysis: Data summaries were analysed to identify key themes. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; incomplete and uncertain knowledge of hepatitis C among IDUs; Barriers and facilitators to testing; the impact of hepatitis C testing on behaviour.	Limitations Author: Small sample size Reviewer: Poor reporting of data collection and aspects of the study design methodology; rigour and reliability is unclear and richness of data rather poor. Funding: U.S. National Institute on Drug Abuse.
Habib & Adorjany, 2003 Title: Hepatitis C and injecting drug use: The realities of stigmatisation and discrimination. Country: Australia. Quality score: -	Research questions: To examine the extent of discrimination and stigmatisation related to hepatitis C virus infection, as experienced by IDUs Theoretical approach: Not reported Data collection: Survey questionnaire with analysis of qualitative data.	Source: Clients attending NSPs across Sydney, Australia. Recruitment: Recruited directly by approaching clients at 10 NSP clinics and one methadone clinic Sample: 247 participants (141 male).	Analysis: Not reported Key themes: Stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: No justification or rationale for theoretical approach. Poor reporting of methods meant difficult to judge reliability and rigour. Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Harris, 2009a Title: Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis. Country: Australia, New Zealand. Quality score: +	Research questions: To explore the diagnosis meaning-making processes of people living with chronic hepatitis C. Theoretical approach: Bury's theory of biographical disruption along with theoretical frameworks of normalisation and disappearance. Data collection: Semi-structured in-depth interviews.	Source: People living with chronic hepatitis C in New Zealand and Australia. Recruitment: Through research notices placed in a newsletter and a magazine. Sample: 40 participants. Hepatitis C positive. 22 were female and 18 male. Median age 47 years.	Analysis: Analysed with attention to individual narrative form and structure as well as thematic commonalities and differences. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; Incomplete and uncertain knowledge of hepatitis C among IDUs; a relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis.	Limitations Author: Not reported Reviewer: Study purpose not clearly defined; reliability of methods not established. Funding Author was funded by a New Zealand Tertiary Commission Bright Futures Doctoral Scholarship.
Harris, 2009b Title: Injecting, Infection, Illness: Abjection and Hepatitis C Stigma Country: Australia and New Zealand. Quality score: -	Research questions: To explore the ways in which participants experiences interacted to inform their practices around, and understandings of living with the virus. Theoretical approach: Not reported Data collection: Semi-structured interviews and reflection on the researchers experience of injecting drugs and being hepatitis C positive	Source: People living with chronic hepatitis C Recruitment: Via hepatitis C community magazines, a hepatitis C peer support website and Narcotics Anonymous meetings Sample: 40 participants living with chronic hepatitis C. 34 were former IDUs. 22 females and 18 males aged 25 to 63.	Analysis: Analysed with attention to narrative structure for emerging themes Key themes: Stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: No justification for theoretical approach used; rigour and reliability not clear. Funding: author funded by the New Zealand Tertiary Commission Bright Futures Doctoral Scholarship.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Khaw et al., 2007 Title: 'I just keep thinking I haven't got it because I'm not yellow': A qualitative study of the factors that influence the uptake of hepatitis C testing by prisoners. Country: UK. Quality score: +	Research questions: To identify the factors that influence the uptake of testing for hepatitis C infection by prisoners. Theoretical approach: Not reported. Data collection: Semi-structured Interviews.	Source: Prisoners aged 18 years or over, who had injected drugs in the past (male and female prisons including long stay and short stay) Recruitment: Purposive sample from three prisons in Northeast England. Sample: 30 participants. 25 were male and 5 female. 21 had been tested for hepatitis C.	Analysis: Constant comparative analysis. Key themes: A relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: A potential for bias because data saturation was not reached amongst female participants - only five females were interviewed, none from long stay prisons. The presence of CARAT workers may have influenced interview content. Unable to interview prison personnel and health professionals due to resources. Reviewer: Some aspects of reporting were poor; theoretical approach not defined; trustworthiness not established. Funding: National Treatment Agency for Substance Misuse.
Kinder, 2009 Title: The Lived Experience of Treatment for Hepatitis C. Country: USA. Quality score: ++	Research questions: To explore and describe male patients' experiences of undergoing and completing treatment for the hepatitis C virus Theoretical approach: Not reported Data collection: semi-structured interviews.	Source: Individuals who had received hepatitis C treatment Recruitment: A purposeful sample was used by inviting participants who had completed treatment for hepatitis C (via a group for hepatitis C patients). Sample size: Eight hepatitis C positive males. Aged 41-60. Discusses IDU but does not specify the number of IDUs.	Analysis: The transcripts were analysed by multiple readings and theme coded Key themes: Hepatitis C as normal, ubiquitous and socially accepted; barriers and facilitators to testing; experience of testing and reactions to diagnosis; barriers and facilitators to subsequent care and treatment.	Limitations Author: Not reported Reviewer: None identified Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Lally et al.,2008 Title: A Qualitative Study Among Injection Drug Using Women in Rhode Island: Attitudes Toward Testing, Treatment, and Vaccination for Hepatitis and HIV. Country: USA Quality score: ++	Research questions: examines the barriers to and facilitators of testing for hepatitis and HIV, receiving results and treatment for those infections, and getting vaccinated for hepatitis among injection drug using females. Theoretical approach: Not reported Data collection: Semi-structured interviews.	Source: Drug treatment centre in Rhode Island Recruitment: Invited females attending the drug treatment centre to participate Sample: 20 female IDUs in drug treatment	Analysis: Transcripts were coded and key themes identified. Key themes: hepatitis C as normal, ubiquitous and socially accepted; barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment.	Limitations Author: although sample size was consistent with qualitative research, it is small and the findings cannot be generalised to female IDUs who are not in treatment. The study does not allow for stratification by participant characteristics. The participants were recruited from a detoxification centre therefore they may have had a higher baseline knowledge of hepatitis and may have been more willing to accept treatment, than IDUs not in treatment with no prior knowledge. Participants may have potentially given socially desirable answers. Reviewer: None identified Funding: National Institute on Drug Abuse and the Ittleson Foundation.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
