

**Report: January 2012** 

# Hepatitis C and HIV Co-infection

# **Contents**

Overview	3
The hepatitis C epidemic in the UK	4
Hepatitis C and HIV: Key Facts	4
Hepatitis C co-infection in patients with HIV	6
How is hepatitis C being transmitted?	8
Hepatitis C prevention	9
Hepatitis C diagnosis and treatment	11
Supporting people with HIV and hepatitis C	12
Recommendations	13
Further information and sources of support	15
End notes	16

# **Acknowledgements**

NAT would like to thank Michael Carter, the consultant who undertook the research and initial drafting of this policy paper.

NAT would also like to acknowledge the helpful advice and suggestions of the Hepatitis C Trust in the preparation of this paper.

The content and conclusions of the paper remain the responsibility of NAT alone.





#### **Overview**

- Approximately 9% of HIV positive people in the UK are co-infected with hepatitis C.
- Liver disease caused by hepatitis B and/ or C is a leading cause of serious illness and death in people who are HIV/hepatitis C co-infected. The BHIVA mortality audit in 2006 attributing 6% of all deaths in HIV positive patients to these infections.
- Hepatitis C is a blood-borne infection and prevalence and incidence of the infection is high in HIV positive injecting drug users (83% of HIV positive injecting drug users are co-infected with hepatitis C).
- There is also an epidemic of hepatitis C among HIV positive gay men (7% of HIV positive gay men are co-infected with hepatitis C). Infections are largely due to sexual risk factors, but drug use behaviours may also have a role.
- There is currently no national strategic approach to prevent hepatitis C infections in gay men.

- Accurate and specific information on the risk factors for hepatitis C transmission should be provided to HIV positive individuals.
- Regular screening for hepatitis C is recommended for people with HIV. This should be promoted and encouraged as early diagnosis and treatment has a high response rate. Promising new hepatitis C therapies are becoming available, but there is uncertainty about how to use them in HIV-infected patients.
- Evidence suggests high levels of mental health distress among men at risk of and living with hepatitis C co-infection.
- The stigma surrounding hepatitis C is fuelling the epidemic, and there is some evidence that HIV positive gay men engaging in high risk behaviours are relying on disclosure as a prevention strategy.

This report concludes with a set of recommendations to improve the UK response to HIV/hepatitis C co-infection.

Hep C is not yet owned by the gay community like HIV, and if it isn't owned, then it is outside and more stigmatised ... Even within the gay community, and the HIV community too, it has created a 'them' and 'us' type situation.

-Research Participant

# The hepatitis C epidemic in the UK

Hepatitis C is a blood-borne infection that can cause liver inflammation and other long-term health problems. Unlike hepatitis A and hepatitis B there is no vaccine against hepatitis C.

Approximately 25% of people naturally clear the infection at the acute phase (the first six months of infection), but for the remaining 75%, hepatitis C infection becomes chronic. Treatment for hepatitis C is available, and the current standard of care is 24 or 48 weeks of therapy with pegylated interferon and ribavirin. Response rates vary from approximately 40% to 80% and therapy can cause significant sideeffects. Unless successfully treated, the infection can lead to liver fibrosis and cirrhosis, end stage liver disease and liver cancer, and death. Several new anti-hepatitis C drugs have recently been approved and several others are currently in clinical trials.

At the end of 2010 there were an estimated 216,000 chronic hepatitis C infections in the UK. Although there were approximately 10,400 new diagnoses in 2010, anonymous testing shows that vast majority of hepatitis C infection are undiagnosed.1 Approximately 90% of diagnosed infections are in current or former injecting drug users.2

# **Hepatitis C and HIV: Key Facts**

Hepatitis C is a blood-borne virus which primarily affects the liver. Only a minority of patients experience symptoms when they are first infected (the 'acute infection' stage, lasting six months), but when they do occur symptoms include diarrhoea, nausea and jaundice. In the longer term about half of people with hepatitis C experience symptoms such as generally feeling unwell, extreme tiredness, weight loss, intolerance of fatty food, and depression.

