

Title: Views and experiences of hepatitis C testing and diagnosis among people who inject drugs:
systematic review of qualitative research

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ABSTRACT

Background: Many developed countries are facing a major challenge to improve identification of individuals acutely and chronically infected with hepatitis C virus (HCV) infection. We explored the views and experiences of people who inject drugs (PWID) in relation to HCV testing, and diagnosis through a review and synthesis of qualitative research.

Methods: Based on the thematic synthesis of qualitative research. Searches were conducted in 14 databases and supplemented by reference checking, hand searching of selected journals, and searches of relevant websites. Studies of any qualitative design that examined the views and experiences of, and attitudes towards, HCV testing and diagnosis among PWID or practitioners involved in their care were included. Key themes and sub-themes were systematically coded according to the meaning and content of the findings of each study which proceeded to the preparation of a narrative account of the synthesis.

Results: 28 qualitative studies were identified. We identified a number of overarching descriptive themes in the literature, finding overall that PWID hold complex and differing views and experiences of testing and diagnosis. Three major themes emerged: missed opportunities for the provision of information and knowledge; shifting priorities between HCV testing and other needs; and testing as unexpected and routine. Evidence of missed opportunities for the provision of knowledge and information about HCV were clear, contributing to delays in seeking testing and providing a context to poor experiences of diagnosis. Influenced by the nature of their personal circumstances, perceptions of the risk associated with HCV and the prioritisation of other needs acted both to encourage and discourage the uptake of HCV testing. Undergoing HCV testing as part of routine health assessment, and an unawareness of being testing was common. An unexpected positive diagnosis exacerbated anxiety and confusion.

Conclusions: This review has identified that there are modifiable factors that affect the uptake of HCV testing and experiences of HCV diagnosis among PWID. Intervention development should focus on addressing these factors. There is a need for further research that engages PWID from a diverse range of populations to identify interventions, strategies and approaches that they consider valuable.

INTRODUCTION

Worldwide, around 150 million people are chronically infected with the hepatitis C virus (HCV) and injecting drug use is an important risk factor for acquiring the infection in high-income countries (World Health Organization, 2012a). HCV infection is highly prevalent among people who inject drugs (PWID), varying from around 60–80% of PWID infected across national samples in Western Europe, the USA and Canada (Nelson et al., 2011). Early diagnosis of HCV provides the best opportunity for effective medical support and the prevention of further transmission (Corey, Mendez-Navarro, Gorospe, Zheng, & Chung, 2010). However, despite the high burden of disease associated with HCV, it is still a neglected disease in many countries and many individuals remain unaware of their HCV positive status (Volk et al., 2009; Mühlberger et al., 2009). The World Health Organization has recognised the need to integrate proven public health strategies for preventing viral hepatitis across health systems (World Health Organization, 2012b). However, while effective government-led programmes to improve screening have been implemented in some European countries (for example France; Hatzakis et al., 2011), in others, including Australia (Hopwood & Treloar, 2004), the UK (Morris, 2011) and USA (Volk et al., 2009), evidence suggests continued variation in the availability and uptake of HCV testing, treatment, care and support services. Many high-income countries are therefore facing a major challenge to improve the identification of individuals with HCV infection. In order to inform policy and practice responses and to address questions about appropriateness and acceptability of interventions aimed at increasing HCV testing uptake, we carried out a systematic review of qualitative research. The purpose of the review was to provide a narrative perspective on how PWID view HCV testing, their experiences of the communication of test results and what they perceive as the barriers and facilitators to participation in these strategies.