McCreaddie et al., 2011 Title: The isolating and insulating effects of hepatitis C. Country: UK. Quality score: ++	Research questions: To review patients' and service providers' perspectives on hepatitis C as an enduring condition. Theoretical approach: Grounded theory. Data collection: Semi-structured interviews, three focus groups of providers, and memos.	Source: Hepatitis C patients not currently on treatment with one or more comorbidities; staff working with hepatitis C -infected comorbid patients in various settings. Recruitment: Purposive theoretical sampling from hospital and community sites. Sample: 16 patients. 4 were female and 12 male. 13 contracted hepatitis C through IDU. 11 were unemployed. Age range 34- 61. 17 providers.	Analysis: Constant comparative approach. Key themes: Stigma as a barrier to disclosure and hepatitis C services; experience of testing and reactions to diagnosis; barriers and facilitators to subsequent care and treatment.	Limitations Author: findings cannot be generalised because study was carried out in a particular health board are in Scotland. Only patients who were in contact with services were interviewed (and didn't reach individuals not in treatment). Focus groups may have attracted motivated staff. Reviewer: None identified Funding: Centre for Integrated Health Care, Edinburgh, Pump Priming Grants.
Munoz-Plaza et al., 2004 Title: Drug treatment programmes as sites of opportunity for the delivery if hepatitis C prevention education: client and staff perspectives. Country: USA. Quality score: +	Research questions: Examined client and staff attitudes regarding the role of drug treatment programmes in the provision of hepatitis C prevention education services and the types of services available Theoretical approach: Not reported. Data collection: Semi structured interviews and focus groups.	Source: Drug treatment clients and staff. Recruitment: key staff were identified to recruit clients Sample: 29 drug treatment clients and 23 staff (59% female)	Analysis: Content was analysed for emerging patterns and themes. Data were coded and analysed using ATLASti. Key themes: Incomplete and uncertain knowledge of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment.	Limitations Author: participants may have provided socially desirable answers. Potential bias through interviewing staff with a potentially vested interest in the delivery of hepatitis C related services. Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: National Institute on Drug Abuse.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Munoz-Plaza et al., 2005a Title: hepatitis C pre-test and post-test counselling services at drug treatment programs: missed opportunities for primary prevention. Country: USA. Quality score: +	Research questions: To examine client and staff perceptions about the communication of hepatitis C primary prevention messages through pre-test and post-test counselling services at five drug treatment programmes Theoretical approach: Not reported Data collection: Interviews and focus groups.	Source: Drug treatment clients. Recruitment: a key staff person was identified at each programme to explain the purpose of the study to both clients and staff Sample: 51 participants (32 interviews, 5 case studies and 19 in focus groups) (39% female).	Analysis: Interviews were transcribed verbatim and analysed using ATLASti. Codes were used to index the thematic content of the data. Key themes: Barriers and facilitators to testing; Experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: findings are not representative of clients and staff in all drug treatment programmes. Participants may have provided socially desirable responses. Any delay between hepatitis C testing and the interview may have affected the participant's memory of their testing experience. Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: National Institute on Drug Abuse.
Munoz-Plaza et al., 2005b Title: Hepatitis C Service Delivery in Prisons: Peer Education From the ''Guys in Blue" Country: USA. Quality score: +	Research questions: to describe the hepatitis C services offered at the drug treatment programme; client and staff perceptions of the advantages, benefits, and barriers to delivering existing services and their recommendation for enhancing services. Theoretical approach: Not reported Data collection: Interviews and focus groups.	Source: Drug treatment clients. Recruitment: A staff member from the drug treatment programme was identified and advertised the study to inmates and staff within the programme Sample: 31 participants (all male, aged 20 to 50)	Analysis: The data were transcribed and analysed by identifying patterns and themes that emerged from the participants responses and coded to create an index of these themes, the data were coded and content analysed using ATLASti, (qualitative data processing software programme). Key themes: Hepatitis C as normal, ubiquitous and socially accepted; barriers and facilitators to testing; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Findings may not be representative of views from all staff and inmates from the study site or from other prison based drug treatment programme. Participants were recruited by the programme so may have felt influenced to provide socially desirable answers. Interviews were not recorded due to institutional regulations. Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Munoz-Plaza et al., 2006 Title: Staff Perspectives on Facilitating the Implementation of Hepatitis C Services at Drug Treatment Programs. Country: USA. Quality score: +	Research questions: To describe the hepatitis C education and support services available at four drug treatment programmes and examine staff and client perspectives on factors that facilitated the implementation of these services Theoretical approach: Not reported Data collection: Interviews and focus groups.	Source: Staff from four drug treatment programmes. Recruitment: Staff from each programme volunteered to participate, a key member of staff was indentified to help recruit participants. Sample: 26 drug treatment staff.	Analysis: Interviews were transcribed verbatim and analysed using ATLASti. A coding framework was developed to map narrative themes. Key themes: Barriers and facilitators to subsequent care and treatment	Limitations Author: Findings are not representative of the views of all staff in drug treatment programmes. Staff directly involved in hepatitis C related services may have been biased in responses. Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: Not reported.
Munoz-Plaza et al., 2008 Title: Exploring drug users' attitudes and decisions regarding hepatitis C treatment in the US Country: USA Quality score: +	Research questions: To examine how drug users perceive the treatment, as well as the processes by which hepatitis C positive individuals examined the advantages and disadvantages of starting hepatitis C medications. Theoretical approach: Not reported Data collection: Individual face-to-face interviews and focus groups with patients conducted at 14 drug treatment programmes	Source: Patients attending 14 drug treatment programmes (outpatient or residential programme that did not provide medication to treat drug dependence, or outpatient methadone maintenance treatment programme) Recruitment: Recruitment conducted by designated staff at each drug treatment programme. Sample: 62 interview participants and 102 focus group participants. 63% were male and 89% heterosexual. 27% identified as African-American, 29% Hispanic, 60% non-Hispanic White, 3% more than one race and 3%American Indian/Alaskan Native.	Analysis: Development of primary and secondary coding structures, which were analysed both individually and within larger coding networks. Key themes: Barrier and facilitators to subsequent care and treatment.	Limitations Author: Findings may not be representative of all drug users. All of the participants were enrolled in a drug treatment programme at the time of interview which may have influenced their perspectives. Answers may have been affected for participants who were hepatitis C positive but unwilling to disclose their status. Reviewer: Little rationale or justification for theoretical approach; rigour of analysis not clear Funding: Not reported