About 25% of people infected with Hepatitis C clear the virus naturally from their blood during acute infection whilst the other 75% go on to develop chronic hepatitis C. Those who clear the virus are no longer infectious. Complications which may arise from chronic hepatitis C infection are chronic liver inflammation, liver cirrhosis and liver cancer. But experiences vary - some people never experience complications whilst about a third of people with chronic hepatitis C infection will develop serious liver disease after 15 to 25 years of infection. Some factors have been identified which appear to accelerate hepatitis C disease progression - alcohol, older age and untreated HIV for example.

Hepatitis C testing is recommended for anyone diagnosed with HIV and also at least annually for all HIV patients since there are immense advantages to being diagnosed with hepatitis C co-infection early. Liver function tests and sometimes liver biopsies are used to assess whether liver damage has occurred in someone with hepatitis C. A genotype test is important in determining the chances of treatment being effective and its duration.

Generally co-infection with HIV and hepatitis C complicates each disease. As has been stated, untreated HIV makes it more likely the individual will develop liver damage compared with those infected with hepatitis C alone. There is, however, also evidence HIV treatment can slow hepatitis C progression and it may be recommended for someone co-infected that they

start HIV treatment somewhat earlier than normal. Liver disease is now a major cause of hospital admission and death amongst HIV positive people because of hepatitis B and C liverrelated problems.

People co-infected with HIV and hepatitis C appear to have higher rates of diabetes and of cardiovascular disease.

HIV treatment can be used safely and effectively if you have hepatitis C, and you can be treated for both conditions at the same time. There are some older and less commonly used anti-HIV drugs which can cause liver side-effects, but doctor and patient can bear this in mind when determining medication.

Treatment aimed at curing the condition is available for hepatitis C, currently with the drugs ribavirin and pegylated interferon. There are currently a large number of treatments for hepatitis C in trial. Two drugs that have already been approved for safety by the FDA and the European equivalent are Incivek/Telaprevir (Janssen) and Victrelis/Boceprevir (MSD). Both of these drugs are protease inhibitors, which are treatments that aim to prevent HCV from replicating. They will be used in combination with Peg-interferon and ribavirin.

A 'Sustained Virological Response' (SVR) means that hepatitis C is not detectable in the blood six months after completing treatment - and this means the individual is cured of hepatitis C infection. There are at least six different genotypes of hepatitis C and there are different response rates to treatment depending on the genotype (with genotype one having significantly lower response rates). Best results are amongst those who have been recently infected with high treatment success rates during the acute infection period. Overall response rates in co-infected patients are approximately 60% of

those seen in hepatitis C mono-infected patients.

The treatment is not indefinite and the length of treatment will depend on the genotype and the patient response. The normal duration of treatment for co-infected patients is 48 weeks. After 12 weeks a test can predict if you are not going to respond at all to treatment in which case it would be discontinued - on the other hand some respond to the treatment slowly in which case it may last up to 72 weeks.

If you have had hepatitis C but are no longer infected, you are not protected from contracting it again in the future.

Side-effects of hepatitis C treatment vary considerably and for some people can be severe. They can include high temperatures, joint pain, weight loss, skin problems, thinning hair, feeling sick, anaemia and depression. Depression associated with interferon in particular can cause serious difficulty and distress for those taking the treatment. However, these side-effects are not inevitable and sometimes lessen or go away. They can also be alleviated by taking treatments to reduce pain and fever, to support red blood cell counts and by antidepressants.

See further reading below:

- NAM 'HIV and hepatitis' 2010 sixth edition
- HIV i-Base 'Guide to hepatitis C for people living with HIV' March 2009
- BHIVA 'Guidelines for the management of co-infection with HIV-1 and hepatitis B or C virus' 2010
- · Sigma Research Making It Count Briefing Sheet 5 'Hepatitis C' March 2011

# Hepatitis C co-infection in patients with HIV

Overall hepatitis C prevalence in the UK Collaborative HIV Cohort (UK CHIC) is 8.9%. However, there is considerable disparity between risk groups. Some 83% of HIV positive injecting drug users are co-infected with hepatitis C. whereas the co-infection rate in HIV positive gay men is 7%.3 Whilst this is a much lower prevalence rate than amongst HIV positive injecting drug users, given the large numbers of HIV positive gay men there are more co-infected gay men than there are co-infected injecting drug users.