METHODS

This study was conducted as part of a series of extensive systematic reviews to inform evidence-based policy recommendations on ways of offering hepatitis B and C testing in England by the UK National Institute for Health and Clinical Excellence (NICE). We used established methods for the thematic synthesis of qualitative research (Thomas & Harden, 2008) to explore the views and experiences of PWID, and health professionals involved in their care, in relation to HCV testing and diagnosis. This method was chosen as it enabled us to examine research addressing questions relating to need, appropriateness and acceptability of interventions aimed at increasing HCV testing uptake and subsequently develop analytical themes that could be used to inform intervention development. The following four research questions were formulated in relation to the views and experiences of PWID, and health professionals involved in their care:

- 1: What are their knowledge, beliefs and practices to HCV?
- 2: What are their experiences of barriers and facilitators to HCV testing and diagnosis?
- 3: What are their views, experiences and attitudes of HCV testing, diagnosis, and communication of test results?
- 4: What are their views and perspectives on opportunities for changing behaviour in relation to HCV testing and diagnosis

Literature searching

We utilised a combination of strategies to locate evidence for the review, including searching electronic sources, reference checking of included studies and key review articles, hand searching of selected journals, and searches of relevant websites. A detailed search strategy was developed for 14 databases using a combination of free text and thesaurus terms for HCV combined with free text and thesaurus terms for qualitative methods, and population or social factors (see the example search strategy in the e-only Supplementary files). Searches were conducted in March and April 2011 and limited to studies published since 1990. Following the initial screening of titles and abstracts, potentially relevant references were examined to identify the five journals with the highest yield of references (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.

Study selection

Two reviewers from a team of four (LJ, EMC, GB and LP) independently screened 6,255 titles and abstracts retrieved from the database searches according to the inclusion and exclusion criteria described. Based on title and abstract screening, 285 potentially relevant articles were identified and screened by two reviewers independently from the same team of four. Hand searching identified a further 36 articles but after removal of duplicates only one article was potentially relevant. No further relevant articles were identified by checking reference lists or review articles. We included studies of any qualitative design, including the qualitative elements of mixed methods research. We excluded studies that focused solely on general population groups or other groups at risk of HCV infection where it was not possible to attribute the findings to current and/or former PWIDs, studies that included only HCV/HIV co-infected individuals and studies that used structured questionnaires as the sole method of data collection or that reported only quantitative data. A summary of study identification is provided in a flowchart within the e-only Supplementary files.

Thematic synthesis

Verbatim findings of the included studies were extracted with brief information about the study methodology. Key themes and sub-themes were coded line by line 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 (AA) 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 (AA and LJ) independently assessed the quality of the individual studies in accordance with Methods for the development of NICE public health guidance (National Institute for Health and Clinical Excellence, 2009). 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). The

qualitative synthesis then proceeded to the development of descriptive themes and analytical themes (Thomas & Harden, 2008), which were interpreted by the wider review team (AA, LP and LJ). In addition, two reviewers (AA, LJ), first independently and then in discussion, reconsidered the findings of the qualitative synthesis to draw out clear implications for intervention development in the context of the four overarching research questions. A narrative account of the synthesis was prepared and quotations taken directly from the included studies were used to support the analytical and descriptive themes discussed.

RESULTS

Twenty-eight studies were identified for inclusion (table 1). The majority of studies included people who had acquired, or were at risk of acquiring, infection through injecting drug use; one of which focused on people in, or recently released from, prison (Khaw, Stobbart, & Murtagh, 2007). Two studies included the views of health professionals involved in the care of PWIDs; one as the sole study participants (Perry & Chew-Graham, 2003) and one, in addition to the views and experiences of PWID (Munoz-Plaza, Strauss, Astone, Jarlms, & Hagan, 2004). Most studies specifically examined views and experiences in relation to HCV infection only, though two studies (Gyarmathy, Neaigus, Ujhelyi, Szabo, & Racz, 2006; Lally, Montstream-Quas, Tanaka, Tedeschi, & Morrow, 2008) explored viral hepatitis infection more broadly alongside sexually transmitted infections such as HIV (table 1).

