



## Review

## 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 tested was common. An unexpected positive diagnosis exacerbated anxiety and confusion.

**Conclusion:** 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.

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## 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, Tocco, Saini, & Lok, 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,

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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 6255 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).

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:

**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.
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 and 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 and 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, 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.
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 and Chew-Graham (2003)	UK	Interviews	20 general practitioners	Drug treatment services	Experience of testing and reactions to diagnosis.
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 and Treloar (2007)	Australia	Interviews	36 people with HCV <sup>a</sup> (% 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.
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.

Number of PWIDs not report. HCV: hepatitis C virus. PWID: people who inject drugs.

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; Ellard, 2007; Gyarmathy et al., 2006; Lally et al., 2008; Rhodes, Davis, & Judd, 2004), particularly among those who had not previously been tested (Davis & Rhodes, 2004). Such gaps contributed to delays in seeking testing (Lally et al., 2008; Southgate, Weatherall, Day, & Dolan, 2005; Strauss et al., 2008; Swan et al., 2010) 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, p. 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, p. 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, Wright, & Jones, 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, Strauss, Astone, Des Jarlais, & Hagan, 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, p. 51)

Not bothered because I didn't know what it was (Copeland, 2004, p. 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, 2004; Davis, Rhodes, & Martin, 2004; Harris, 2009b; Rhodes et al., 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 (Harris, 2009b; Roy et al., 2007; Wozniak et al., 2007). 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 et al. (2008) 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, p. 542)

I care, but the last thing on my mind is going to get tested. . . (Lally et al., 2008, p. 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, p. 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, p. 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 1980s (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 (Carrier et al., 2005; Copeland, 2004; Cullen et al., 2005; Roy et al., 2007), 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 et al., 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, p. 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 (Lally et al., 2008; Rhodes et al., 2004; Swan et al., 2010; Tompkins et al., 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, p. 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 Bruggman (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 et al., 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 (Cullen, Stanley, & Langton, 2006; Helsper, van Essen, Bonten, & de Wit, 2010). 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 (Harris & Rhodes, 2013; Rhodes & Treloar, 2008). 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; Lindenburg 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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## Conflict of interest statement

The authors declare no conflicts of interest.

## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.drugpo.2013.11.004>.