Injecting drug users remain at high risk of incident hepatitis C and HIV. A study involving over 400 injecting drug users mainly from London found a hepatitis C incidence of 41% and an HIV incidence of 3%.4

There is also an epidemic of sexually transmitted hepatitis C among HIV positive gay men. This emerged in the early 2000s and infections are mainly clustered in cities with large gay populations, principally London, and to a lesser extent Brighton and Manchester. Epidemics of sexually transmitted hepatitis C in HIV positive gay men have also been reported in Germany, the Netherlands, Milan in Italy, the US and Australia.

The HPA conducts enhanced surveillance for newly acquired hepatitis C infections in gay

men. Data published in 2011, which was based on reports from 22 centres in London, Manchester and Southeast England, reported 218 incident infections in this group between 2008 and 2010. Approximately 92% were in gav men with HIV and 84% were located in London.5 An earlier study showed that by 2007 there had been 400 diagnoses of sexually transmitted hepatitis C in HIV positive gay men in London and Brighton alone.6

There is some uncertainty and controversy about the precise risk factors for sexual transmission of hepatitis C, but unprotected anal sex, fisting, the use of sex toys, group sex, and drug use during sex have all been identified.

There is no significant evidence of sexual transmission of hepatitis C in HIV negative gay men. A cohort study involving over 1,000 HIV negative gay men in Montreal, Canada, found no significant relationship between sexual activity and risk of hepatitis C transmission.7 A study conducted among patients of the sexual health clinic of University College London and presented at the BHIVA annual conference in 2008 found that hepatitis C prevalence in HIV negative gay men was 0.51%, identical to the prevalence observed in HIV negative heterosexual men.8 Similarly lacking are data

demonstrating sexual transmission of the virus in hepatitis C discordant heterosexual couples.9

British HIV Association (BHIVA) guidelines recommend that all patients with HIV should be screened for hepatitis C at the time of their HIV diagnosis, with annual follow-up screening thereafter. More frequent testing is recommended for individuals with a higher risk of hepatitis C infection, including HIV positive gay men with risky sexual behaviour.<sup>10</sup> Overall, 80% of patients enrolled in the UK CHIC had been tested for hepatitis C at least once. This includes 74% of gay men, but only 50% of injecting drug users.11 A BHIVA audit in 2009/10 found that 66% of patients at the 140 participating sites had annual hepatitis C antibody tests.12 Liver function should also be monitored as part of routine HIV care, and abnormalities can prompt screening for infection with hepatitis C.

Prompt diagnosis of hepatitis C is especially important as the provision of therapy during the first year of infection can yield cure rates of up to 80%. By contrast, the response rate to treatment for chronic hepatitis C is approximately 40%. Treatment can cause significant side-effects, and although a number of new anti-hepatitis C agents have been approved

or are in the pipeline there is uncertainty about how they should be best used in patients with HIV.

The prevention and treatment of hepatitis C is a priority for people with HIV. Liver disease caused by hepatitis C is an important cause of death in co-infected patients. Moreover, co-infected patients have a significantly shorter prognosis than HIV positive people who do not have hepatitis C.13

A significant proportion of HIV positive gay men who are successfully treated for

hepatitis C are rapidly re-infected with the virus. A study conducted in Hamburg found a 50% re-infection rate within six years;<sup>14</sup> a 25% re-infection rate within two years has been observed in Amsterdam; 15 and the two-year re-infection rate at the Royal Free Hospital, London, is 40%.16

Hepatitis C is a highly stigmatised illness, and a small qualitative study suggests that the fear and stigma that surrounds the infection is creating an environment that facilitates the continued

transmission of the infection.17 Moreover, there is anecdotal evidence that HIV positive gay men seeking sex that involves a risk of hepatitis C transmission such as unprotected anal sex and fisting are stigmatising and shunning those whose infection has been diagnosed, and are relying on potential sex partners to have an accurate knowledge of their current hepatitis C infection status.