****INSERT TABLE 1 ABOUT HERE****

The included studies covered testing and the impact of diagnosis, including barriers and facilitators to testing, experiences of testing, reactions to diagnosis, and the impact of diagnosis on behaviour, and stigma as a barrier to testing uptake and disclosure. Our review identified a number of overarching descriptive themes in the literature, finding overall that PWID hold complex and differing views and experiences of testing and diagnosis. Three major themes emerged from the analysis of the descriptive themes: missed opportunities for the provision of information and knowledge; shifting priorities between HCV testing and other needs; and testing as unexpected and routine.

Missed opportunities for the provision of knowledge and information

That opportunities for the provision of knowledge and information about HCV had been missed was a clear theme in a number of studies included in the synthesis. Negative views and experiences of testing and diagnosis were contextualised in many cases by the limited provision of information by health professionals, and an individual awareness of incomplete or partial knowledge of HCV by PWID. A lack of knowledge of HCV symptoms and transmission were common among PWID (Davis & Rhodes, 2004; Rhodes, Davis, & Judd, 2004; Gyarmathy et al., 2006; Lally et al., 2008; Ellard, 2007), particularly among those who had not previously been tested (Davis & Rhodes, 2004). Such gaps contributed to delays in seeking testing (Strauss et al., 2008; Swan et al., 2010; Lally et al., 2008; Southgate, Weatherall, Day, & Dolan, 2005) and individual barriers to testing uptake among PWID, such as fear, were often related to incomplete knowledge about HCV.

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'. (Southgate et al., 2005, pg. 4.)

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? (Khaw et al., 2007, pg. 3.)

Experiences of being informed on the outcome of testing were generally poor. Many PWID remained unclear about the meaning of a diagnosis and experienced limited and inadequate information provision by health professionals, leading to substantial gaps in knowledge (Copeland, 2004; Cullen, Kelly, Stanley, Langton, & Bury, 2005; Faye & Irurita, 2003; Khaw et al., 2007; Lally et al., 2008; Rhodes et al., 2004; Southgate et al., 2005; Strauss et al., 2008; Sutton & Treloar, 2007; Swan et al., 2010; Temple-Smith, Gifford, & Stoové, 2004; Tompkins et al., 2005). A policy of not informing

PWID of the outcomes of testing (“a no news is good news approach”), as described in two drugs services (Munoz-Plaza et al., 2005), also produced anxiety.

[On receiving their diagnosis while in prison] I got it (the diagnosis) off a bit of paper... it was slipped under the door in my cell. (Temple-Smith et al., 2004, pg. 51)

Not bothered because I didn't know what it was (Copeland, 2004, pg. 140)

Responses to a positive diagnosis depended on individual circumstances (Craine, Walker, Carnwath & Klee, 2004) but feelings of unconcern or denial among some PWID were commonly underpinned by a lack of knowledge. In many studies PWID had experienced difficulties in obtaining reliable information following testing, regardless of whether they received a positive or negative diagnosis (Astone, Strauss, Munoz-Plaza, Hagan, & Des Jarlais, 2005; Carrier, LaPlante, & Bruneau, 2005; Copeland, 2004; Lally et al., 2008; Rhodes et al., 2004).

Shifting priorities between HCV testing and other health needs

Studies showed that influenced by the nature of their personal circumstances, their drug use and the extent to which they were engaged with ‘mainstream’ society, PWID expressed a motivation to, or actively, sought testing due to concerns both related and unrelated to their injecting behaviour and broader health needs. PWID perceived themselves as never being completely safe from, or in control of HCV transmission despite their intentions and actions to reduce risk (Carrier et al., 2005; Davis, Rhodes, & Martin, 2004; Davis & Rhodes, 2004; Harris, 2009b; Rhodes, Davis, & Judd, 2004; Roy, Nonn, Haley, & Cox, 2007; Sutton & Treloar, 2007; Swan et al., 2010; Wozniak, Prakash, Taylor, & Wild, 2007). However, there were exceptions, with studies noting that the extent to which PWID participated in the ‘normalised discourse’ was influenced by their situation, social context and personal relationships (Wozniak et al., 2007; Roy et al., 2007; Harris, 2009b). While PWID were motivated by concerns that they may have acquired HCV through injecting and the belief that HCV was an expected consequence of injecting drug use (Khaw et al., 2007; Roy et al., 2007; Swan et al.,