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Munoz-Plaza et al., 2010 Title: Research note: perspectives on the hierarchy of HIV and Hepatitis C disease: consequences from drug treatment program patients. Country: USA. Quality score: +	Research questions: Explored the comparative perceptions of both staff and clients at drug treatment programmes with regard to HIV and hepatitis C in terms of disease stigma and severity. Theoretical approach: Not reported Data collection: Interviews and focus groups.	Source: 19 drug treatment programmes located throughout the U.S (including outpatient, residential and methadone maintenance treatment programmes) Recruitment: via drug treatment programmes Sample: 215 drug treatment clients and 165 staff (60% male)	Analysis: Transcripts were coded with a combination of pre-determined and open-coding categories using ATLASti software Key themes: A relative understanding of hepatitis C among IDUs.	Limitations Author: Participants were recruited using a convenience sampling framework therefore findings may not be representative of all staff and clients in participating programmes (and all drug treatment programmes across USA). Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: National Institute for Mental Health.
Paterson et al., 2006 Title: The construction of hepatitis C as a chronic illness. Country: Canada. Quality score: ++	Research questions: To explore the self-care decision making of adults diagnosed with chronic hepatitis C. Theoretical approach: Grounded theory. Data collection: Modified “think aloud” technique and formal face-to-face interviews.	Source: People diagnosed with hepatitis C living in British Columbia. Recruitment: Through healthcare sites, a newsletter, web-based networks and community groups. Sample: 33 participants. All hepatitis C positive. 18 were male and 15 females. Mean age 47 years. 16 reported contracting hepatitis C through drug use.	Analysis: Constant comparative analytic approach. The analytic framework included consideration of components of self-care decisions, types of self-care decisions, antecedents, and factors affecting self-care decisions. Key themes: The impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: None identified Funding: funded by British Columbia Medical Services Research Foundation.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Paterson et al., 2007 Title: The depiction of stigmatization in research about hepatitis C. Country: English language research reports. Quality score:++	Research questions: to critically examine the representation of stigmatization in published research reports from 1995 to 2006, with a specific focus on how these depictions have shaped the current understanding of interventions to address stigmatization of people with hepatitis C by health care practitioners. Theoretical approach: Not reported. Data collection: Literature review.	Source: English language research reports on stigma and IDUs. Recruitment: NA Sample: 21 research reports.	Analysis: Approach to synthesis not reported. Key themes: Barriers and facilitators to testing; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: the review shows that research pertaining to hepatitis C related stigma does not differentiate between stigma of hepatitis and other factors such homeless or poor people (it is not clear whether the stigma is associated with injecting drug use) Reviewer: Methods not reported. Funding: Not reported.
Perry & Chew-Graham, 2003 Title: Finding a vein or obtaining consent: a qualitative study of hepatitis C testing in GP methadone clinics. Country: UK. Quality score: +	Research questions: To understand GPs' ethical practice when negotiating consent to hepatitis C testing with IDUs Theoretical approach: Not reported. Data collection: Semi-structured interviews	Source: GP's working in drug treatment/methadone clinics. Recruitment: GPs were sampled in alphabetical sequence from three Greater Manchester Drug Services' area lists of practices offering methadone prescribing. Sample: 20 participants (GPs)	Analysis: Transcribed interviews were subjected to constant comparative analysis by the authors until category saturation was reached. a prior theory and the emergent categories were mutually adapted throughout the research process Key themes: Barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: Lack of reporting on rigour and reliability of methods Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Rhodes et al., 2004 Title: Hepatitis C and its risk management among drug injectors in London: Renewing harm reduction in the context of uncertainty. Country: UK. Quality score: ++	Research questions: To explore drug injectors' accounts of risk management in relation to hepatitis C and participants' narratives about hepatitis C and its risk management. Theoretical approach: Not reported. Data collection: In-depth interviews based on a topic guide.	Source: People who had injected drugs in the previous 4 weeks. Recruitment: Combination of drug user networks, community-based drug services and snowballing. Sample: 59 participants. 40 were male and 19 female. Mean age 29.8 years. 19 were hepatitis C positive.	Analysis: Thematic analysis. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; a relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reaction to diagnosis.	Limitations Author: Due to study being qualitative, the findings are not representative of a population of IDUs in general. Reviewer: None identified Funding: supported by the Policy Research Programme of the Department of Health.
Rhodes & Treloar, 2008 Title: The social production of hepatitis C risk among IDUs: a qualitative synthesis. Country: UK Quality score: ++	Research questions: To review English-language qualitative empirical studies of hepatitis C risk among IDUs. Theoretical approach: Not applicable Data collection: Searching of eight electronic databases and reference lists identified manually papers in peer-reviewed journals since 2000.	Source: English-language qualitative empirical studies of hepatitis C risk among IDUs. Recruitment: Not applicable Sample: 31 papers, representing 24 studies among over 1000 IDUs.	Analysis: Qualitative synthesis using a meta-ethnographic approach. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs; Barriers and facilitators to testing; experience of testing and reactions to diagnosis	Limitations Author: Unable to provide an account of socio-political factors in each setting; findings cannot be generalised. Reviewer: None identified Funding: UK Department of Health.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Roy et al., 2007 Title: Hepatitis C meanings and preventive strategies among street-involved young injection drug users in Montréal. Country: Canada. Quality score: ++	Research questions: To examine what hepatitis C virus infection means to street-involved young IDUs and how this impacts on their health behaviours, based on social contexts in which they live. Theoretical approach: Symbolic interactionism perspective, grounded theory. Data collection: In-depth interviews covering the period between the time participants started injecting and the moment they learnt they were infected; then the moment they were tested; and finally the period during which they had been living with the infection.	Source: Street-involved young IDUs (<30 years old), currently injecting drugs or in the process of quitting injection. Recruitment: Recruited from ongoing cohort study on HIV and hepatitis C incidence among street youth and from methadone programmes and medical clinics. Sample: 39 participants. 23 were male and16 female. Age range 18–27 years. All hepatitis C positive.	Analysis: Constant comparative analysis. Key themes: Injecting practices, risk Behaviour and implications for hepatitis C Transmission; hepatitis C as normal ubiquitous and socially accepted; a relative understanding of hepatitis C among IDUs; barriers and facilitators to Testing; experience of testing and reaction to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barrier and facilitators to subsequent care and treatment.	Limitations Author: Due to study being qualitative, it focuses on specific areas and does not allow in-depth analysis of all possible aspects. Participants' accounts may be influenced by what they believe is socially desirable. Findings may not be representative of all IDUs and users from different areas or settings. Reviewer: None identified Funding: funded by the Canadian Institutes of Health Research.
Sosman et al., 2005 Title: Screening for sexually transmitted diseases and hepatitis in 18–29-year-old men recently released from prison: feasibility and acceptability. Country: USA Quality score: +	Research questions: sought to determine the acceptability and feasibility of screening for STD and hepatitis in young men released from prison Theoretical approach: grounded theory Data collection: Interviews.	Source: Prisons in four states (California, Mississippi, Rhode Island, and Wisconsin) Recruitment: males who had completed a six-month post release interview as part of a prior longitudinal cohort study of health risks and behaviours among former inmates. Sample: 42 ex prisoners	Analysis: Data summaries were analysed for emergent themes using grounded theory analysis. Key themes: Incomplete and uncertain knowledge of hepatitis C among IDUs; barriers and facilitators to testing; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Small sample size, increases the potential for self selection bias and reduces the generalisability of the results. Reviewer: Lack of reporting on rigour and reliability of methods; richness of data was poor Funding: Centers for Disease Control and Prevention (CDC).