These data have a number of serious and immediate implications for HIV positive patients.

Overall, 80% of patients enrolled in the UK CHIC had been tested for hepatitis C at least once. This includes 74% of gay men, but only 50% of injecting drug users. A BHIVA audit in 2009/10 found that 66% of patients at the 140 participating sites had annual hepatitis C antibody tests.

# How is hepatitis C being transmitted?

As a blood-borne infection. there is a significant risk of hepatitis C infection for HIV positive injecting drug users who share needles and other injecting paraphernalia. Although sexual transmission is clearly occurring in HIV positive gay men, the precise risks are not yet clear.

Soon after the epidemic emerged in the early 2000s, unprotected anal sex was identified as a risk factor. 18 A mechanism by which the generally blood-borne virus could be sexually transmitted was suggested in a study that found that hepatitis C was found more often in the semen of HIV positive men than that of HIV negative men.<sup>19</sup> However, this research was not definitive, and a separate study showed that the virus was only intermittently present in the semen of HIV-infected men. and then at low and uninfectious quantities.20 Moreover, lack of transmissions in both hepatitis C serodiscordant heterosexual couples and HIV negative gay men may suggest that the virus is not readily transmitted via semen. Nevertheless, a significant proportion of hepatitis C infections in HIV positive gay men involve individuals whose only reported risk factor was unprotected anal sex.

However, rather than unprotected sex per se, sexual behaviour that potentially involves contact with blood may

be a more important risk factor. Anal sex can cause bleeding. and even small quantities of hepatitis C-infected blood can pose a transmission risk. Trauma and bleeding is even more likely to be caused by activities such as fisting and the use of sex toys. Indeed, fisting is a consistently reported risk factor for the sexual transmission of hepatitis C in HIV positive gay men. For instance, fisting was reported by 17 of the 20 men with incident hepatitis C at the Royal Free Hospital between 2001 and 2003, and subsequent research involving 308 men found that fisting was the sexual activity most strongly associated with hepatitis C infection.21

Sexual transmission of hepatitis C also appears to be occurring within the context of recreational drug use. Stimulant drugs can prolong sexual activity, increasing the likelihood of trauma and bleeding, and painkilling drugs such as ketamine can mean that individuals are unaware that they have experienced trauma or bleeding during lengthy sex sessions.

The mode of drug administration may also have a direct role in infections. Hepatitis C has been detected in the nose and in straws used for inhaling substances such as cocaine.22

Moreover, it is possible that injecting drug use may have a role in some infections in gay men that have attributed to sexual transmission. Investigators from the UK CHIC have suggested that injecting drug use may be "underreported by some MSM [men who have sex with men], sufficient to place them at risk of HCV infection... underreporting of IDU as a risk for HCV transmission in MSM may also affect other cohorts." It is therefore significant that research in Australia showed that injecting drug use was the single most important risk factor for infection with hepatitis C in gav men.23

Large numbers of sex partners are consistently reported by gay men infected with hepatitis C. "Serosorting" (selecting sexual partners of the same HIV status) may also have a role in the hepatitis C epidemic. Phylogenetic analysis has found clusters of hepatitis C infections revealing transmission networks.

Unpicking the precise mode of hepatitis C transmission is complicated by the multiple risk factors reported by many people with incident hepatitis C. Overlapping risk factors including unprotected anal sex, fisting, drug use, large numbers of sex partners and group sex with other HIV positive people are often present, as are activities such as rimming and oral sex which have also been implicated in hepatitis C transmissions in some studies.24

# **Hepatitis C prevention**

Hepatitis C is mentioned together with other potentially dangerous sexually transmissible infections in the 2011 edition of Making it Count (the national HIV prevention framework in England for gay and bisexual men). Although the infection receives no other substantive discussion in the document it is the subject of the Making It Count Briefing Sheet Number 5. Nevertheless, there is currently no national framework to address the epidemic of sexually transmitted hepatitis C in HIV positive gay men. However, data have been gathered in the UK Gay Men's Sex Survey illustrating hepatitis C screening history, and the surveys have also gathered information on the prevalence of risk behaviours most strongly associated with hepatitis C transmission. Results of the 2006 survey showed that approximately 50% of respondents thought that they

had been tested for hepatitis C, and 4.4% of this group and 2.1% of the total survey sample said they were infected with hepatitis C.