2010; Temple-Smith et al., 2004; Wozniak et al., 2007) there was also evidence that PWID perceived themselves to be at low risk of infection related to a belief in the minimisation of infection risk within their injecting network (Gyarmathy et al., 2006). In a UK study (Perry & Chew-Graham, 2003) of GP's experiences of HCV testing, denial of possible infection among PWID was viewed as a barrier to the informed consent process and therefore testing. Lally and colleagues also noted that for some PWID a prioritization of obtaining drugs was perceived as interfering with their ability to attend to their health needs.

[GP in a methadone clinic] Either they understand that they're going to address their lifestyle, or they don't understand and it will make no difference... (Perry & Chew-Graham, 2003, pg. 542)

I care, but the last thing on my mind is going to get tested... (Lally et al., 2008, pg. 56)

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." (Wozniak et al., 2007, pg. 392)

Reactions to a positive diagnosis, primarily among people who were injecting drugs at the time of diagnosis, included being unaware of or indifferent to the meaning of a positive diagnosis, and commonly denial (Astone et al., 2005; Copeland, 2004; Faye & Irurita, 2003; Swan et al., 2010; Temple-Smith et al., 2004). A diagnosis of HCV (Harris, 2009b; Roy et al., 2007) was not viewed as overly concerning as there was a perception of HCV as a health condition that developed over many years; as such HCV was viewed as inconsequential relative to other disruptions, for example, a drugs overdose. However, injecting behaviour was also a motivation for testing with PWID citing social or personal responsibility to others, such as those within their injecting networks (Craine et al., 2004; Khaw et al., 2007; Roy et al., 2007). For those with concerns about a positive diagnosis, anxiety over the impact of HCV on the chances of finding a long term partner, sexual relations, starting a family and the possibility of transmission predominated (Carrier et al., 2005; Harris, 2009b; Temple-Smith et al., 2004; Tompkins et al., 2005; Wright, Tompkins, & Jones, 2005). A positive diagnosis led some

PWID to re-evaluate their lives and make the first steps towards a life away from their drug use (Roy et al., 2007; Sutton & Treloar, 2007; Swan et al., 2010) or towards adopting a healthier lifestyle, such as eating more healthily and reducing alcohol and drug use (Cullen et al., 2005; Faye & Irurita, 2003; Khaw et al., 2007; Roy et al., 2007; Sutton & Treloar, 2007; Wozniak et al., 2007; Wright et al., 2005).

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. (Roy et al., 2007, pg. 402.)

HCV was often understood relative to HIV; a product of joint testing procedures, a bias towards HIV services in practice, the relative trivialisation in comparison to HIV by others (including health professionals) and the social dominance of popular HIV discourse since the 1980's (Davis & Rhodes, 2004; Harris, 2009a; Khaw et al., 2007; Munoz-Plaza et al., 2010; Rhodes et al., 2004). Studies that described the trivialisation of a positive HCV diagnosis, relating both to those delivering (Rhodes et al., 2004) and those receiving the diagnosis (Roy et al., 2007; Copeland, 2004; Carrier et al., 2005; Cullen et al., 2005), noted that this trivialisation tended to be relative and in comparison to a HIV diagnosis.

Testing as unexpected and routine

Studies showed that undergoing routine testing was common among PWID, but when consent for testing was not explicitly sought, this exacerbated anxiety and confusion over a positive diagnosis. At a structural level, convenient and opportunistic testing were important facilitators for testing.

Participants in many studies had experienced HCV testing opportunistically as part of routine health assessments (Craine et al., 2004; Lally et al., 2008; Munoz-Plaza et al., 2005; Rhodes et al., 2004; Swan et al., 2010; Tompkins, Wright, & Jones, 2005) and among those unlikely to deliberately seek testing, had been an important facilitator of testing uptake (Rhodes et al., 2004; Temple-Smith et al., 2004).