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Southgate et al., 2005 Title: What's in a virus? Folk understandings of hepatitis C infection and infectiousness among IDUs in Kings Cross, Sydney. Country: Australia. Quality score: ++	Research questions: To explore folk understandings of blood borne virus infection and infectiousness among IDUs Theoretical approach: Not reported Data collection: In-depth interviews. Observational fieldwork.	Source: IDUs Recruitment: Not reported Sample: 24 participants (14 males and 10 females, aged 19 to 47).	Analysis: Interviews and field notes were coded for key words, themes, issues and events. These were compared, contrasted and synthesised to create a system of thematic classification. A number of processes were used to assess the validity of the analysis. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; Incomplete and uncertain knowledge of hepatitis C among IDUs; a relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis.	Limitations Author: Not reported Reviewer: None identified Funding: Australian National Council on Drugs and the Australian National Council on AIDS, Hepatitis and Related Diseases

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Strauss et al., 2008 Title: Barriers and Facilitators to Undergoing Hepatitis C Virus Testing Through Drug Treatment Programmes. Country: USA. Quality score: +	Research questions: to identify barriers and facilitators to being tested for hepatitis C through the programme Theoretical approach: Not reported Data collection: Interviews.	Source: patients in 11 drug treatment programmes in New York Recruitment: A designated staff person at each programme informed patients of the research Sample: 62 participants.	Analysis: Not reported Key themes: Barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment	Limitations Author: the programmes involved in the research may not be representative of drug treatment programmes nationwide. Hepatitis C status was categorised by self report. Participants may have provided socially desirable answers. Staff informing participants about the study may have caused patients bias in bias selection. Reviewer: Theoretical approach not described; lack of reporting on rigour and reliability of methods Funding: funded by the National Institute on Drug Abuse.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Sutton & Treloar, 2007 Title: Chronic Illness Experiences, Clinical Markers and Living with Hepatitis C. Country: Australia. Quality score:++	Research questions: To explore the experiences of people with hepatitis C within two models of chronic illness trajectory and shifting perspectives and examines the effects of clinical markers of disease in relation to perceived health Theoretical approach: Not reported Data collection: Semi-structured interviews.	Source: Former and current IDUs, blood donors, blood recipients, persons with blood disorders Recruitment: Selected from an original, larger study of 78 participants who were interviewed with regard to perspectives on blood and related issues. Sample: 36 participants. All hepatitis C positive. Included IDUs (numbers not specified).	Analysis: Transcripts were independently coded by researchers, who systematically made comparisons and resolved any discrepancies through discussion. Transcripts and codes were entered into NVIVO, and codes relating to the research topic retrieved. Key themes: hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; a relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to Diagnosis; the impact of hepatitis C testing on Behaviour; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Findings may not be representative of the hepatitis C population. The sample was comprised of white participants therefore findings may not be representative of ethnic minority populations. Participants were all from Sydney and findings may not represent experiences of people from other areas. Reviewer: None identified Funding: National Health and Medical Research Council