## References

- Astone, J. M., Strauss, S. M., Munoz-Plaza, C., Hagan, H., & Des Jarlais, D. C. (2005). Providing support to drug users infected with hepatitis C: The role of methadone maintenance treatment staff. *Journal of Maintenance in the Addictions*, 3(1), 33–46.
- Bruce, R. D. (2012). One stop shopping – Bringing services to drug users. *Journal of International Drug Policy*, 23, 103–110.
- Bruggman, P. (2012). Accessing Hepatitis C patients who are difficult to reach: It is time to overcome barriers. *Journal of Viral Hepatitis*, 19, 829–835.
- Carrier, N., LaPlante, J., & Bruneau, J. (2005). Exploring the contingent reality of biomedicine: Injecting drug users, hepatitis C virus and risk. *Health, Risk & Society*, 7(2), 123–140.
- Copeland, L. (2004). The drug user's identity and how it relates to being Hepatitis C antibody positive: A qualitative study. *Drugs-Education Prevention and Policy*, 11(2), 129–147.
- Corey, K. E., Mendez-Navarro, J., Gorospe, E. C., Zheng, H., & Chung, R. T. (2010). Early treatment improves outcomes in acute hepatitis C virus infection: A meta-analysis. *Journal of Viral Hepatitis*, 17, 201–207.
- Craine, N., Walker, M., Carnwath, T., & Klee, H. (2004). Hepatitis C testing and injecting risk behaviour: The results of a UK based pilot study. *International Journal of Drug Policy*, 15(2), 115–122.
- Cullen, B. L., Hutchinson, S. J., Cameron, S. O., Anderson, E., Ahmed, S., Spence, E., et al. (2012). Identifying former injecting drug users infected with hepatitis C: An evaluation of a general practice-based case-finding intervention. *Journal of Public Health*, 34(1), 14–23.
- Cullen, W., Kelly, Y., Stanley, J., Langton, D., & Bury, G. (2005). Experience of hepatitis C among current or former heroin users attending general practice. *Irish Medical Journal*, 98(3), 73–74.
- Cullen, W., Stanley, J., & Langton, D. (2006). Hepatitis C infection among injecting drug users in general practice: A cluster randomised controlled trial of clinical guidelines' implementation. *British Journal of General Practice*, 56(532), 848–856.
- Davis, M., & Rhodes, T. (2004). Beyond prevention? Injecting drug user narratives about hepatitis C. *International Journal of Drug Policy*, 15(2), 123–131.
- Davis, M., Rhodes, T., & Martin, A. (2004). Preventing hepatitis C: 'Common sense', 'the bug' and other perspectives from the risk narratives of people who inject drugs. *Social Science & Medicine*, 59(9), 1807–1818.
- Ellard, J. (2007). '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 injecting drug users. *International Journal of Drug Policy*, 18(3), 225–234.
- Faye, B., & Irurita, V. F. (2003). Balancing perspective: The response to feelings of being condemned with the hepatitis C virus. *Journal of Substance Use*, 8(2), 92–103.
- Grebely, J., de Vlaming, S., Duncan, F., Viljoen, M., & Conway, B. (2008). Current approaches to HCV infection in current and former injection drug users. *Journal of Addictive Diseases*, 27(2), 25–35.
- Grebely, J., & Dore, G. J. (2011). Hepatitis C: Enhancing treatment for hepatitis C among drug users. *Nature Reviews Gastroenterology and Hepatology*, 8, 11–13.
- Gyarmathy, V. A., Neaigus, A., Ujhelyi, E., Szabo, T., & Racz, J. (2006). Strong HIV and hepatitis disclosure norms and frequent risk behaviors among Hungarian drug injectors. *Drug & Alcohol Dependence*, 82(Suppl. 1), S65–S69.
- Harris, M. (2009a). Injecting, infection, illness: Abjection and hepatitis C stigma. *Body & Society*, 15(4), 33–51.
- Harris, M. (2009b). Troubling biographical disruption: Narratives of unconcern about hepatitis C diagnosis. *Sociology of Health & Illness*, 31(7), 1028–1042.
- Harris, M., & Rhodes, T. (2013). Hepatitis C treatment access and uptake for people who inject drugs: A review mapping the role of social factors. *Harm Reduction Journal*, 10, 7.
- Hatzakis, A., Wait, S., Bruix, J., Buti, M., Carballo, M., Cavaleri, M., et al. (2011). The state of hepatitis B and C in Europe: Report from the hepatitis B and C summit conference. *Journal of Viral Hepatitis*, 18(Suppl. 1), 1–16.
- Helsper, C. W., van Essen, G. A., Bonten, M. J. M., & de Wit, N. J. (2010). A support programme for primary care leads to substantial improvements in the effectiveness of a public hepatitis C campaign. *Family Practice*, 27(3), 328–332.
- Hickman, M., McDonald, T., Judd, A., Nichols, T., Hope, V., Skidmore, S., et al. (2008). Increasing the uptake of hepatitis C virus testing among injecting drug users in specialist drug treatment and prison settings by using dried blood spots for diagnostic testing: A cluster randomized controlled trial. *Journal of Viral Hepatitis*, 15(4), 250–254.
- Hopwood, M., & Treloar, C. (2004). Receiving a hepatitis C-positive diagnosis. *Internal Medicine Journal*, 34, 526–531.
- Jack, K., Willott, S., Manners, J., Varnam, M. A., & Thomson, B. J. (2009). Clinical trial: A primary-care-based model for the delivery of anti-viral treatment to injecting drug users infected with hepatitis C. *Alimentary Pharmacology & Therapeutics*, 29(1), 38–45.
- Jones, L., Bates, G., McCoy, E., Beynon, C., McVeigh, J., & Bellis, M. A. (2013). Effectiveness of interventions to increase hepatitis C testing uptake among high-risk groups: A systematic review. *European Journal of Public Health*, <http://dx.doi.org/10.1093/eurpub/ckt156>
- Khaw, F.-M., Stobbart, L., & Murtagh, M. J. (2007). '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. *BMC Public Health*, 7, 98.
- Lally, M. A., Montstream-Quas, S. A., Tanaka, S., Tedeschi, S. K., & Morrow, K. M. (2008). A qualitative study among injection drug using women in Rhode Island: attitudes toward testing, treatment, and vaccination for hepatitis and HIV. *AIDS Patient Care and STDs*, 22(1), 53–64.
- Lindenburg, C. E. A., Lambers, F. A. E., Urbanus, A. T., Schinkel, J., Jansen, P. L. M., Krol, A., et al. (2011). Hepatitis C testing and treatment among active drug users in Amsterdam: Results from the DUTCH-C project. *European Journal of Gastroenterology & Hepatology*, 23(1), 23–31.
- Morris, K. (2011). Tackling hepatitis C: A tale of two countries. *The Lancet*, 377, 1227–1228.
- Mühlberger, N., Schwarzer, R., Lettmeier, B., Sroczyński, G., Zeuzem, S., & Siebert, U. (2009). HCV-related burden of disease in Europe: A systematic assessment of incidence, prevalence, morbidity, and mortality. *BMC Public Health*, 9, 34.
- Munoz-Plaza, C. E., Strauss, S. M., Astone, J. M., Des Jarlais, D. C., & Hagan, H. (2005). HCV (Hepatitis C virus) pre-test and post-test counseling services at drug treatment programs: Missed opportunities for primary prevention. *Contemporary Drug Problems: An Interdisciplinary Quarterly*, 32(4), 655–675.
- Munoz-Plaza, C. E., Strauss, S. M., Astone, J. M., Jarlms, D. C. D., & Hagan, H. (2004). Drug treatment programs as sites of opportunity for the delivery of hepatitis C