[Registered Nurse at a drug treatment programme] 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.” (Munoz-Plaza et al., 2005, pg. 664)

Concerns over informed consent related to routine testing were raised in a number of studies (Munoz-Plaza et al., 2005; Rhodes et al., 2004; Tompkins et al., 2005). Studies showed that when testing was routine, PWID were often unaware that they had been tested and although this was perceived by some (among both PWID and providers) as non-problematic (Munoz-Plaza et al., 2005), studies showed that an expectation of testing was concerning for some and restricted patient choice. In addition, for those who participated in testing, an unexpected diagnosis exacerbated anxiety and confusion (Rhodes et al., 2004; Swan et al., 2010; Lally et al., 2008; Tompkins, Wright, & Jones, 2005).

I think they have to [take your blood]. It's not an option... it should be like if you want it or not, it's an option, you know, but they did do it anyway... (Munoz-Plaza et al., 2005, pg. 665)

Positive experiences of testing were rare, but studies conducted within drugs services identified that trust and rapport with health professionals and drug treatment staff, and support and encouragement were important motivators for testing (Munoz-Plaza et al., 2005; Strauss et al., 2008). When asked about convenient locations for testing, some PWID referred to drug treatment programme sites and methadone clinics (Munoz-Plaza et al., 2004; Strauss et al., 2008) whilst others expressed a preference for primary care settings (Temple-Smith et al., 2004).

DISCUSSION

This review sought to examine the views and experiences of PWID in relation to HCV testing and diagnosis through a review and synthesis of qualitative research. Our review of 28 qualitative studies showed that despite holding complex views and differing experiences, in relation to HCV testing and diagnosis, PWID experienced missed opportunities for the provision of knowledge and information,

had shifting priorities around HCV testing and their other health needs, and experienced testing as unexpected and routine.

The evidence identified through this review suggests that there are modifiable factors that could be addressed through interventions that aim to encourage HCV testing uptake. As noted by Bruggmann (2012), increasing access to testing requires the breakdown of barriers at multiple levels; at a healthcare system level, provider level, and indirectly at an individual patient level. A recent systematic review of the effectiveness of interventions aimed at increasing HCV testing uptake (Jones, Bates, McCoy, Beynon, McVeigh & Bellis, 2013) identified eight controlled studies that examined a range of intervention approaches, including those designed to enhance case finding and testing uptake in primary care, offer alternative methods of testing, deliver services in non-specialist community settings and improve HCV management among health professionals. The effects of the interventions on testing uptake were variable and a comparison with the themes identified in this review suggest that factors identified in the qualitative research have yet to be fully addressed. Appropriate interventions are required to tackle knowledge and awareness of HCV, and how such knowledge is disseminated between health care providers and PWID. By targeting health professionals' management of HCV, complex interventions that go some way to addressing this factor have shown promise (Helsper, van Essen, Bonten, & de Wit, 2010; Cullen, Stanley, & Langton, 2006). For example, a nurse-led intervention supporting the implementation of clinical guidelines in primary care improved HCV testing rates amongst PWID receiving methadone maintenance treatment (Cullen et al., 2006). HCV is a relative concern among PWID (Rhodes & Treloar, 2008; Harris & Rhodes, 2013). Acknowledgement of shifting priorities among PWID requires consideration in intervention development and in relation to how consent for testing is understood and obtained. The importance and need to integrate peer support in pre- and post-test discussions should also be considered (Treloar, Newland, Harris, Deacon, & Maher, 2010). However, interventions studies are lacking that address these factors. To address testing as routine and unexpected, healthcare services are required that meet the specific and unique needs of people who use drugs (Bruce, 2012). Structural barriers need to be tackled and opportunities for PWID to access testing and other HCV services enhanced through