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Swan et al., 2010 Title: Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former IDUs: A qualitative exploration. Country: Ireland. Quality score: ++	Research questions: To examine IDUs experiences of what enables or prevents them engaging at every level of hepatitis C care, including testing, follow-up, management and treatment processes. Theoretical approach: Grounded Theory. Data collection: Semi-structured in-depth interviews using an interview guide.	Source: Current and former IDUs who varied in their experience of and engagement with hepatitis C care. Recruitment: Recruited from a range of settings including two addiction clinics, a community drop-in centre, a general practice, two hepatology clinics, and an infectious diseases clinic. Sample: 36 participants. 28 were male and 8 female. Median age of 32 year. 33 hepatitis C positive.	Analysis: Constant comparison method. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C a normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barrier and facilitators to subsequent care and treatment.	Limitations Author: a relatively small number of females were interviewed. Service users with ongoing psychiatric difficulties were excluded which limited the exploration of mental health problems as a barrier to treatment. Only one person who had never been screened for hepatitis C was interviewed. Most participants were on a methadone treatment programme and those not, had already given up drug use and therefore the experience of current IDUs was under-reported. Reviewer: None indentified Funding: funded by a Health Research Board

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Temple-Smith et al., 2005 Title: The lived experience of men and women with hepatitis C: implications for support needs and health information. Country: Australia. Quality score: +	Research questions: To examine the experiences of diagnosis, support and discrimination among men and females living with hepatitis C in Melbourne. Theoretical approach: Not reported Data collection: Interviews	Source: Males and females living with hepatitis C in Melbourne Recruitment: A purposive sampling strategy was used. Information about the study was left with key agencies (needle-syringe exchanges, Liver Clinics, Hepatitis C Council) and staff working at these agencies assisted in informing clients about the study. Sample: 32 hepatitis C positive participants (20 female and 12 male, age 17 to 56). 8 were current and 22 past IDUs	Analysis: Interviews were fully transcribed, coded and subjected to content and thematic analysis. Key themes: Barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Not reported Reviewer: Unclear reporting of some aspects of the methods. Funding: Not reported
Tompkins et al., 2005 Title: Impact of a positive hepatitis C diagnosis on homeless IDUs: A qualitative study. Country: UK. Quality score: ++	Research questions: To explore the impact of a positive hepatitis C diagnosis on homeless IDUs. Theoretical approach: Not reported Data collection: In-depth interviews using a topic guide.	Source: Homeless people attending a primary care centre. Recruitment: Purposive sample. Hepatitis C positive patients were identified and invited to participate in the study. Posters in the health centre also advertised the research. Sample: 17 participants. 15 were male and 2 female. Age range 22-49 years. All were Caucasian. 16 were from the UK and one southern European.	Analysis: Framework approach. **Key themes: Hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis ; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services.**	Limitations Author: Female IDUs with hepatitis C and homeless drug users from ethnic minorities were underrepresented. Reviewer: None identified. Funding: funded by Leeds Community and Mental Health Services Teaching NHS Trust.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Treloar & Holt, 2008 Title: Drug treatment clients' readiness for hepatitis C treatment: Implications for expanding treatment services in drug and alcohol settings. Country: Australia. Quality score: ++	Research questions: To explore the perception of and readiness for hepatitis C treatment among clients participating in drug treatment. Theoretical approach: Grounded theory. Data collection: Semi-structured interviews.	Source: Clients participating in drug treatment services. Recruitment: peer recruitment, word of mouth, advertising in local drug treatment services Sample: 77 participants. 39 were male and 28 female. 63 born in Australia. Mean age 37 years. 55 were hepatitis C positive.	Analysis: Interviews transcribed verbatim and coded using Nvivo. They were coded by two authors and checked for consistency. Key themes: hepatitis C as normal, ubiquitous and socially accepted; barriers and facilitators to testing; barrier and facilitators to subsequent care and treatment.	Limitations Author: study is not representative of all people in drug treatment. Sample was limited to the area of recruitment. Reviewer: None identified Funding: funded by the Australian Government Department of Health and Ageing.
Treloar & Hopwood, 2004 Title: Infection Control in the Context of Hepatitis C Disclosure: Implications for Education of Healthcare Professionals Country: Australia. Quality score:+	Research questions: To examine the perceptions and experiences of people with hepatitis C of their interactions with healthcare workers Theoretical approach: social identity theory Data collection: Semi-structured interviews	Source: Drug treatment clients with Hepatitis C. Recruitment: via an advertisement inserted in The Hep C Review and by snowballing through the social networks of participants. Sample : 77 participants	Analysis: The authors independently coded the transcripts using a code list constructed from issues emerging from the transcripts. The coded interview transcripts were entered into NVIVO Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; stigma as a barrier to disclosure and hepatitis C services.	Limitations Author: Findings are not representative of all infection control related episodes experienced by people with hepatitis C. Reviewer: Lacking in detail to determine rigour of the analysis Funding: Not reported.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Treloar & Rhodes, 2009 Title: The Lived Experience of Hepatitis C and its Treatment Among IDUs: Qualitative Synthesis Country: English language papers. Quality score: ++	Research questions: To review research focusing on the lived experience of hepatitis C among IDUs. Theoretical approach: Not reported. Data collection: Systematic review.	Source: English language papers on lived experience of hepatitis C among IDUs. Recruitment: Not applicable Sample: 25 published articles representing 20 unique studies.	Analysis: Meta-ethnographic approach to qualitative synthesis Key themes: Hepatitis C as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of hepatitis C among IDUs; relative understanding of hepatitis C among IDUs; Barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure and hepatitis C services; barrier and facilitators to subsequent care and treatment.	Limitations Author: Limited generalisibility; studies typically focused on English speaking and culturally mainstream participants and did not include cultural and linguistic diverse backgrounds. Reviewer: None identified Funding: Not reported.
Treloar et al., 2010 Title: Uptake and delivery of hepatitis C treatment in opiate substitution treatment: perceptions of clients and health professionals. Country: Australia. Quality score: ++	Research questions: to explore OST clients and health professionals reports of the barriers and incentives to the delivery and uptake of hepatitis C treatment in OST clinics. Theoretical approach: Not reported Data collection: Semi-structured interviews.	Source: Clients and staff from OST sites. Recruitment: Recruited from needle and syringe programmes, OST clinics and community pharmacies dispensing OST across New South Wales, Australia Sample: 27 Opiate Substitution treatment clients (OST) and 22 OST health professionals	Analysis: Independently constructed a coding frame and compared coding decisions to reach a consensus Key themes: Stigma as a barrier to disclosure and hepatitis C services; barrier and facilitators to subsequent care and treatment.	Limitations Author: Findings cannot be generalised to other OST clients, health professionals and services. Reviewer: None identified Funding: Australian Government Department of Health and Ageing and the New South Wales Health Department.