- prevention education: Client and staff perspectives. *Journal of Drug Issues*, 34(4), 861–878.
- Munoz-Plaza, C., Strauss, S. M., Tiburcio, N., Astone-Twerell, J. M., Des Jarlais, D. C., Gwadz, M., et al. (2010). Perspectives on the hierarchy of HIV and hepatitis C disease: Consequences for drug treatment program patients. *Journal of Drug Issues*, 40(2), 517–535.
- National Institute for Health and Clinical Excellence. (2009). *Methods for the development of NICE public health guidance* (2 ed.). London: National Institute for Health and Clinical Excellence.
- Nelson, P. K., Mathers, B. M., Cowie, B., Hagan, H., Des Jarlais, D., Horyniak, D., et al. (2011). Global epidemiology of hepatitis B and hepatitis C in people who inject drugs: Results of systematic reviews. *The Lancet*, 378(9791), 571–583.
- Perry, M., & Chew-Graham, C. (2003). Finding a vein or obtaining consent: A qualitative study of hepatitis C testing in GP methadone clinics. *Family Practice*, 20(5), 538–544.
- Rhodes, T., Davis, M., & Judd, A. (2004). Hepatitis C and its risk management among drug injectors in London: Renewing harm reduction in the context of uncertainty. *Addiction*, 99(5), 621–633.
- Rhodes, T., & Treloar, C. (2008). The social production of hepatitis C risk 567 among injecting drug users: A qualitative synthesis. *Addiction*, 103(10), 1593–1603.
- Roy, E., Nonn, E., Haley, N., & Cox, J. (2007). Hepatitis C meanings and preventive strategies among street-involved young injection drug users in Montreal. *International Journal of Drug Policy*, 18(5), 397–405.
- Southgate, E., Weatherall, A. M., Day, C., & Dolan, K. A. (2005). What's in a virus? Folk understandings of hepatitis C infection and infectiousness among injecting drug users in Kings Cross, Sydney. *International Journal for Equity in Health*, 4(5.), <http://dx.doi.org/10.1186/1475-9276-4-5>
- Strauss, S. M., Munoz-Plaza, C., Tiburcio, N. J., Astone-Twerell, J., Des Jarlais, D. C., Gwadz, M., et al. (2008). Barriers and facilitators to undergoing hepatitis C virus (HCV) testing through drug treatment programs. *Journal of Drug Issues*, 38(4), 1161–1185.
- Sutton, R., & Treloar, C. (2007). Chronic illness experiences, clinical markers and living with hepatitis C. *Journal of Health Psychology*, 12(2), 330–340.
- Swan, D., Long, J., Carr, O., Flanagan, J., Irish, H., Keating, S., et al. (2010). Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: A qualitative exploration. *AIDS Patient Care and STDs*, 24(12), 753–762.
- Temple-Smith, M., Gifford, S., & Stooé, M. (2004). The lived experience of men and women with hepatitis C: Implications for support needs and health information. *Australian Health Review*, 27(2), 46–56.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45.
- Tompkins, C. N. E., Wright, N. M. J., & Jones, L. (2005). Impact of a positive hepatitis C diagnosis on homeless injecting drug users: A qualitative study. *British Journal of General Practice*, 55(513), 263–268.
- Treloar, C., Newland, J., Harris, M., Deacon, R., & Maher, L. (2010). A diagnosis of hepatitis C: Insights from a study on patients' experiences. *Australian Family Physician*, 39(8), 589–592.
- Treloar, C., Rance, J., & Backmund, M. (2013). Understanding barriers to hepatitis C virus care and stigmatization from a social perspective. *Clinical Infectious Diseases*, 57(Suppl. 2), S51–S55.
- Volk, M. L., Tocco, R., Saini, S., & Lok, A. S. (2009). Public health impact of antiviral therapy for hepatitis C in the United States. *Hepatology*, 50(6), 1750–1755.
- World Health Organization. (2012a). *Prevention and control of viral hepatitis infection: Framework for global action*. Geneva: World Health Organisation.
- World Health Organization. (2012b). *Guidance of the prevention of viral hepatitis B and C among people who inject drugs*. Geneva: World Health Organisation.
- Wozniak, L., Prakash, M., Taylor, M., & Wild, T. C. (2007). Everybody's got it, but...: Situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *International Journal of Drug Policy*, 18(5), 388–396.
- Wright, N. M. J., Tompkins, C. N. E., & Jones, L. (2005). Exploring risk perception and behaviour of homeless injecting drug users diagnosed with hepatitis C. *Health & Social Care in the Community*, 13(1), 75–83.