multidisciplinary or shared care approaches (Grebely, de Vlaming, Duncan, Viljoen, & Conway, 2008). In a UK study, HCV testing uptake was increased by offering dry blood spot testing within substance misuse services, drug clinics and prisons (Hickman et al., 2008). In addition, evidence from two recent case series (Jack, Willott, Manners, Varnam, & Thomson, 2009; Lindenberg et al., 2011) suggests that shared care approaches may be associated with good uptake of follow-up services for HCV, and treatment outcomes considered comparable to those seen in non-drug using populations. Reducing stigma and discrimination related to HCV and PWID is also essential in breaking down barriers to access (Grebely & Dore, 2011; Treloar, Rance, & Backmund, 2013). This review identifies that research is lacking on what PWID think could be done to increase uptake of testing and to improve experiences related to a HCV diagnosis. There is therefore a need for research that engages with a diverse range of injecting populations to identify interventions, strategies and approaches that they consider valuable.

As with other syntheses of qualitative research there were limitations associated with this review. Overall, 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, this review was unable to fully consider the influence of context and setting. Studies were conducted with diverse samples across a range of settings with differences in healthcare systems, accessibility to testing and circulating background information about the need for testing. We also found that it was difficult to disaggregate the views and experiences of hidden populations affected by HCV, such as former users of injecting drugs, from the broader literature on current PWID. In some settings these populations may comprise a significant proportion of individuals with undiagnosed chronic HCV (Cullen et al., 2012). The applicability of the themes arising from this synthesis should therefore be considered and verified according to the setting and context of local PWID populations. There is also 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, and as a range of literature sources were searched, it is unlikely that key studies were missed.

This review provides evidence to show that there are modifiable factors that affect the uptake of HCV testing and experiences of diagnosis among PWID. While existing interventions go some way to addressing these factors, this review has shown that gaps exist and that future development of interventions should consider addressing the broader array of factors identified here. The review also identifies that there is a clear need for research that engages PWID from a diverse range of populations to identify interventions, strategies and approaches that they consider valuable.

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Table 1. Description of included studies

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
Astone et al., 2005	USA	Interviews, focus groups	49 male and female PWIDs with HCV (58% male)	Methadone maintenance treatment programmes	Experience of testing and reactions to diagnosis
Carrier et al., 2005	Canada	Interviews, observations	36 male and female PWIDs (75% male)	Drug services (needle exchange facility and drop-in resource), street and public parks	HCV as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis; the impact of testing on behaviour; stigma as a barrier to disclosure.
Copeland, 2004	UK	Interviews	16 male and female current or former PWIDs with HCV (antibody positive) (56% male)	A single medical practice	HCV as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of HCV; relative understanding of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Craine et al., 2004	UK	Interviews	43 PWIDs (24 tested for HCV) (% male NR)	Drug treatment services	Barriers and facilitators to testing; experience of testing and reactions to diagnosis; impact of testing on behaviour; stigma as a barrier to disclosure.

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
Cullen et al., 2005	Ireland	Survey	25 male and female current and past heroin users (22 with HCV) (56% male)	A single general practice	Experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Davis & Rhodes 2004; Davis et al., 2004	UK	Interviews	59 male and female current PWIDs (19 HCV positive) (68% male)	Drug user networks, community-based drug services and snowballing	HCV as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of HCV; relative understanding of HCV.
Ellard, 2007	Australia	Interviews	31 males and females (13 PWIDs) (% male NR)	Inner city dance/club scene	Incomplete and uncertain knowledge of HCV; stigma as a barrier to disclosure.
Faye & Irurita, 2003	Australia	Interviews	24 people with HCV (13 PWIDs) (% male NR)	Substance use services	Experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Gyarmathy et al., 2006	Hungary	Interviews, focus groups	29 PWIDs aged ≤30 years (% male NR)	Non treatment settings	Incomplete and uncertain knowledge of HCV; barriers and facilitators to testing.
Harris, 2009a; Harris, 2009b	Australia	Interviews	40 people with chronic HCV (34 former PWIDs) (45% male)	HCV-related publications and websites	HCV as normal, ubiquitous and socially accepted; relative understanding of HCV; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure.