Study Details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Notes
Wozniak et al., 2007 Title: Everybody's got it, but...: Situational and strategic participation in normalized hepatitis C discourse among injection drug users in Edmonton, Canada. Country: Canada. Quality score: ++	Research questions: explored the utility of normalization for understanding the social accommodation of hepatitis C among street-involved injection drug users Theoretical approach: Not reported Data collection: A secondary analysis of interviews conducted with two samples of IDUs.	Source: needle exchanges and other harm reduction and health services accessed by the Edmonton IDU population Recruitment: snowball sampling and peer referral techniques initiated through needle exchanges and other harm reduction and health services Sample: first sample -30 participants. Half were hepatitis C positive. Second sample- 31 participants. Two thirds were hepatitis C positive.	Analysis: transcribed verbatim and thematic analysis identified and verified for accuracy by 2 researchers. A third researcher was used to assess trustworthiness. Constant comparative method. Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; hepatitis C as normal, ubiquitous and socially accepted; A relative understanding of hepatitis C among IDUs; barriers and facilitators to testing; experience of testing and reactions to diagnosis; Incomplete and uncertain knowledge of hepatitis C among IDUs	Limitations Author: cannot be generalised beyond the present sample. Potential of socially desirable answers given. Study is limited because it focuses exclusively on the social accommodation dimension of normalization. Reviewer: None identified. Funding: Alberta Heritage Foundation for Medical Research and the Canadian Institutes of Health Research.
Wright et al., 2005 Title: Exploring risk perception and behaviour of homeless IDUs diagnosed with hepatitis C. Country: UK. Quality score:++	Research questions: to explore the impact of a positive diagnosis of hepatitis C on risk behaviour and explored the attitudes, behaviours and risk perceptions of homeless IDUs Theoretical approach: Not reported Data collection: In-depth interviews	Source: homeless IDUs with hepatitis C Recruitment: purposively sampled from a primary care health centre for homeless people in the north of England by searching the computerised medical records for all current patients who had received a positive antibody test for hepatitis C. Sample: 71 hepatitis C positive homeless IDUs.	Analysis: interviews were transcribed independently to identify key themes. the themes and categories were charted to carry out within and between case analysis Key themes: Injecting practices, risk behaviour and implications for hepatitis C transmission; incomplete and uncertain knowledge of hepatitis C among IDUs; experience of testing and reactions to diagnosis; the impact of hepatitis C testing on behaviour; stigma as a barrier to disclosure and hepatitis C services; barriers and facilitators to subsequent care and treatment.	Limitations Author: the study may not fully represent the gender profile of the population of homeless IDUs with Hepatitis C (attending the health centre) Reviewer: None identified. Funding: Not reported.