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
Khaw et al., 2007	UK	Interviews	30 male and female prisoners who were former PWIDs (21 tested for HCV) (83% male)	Three prisons	Relative understanding of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Lally et al., 2008	USA	Interviews	20 female PWIDs	A single drug treatment centre	Incomplete and uncertain knowledge of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis.
Munoz-Plaza et al., 2004	USA	Interviews, focus groups	29 male and female drug treatment clients and 23 staff (41% male)	Drug treatment service	Barriers and facilitators to testing.
Munoz-Plaza et al., 2005	USA	Interviews, focus groups	51 male and female drug treatment clients (61% male)	Drug treatment service	Barriers and facilitators to testing; experience of testing and reactions to diagnosis.
Munoz-Plaza et al., 2010	USA	Interviews, focus groups	215 male and female drug treatment clients; 165 staff members	14 drug treatment programmes	Relative understanding of HCV.
Perry & Chew-Graham, 2003	UK	Interviews	20 general practitioners	Drug treatment services	Experience of testing and reactions to diagnosis.

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
Rhodes et al., 2004	UK	Interviews	59 male and female current PWIDs (68% male)	Drug user networks, community-based drug services and snowballing	HCV as normal, ubiquitous and socially accepted; incomplete and uncertain knowledge of HCV; relative understanding of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis.
Roy et al., 2007	Canada	Interviews	39 street-involved young PWIDS (aged <30 years old) (59% male)	On-going cohort study; methadone programmes and medical clinics	HCV as normal, ubiquitous and socially accepted; relative understanding of HCV; barriers and facilitators to testing; experience of testing and reactions to diagnosis.
Southgate et al., 2005	Australia	Interviews, observations	24 male and female current PWIDs (58% male)	Open-air drug market and 'red light' district	Barriers and facilitators to testing; experience of testing and reactions to diagnosis.
Strauss et al., 2008	USA	Interviews	62 drug treatment clients (% male NR)	11 drug treatment programmes	Barriers and facilitators to testing; experience of testing and reactions to diagnosis; stigma as a barrier to disclosure.
Sutton & Treloar, 2007	Australia	Interviews	36 people with HCV ^a (% male NR)	Not reported	HCV as normal, ubiquitous and socially accepted; experience of testing and reactions to diagnosis; impact of diagnosis on behaviour; stigma as a barrier to disclosure.

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
Swan et al., 2010	Ireland	Interviews	36 male and female current and former PWIDs (33 with HCV) (78% male)	Two addiction clinics, community drop-in centre, general practice, two hepatology clinics, and infectious diseases clinic	HCV as normal, ubiquitous and socially accepted; barriers and facilitators to testing; experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Temple-Smith et al., 2004	Australia	Interviews	32 males and females with HCV (8 current and 22 former PWIDs) (38% male)	‘Key’ agencies (including needle-syringe exchanges, Liver Clinics, and Hepatitis C Council)	HCV as normal, ubiquitous and socially accepted; barriers and facilitators to testing; experience of testing and reactions to diagnosis; impact of diagnosis on behaviour.
Tompkins et al., 2005	UK	Interviews	17 homeless PWIDs with HCV (88% male)	Primary care centre	Experience of testing and reactions to diagnosis; stigma as a barrier to disclosure.
Wozniak et al., 2007	Canada	Interviews	61 street-involved PWIDs (62% male)	Needle exchanges and other harm reduction and health services; snowballing	HCV as normal, ubiquitous and socially accepted; barriers and facilitators to testing; impact of diagnosis on behaviour.
Wright et al., 2005	UK	Interviews	17 homeless PWIDs with HCV (% male NR)	A primary care health centre for homeless people	Experience of testing and reactions to diagnosis; impact of diagnosis on behaviour; stigma as a barrier to disclosure.

Study	Country	Study type	Population	Recruitment source	Major descriptive themes
^a Number of PWIDs not report. HCV = hepatitis C virus. PWID = people who inject drugs.					