Appendix 6. Quality assessment tables

Table 7. Summary of quality assessment: Hepatitis B

Reference	*Theoretical approach*		Study design	Data collection	*Trustworthiness*			*Analysis*						*Ethics*	Overall rating
	Qualitative approach	Study purpose			Role of researcher	Context	Reliable methods	Rigorous data analysis	Rich data	Reliable analysis	Convincing findings	Relevant findings	Conclusions	Clear & coherent reporting	
Buck *et al.*, 2006	Appropriate	Clear	Defensible	Appropriate	NR	Unclear	Reliable	Rigorous	Not sure	Reliable	Convincing	Relevant	Adequate	NR	+
Burke *et al.*, 2004	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	++
Burke *et al.*, 2011	Appropriate	Mixed	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Not sure	Partially relevant	Adequate	NR	+
Chang *et al.*, 2008	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	++
Chen *et al.*, 2006	Appropriate	Clear	Defensible	Appropriate	Unclear	Clear	Reliable	Not sure	Rich	Reliable	Convincing	Relevant	Adequate	NR	++
Choe *et al.*, 2005	Appropriate	Clear	Not sure	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Adequate	++
Hwang *et al.*, 2010	Appropriate	Clear	Defensible	Appropriate	NR	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	++
van der Veen *et al.*, 2009	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	++
Wallace *et al.*, 2011	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Adequate	++

Table 8. Summary of quality assessment: Hepatitis C

Reference	*Theoretical approach*		Study design	Data collection	*Trustworthiness*			*Analysis*						*Ethics*	Overall rating
	Qualitative approach	Study purpose			Role of researcher	Context	Reliable methods	Rigorous data analysis	Rich data	Reliable analysis	Convincing findings	Relevant findings	Conclusions	Clear & coherent reporting	
Astone *et al.,* 2005	Appropriate	Clear	Not sure	Not sure	NR	Clear	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	+
Brener & Treloar, 2009	Not sure	Clear	Defensible	Appropriate	NR	Clear	Not sure	Not sure	Rich	Not sure	Not sure	Relevant	Adequate	Appropriate	+
Carrier *et al.*, 2005	Appropriate	Mixed	Not sure	Appropriate	NR	Clear	Reliable	NR	Not sure	NR	Convincing	Partially relevant	Adequate	Appropriate	+
Copeland, 2004	Appropriate	Clear	Defensible	Appropriate	Partially clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Coupland *et al.*, 2009	Appropriate	Clear	Defensible	Appropriate	Partially clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Craine *et al.*, 2004	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	++
Cullen *et al.,* 2005	Appropriate	Mixed	Not sure	Not sure	Partially clear	Partial	Not sure	NR	Poor	Partial	Convincing	Relevant	Adequate	Appropriate	-
Davis & Rhodes, 2004	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Davis *et al.,* 2004	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Dyer & Tolliday, 2009	Not sure	Mixed	Not sure	Not sure	NR	Clear	Not sure	NR	Not sure	NR	Not sure	Relevant	Adequate	NR	-
Ellard, 2007	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Not sure	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++
Faye & Irurita, 2003	Appropriate	Clear	Defensible	Appropriate	Clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Fraser & Treloar, 2006	Appropriate	Clear	Defensible	Appropriate	Partially clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Reference	*Theoretical approach*		Study design	Data collection	*Trustworthiness*			*Analysis*						*Ethics*	Overall rating
	Qualitative approach	Study purpose			Role of researcher	Context	Reliable methods	Rigorous data analysis	Rich data	Reliable analysis	Convincing findings	Relevant findings	Conclusions	Clear & coherent reporting	
Fraser, 2004	Appropriate	Clear	Not sure	Not sure	NR	NR	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	+
Fraser, 2010	Appropriate	Clear	Not sure	Not sure	NR	NR	Not sure	NR	NR	NR	Convincing	Relevant	Not sure	NR	-
Gyarmathy *et al.*, 2006	Appropriate	Clear	Not sure	Not sure	Unclear	Clear	Reliable	NR	Poor	NR	Convincing	Relevant	Adequate	Appropriate	+
Habib & Adorjany, 2003	Not sure	Clear	Not sure	Not sure	NR	Not sure	Not sure	Not sure	Not sure	Not sure	Not sure	Relevant	Adequate	Appropriate	-
Harris, 2009a	Appropriate	Mixed	Defensible	Appropriate	Clear	Clear	Reliable	NR	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Harris, 2009b	Appropriate	Mixed	Not sure	Appropriate	Clear	Clear	Not sure	Not sure	Rich	Not sure	Not sure	Relevant	Not sure	Appropriate	-
Khaw *et al.*, 2007	Appropriate	Mixed	Not sure	Appropriate	Partially clear	Not sure	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	+
Kinder, 2009	Appropriate	Clear	Defensible	Appropriate	Clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Lally *et al.*, 2008	Appropriate	Clear	Defensible	Appropriate	Unclear	No	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
McCreaddie *et al.*, 2011	Appropriate	Clear	Defensible	Appropriate	Partially clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Munoz-Plaza *et al.*, 2004	Appropriate	Clear	Defensible	Appropriate	Partially clear	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Munoz-Plaza *et al.*, 2005a	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Munoz-Plaza *et al.*, 2005b	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Munoz-Plaza *et al.*, 2006	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+

Reference	*Theoretical approach*		Study design	Data collection	*Trustworthiness*			*Analysis*						*Ethics*	Overall rating
	Qualitative approach	Study purpose			Role of researcher	Context	Reliable methods	Rigorous data analysis	Rich data	Reliable analysis	Convincing findings	Relevant findings	Conclusions	Clear & coherent reporting	
Munoz-Plaza *et al.*, 2008	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	NR	+
Munoz-Plaza *et al.*, 2010	Appropriate	Clear	Not sure	Not sure	NR	Clear	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	+
Paterson *et al.*, 2006	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Perry & Chew-Graham, 2003	Appropriate	Clear	Defensible	Not sure	Clear	Clear	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	NR	+
Rhodes *et al.*, 2004	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++
Roy *et al.*, 2007	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	NR	++
Sosman *et al.*, 2005	Appropriate	Mixed	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Poor	Reliable	Convincing	Relevant	Adequate	NR	+
Southgate *et al.*, 2005	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not sure	++
Strauss *et al.*, 2008	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Not sure	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	+
Sutton & Treloar, 2007	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Swan *et al.*, 2010	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Temple-Smith *et al.*, 2005	Appropriate	Clear	Not sure	Not sure	NR	Not sure	Not sure	NR	Rich	NR	Convincing	Relevant	Adequate	Appropriate	+
Tompkins *et al.*, 2005	Appropriate	Clear	Indefensible	Appropriate	NR	Clear	Partial	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Treloar & Holt, 2008	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Reference	*Theoretical approach*		Study design	Data collection	*Trustworthiness*			*Analysis*						*Ethics*	Overall rating
	Qualitative approach	Study purpose			Role of researcher	Context	Reliable methods	Rigorous data analysis	Rich data	Reliable analysis	Convincing findings	Relevant findings	Conclusions	Clear & coherent reporting	
Treloar & Hopwood, 2004	Appropriate	Clear	Not sure	Appropriate	NR	Clear	Not sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+
Treloar *et al.*, 2010	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Wozniak *et al.*, 2007	Appropriate	Clear	Defensible	Appropriate	Yes	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Wright *et al.*, 2005	Appropriate	Clear	Defensible	Appropriate	NR	Clear	Partial	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++

Appendix 7. Overlap between other reviews of qualitative research and this review

Table 9: Summary of the overlap between other reviews of qualitative research and this review

Study	Included in review(s) of qualitative research		
	Rhodes & Treloar, 2008	Treloar & Rhodes, 2009	Paterson *et al.,* 2007
Included in this review			
Carrier *et al.,* 2005	Yes	No	No
Copeland, 2004	Yes	Yes	No
Craine et al. 2004	Yes	Yes	No
Davis & Rhodes, 2004a	Yes	Yes	No
Davis *et al.,* 2004	Yes	Yes	No
Ellard, 2007	Yes	No	No
Faye & Irurita, 2003	No	Yes	Yes
Fraser & Treloar, 2006	Yes	Yes	No
Fraser, 2004	Yes	No	No
Habib & Adorjany, 2003	No	Yes	Yes
Rhodes *et al.,* 2004	Yes	No	No
Roy *et al.,* 2007	Yes	Yes	No
Southgate *et al.,* 2005	Yes	No	No
Sutton & Treloar, 2007	Yes	Yes	No
Temple-Smith *et al.,* 2004	Yes	Yes	Yes
Tompkins *et al.,* 2005	Yes	Yes	No
Treloar & Hopwood, 2004	No	Yes	Yes
Wozniak *et al.,* 2007	Yes	Yes	No
Wright *et al.,* 2005	Yes	No	No
Excluded from this review			
Banwell *et al.,* 2005	No	No	Yes
Bourgois *et al.,* 2004	Yes	No	No
Butt *et al.,* 2007	Yes	Yes	Yes
Conrad et al. 2006	No	Yes	No
Crocket & Gifford, 2004	Yes	Yes	Yes
Crofts *et al.,* 1997	No	No	Yes
Davis & Rhodes, 2004b	Yes	No	No
Day *et al.,* 2003	No	No	Yes
Day *et al.,* 2004	No	No	Yes
Dunne & Quayle, 2002	No	No	Yes
Fraenkel *et al.,* 2005	No	Yes	No
Fraenkel *et al.,* 2006	No	Yes	No
Gifford *et al.,* 2003	No	No	Yes
Gifford *et al.,* 2005	No	No	Yes
Glacken *et al.,* 2001	No	Yes	No
Grundy & Beeching, 2004	Yes	Yes	Yes
Harris, 2005	Yes	Yes	No
Ho & Maher, 2007	Yes	No	No

Study	Included in review(s) of qualitative research		
	Rhodes & Treloar, 2008	**Treloar & Rhodes, 2009**	**Paterson *et al.,* 2007**
Hopwood & Treloar, 2005	No	Yes	No
Hopwood & Treloar, 2008	No	Yes	No
Hopwood *et al.,* 2006	No	No	Yes
Rhodes *et al.,* 2008	Yes	Yes	No
Rhodes *et al.,* 2008	Yes	No	No
Treloar & Abelson, 2005	Yes	No	No
Treloar & Fraser, 2004	Yes	No	No
Treloar & Hopwood, 2008	No	Yes	No
Treloar *et al.,* 2008	Yes	No	No
Treloar, 2005	Yes	No	No
Van de Mortel, 2002	No	No	Yes
Waldby *et al.,* 2004	Yes	No	No
Zickmund et al. 2003	No	No	Yes
Zickmund et al. 2004	No	No	Yes
Not identified in the searches conducted for this review			
Miller, 2005	Yes	No	No
Minuk *et al.,* 2005	No	No	Yes
Schaefer *et al.,* 2005	No	No	Yes

References to studies not identified in the searches conducted for this review

Miller, P. G. (2005) Scapegoating, self-confidence and risk comparison: the functionality of risk neutralisation and lay epidemiology by injecting drug users. International Journal of Drug Policy, 16, 246–53.

Minuk, G.Y., Gutkin, A.,Wong, S. G.,& Kaita, K. D. E. (2005) Patient concerns regarding chronic hepatitis C infections. Journal of Viral Hepatitis, 12(1), 51–57.

Schaefer, A., Scheurlen, M., Felten, M., & Kraus, M. R. (2005) Physician–patient relationship and disclosure behaviour in chronic hepatitis C in a group of German outpatients. European Journal of Gastroenterology & Hepatology, 17(12), 1387–1394.