However, authors believed that the testing prevalence was an over-estimate, due to confusion about types of viral hepatitis, and also because it is not standard practice to test HIV negative gay men for hepatitis C in sexual health settings. The results also showed that risk factors for hepatitis C transmission were highly prevalent. 13% of men reported fisting in the previous twelve months,25 and the 2008 survey showed that 54% of HIV positive men had had unprotected anal sex in the previous year at least once. This included 28% of HIV positive men who had had unprotected anal sex with a man they knew to be HIV positive.26

Needle exchange programmes are the cornerstone of HIV and hepatitis C prevention for injecting drug users. However, it is estimated that approximately 45% of injecting drug users are unaware of their hepatitis C infection status and in 2009 the Hepatitis C Trust launched a Get Tested! campaign.27

Valuable campaigns have also been targeted at HIV positive gay men to raise awareness of hepatitis C infection and the factors associated with its transmission. In May 2005, THT launched its 'A, B, C is just the start' campaign, alerting gay men to the risk of these infections and the steps they could take to protect themselves against it. The campaign highlighted "sharing needles, razors, snorting pipes, unprotected fucking and fisting" as risk factors for the infection.28 Information on the risks of hepatitis C, prevention, symptoms and treatment are

The failure to prioritise the risk associated with fisting and other sexual activities likely to involve trauma and contact with blood may mean that men are not been sufficiently alerted to what is consistently emerging as a highly important risk factor.

also provided on the Hard Cell website (http://www.hardcell. org.uk/clinic12.htm), which is targeted at gay men involved in "heavier" sex scenes and whose sexual activity is especially risky. The site notes that the use of condoms for penetrative sex and gloves for fisting can reduce the risk of hepatitis C transmission, and it also cautions against sharing drug-taking equipment.

GMFA ran hepatitis C co-infection awareness and prevention campaigns in 2005 and 2009, both campaigns highlighting the risk factors and possible consequences of hepatitis C co-infection.

Information on hepatitis C transmission risks is also provided on several HIV information sites, including THT's MyHIV (http://www. myhiv.org.uk/Staying-healthy/ Coinfection/Hepatitis/Hepatitis-C), and GMFA's Positive Gay Guide (http://www.gmfa.org. uk/positive/sex/protectingvourself). NAM have a booklet on HIV and hepatitis, which includes a lengthy section on the hepatitis C (http://www. aidsmap.com/HIV-hepatitis/ page/1506073/). Its treatment newsletter HTU has also carried articles discussing the epidemiology, risks, and treatment of hepatitis C in patients with HIV.29 A detailed booklet on hepatitis C is also available from iBase (http://ibase.info/guides/hepc).

These campaigns and information literature generally imply that unprotected anal sex, fisting, and sharing drug taking equipment involve equal risks of hepatitis C transmission. Arguably this reflects the lack of clarity in the research data. A priority must be the development of clinical consensus on the key risk factors for sexual transmission of hepatitis C to provide great focus and confidence to prevention interventions.

Further work is necessary, such as that already undertaken by THT and GMFA, informing HIV positive gay men of the risks of hepatitis C transmission, with, as has been said, greater focus on the most significant risks. In addition, complementing this vital health promotion work, HIV clinics need to have clear strategies to minimise hepatitis C transmission (and maximise early hepatitis C diagnosis) amongst their gay HIV positive patients, with consistent testing and counselling processes.

The failure to prioritise the risk associated with fisting and other sexual activities likely to involve trauma and contact with blood may mean that men are not been sufficiently alerted to what is consistently emerging as a highly important risk factor. Moreover, the high prevalence of recreational drug use among gay men, especially those with HIV, suggests that greater emphasis should be placed on

both the direct role of sharing drug taking equipment in hepatitis C transmissions and the facilitative role of drug use to prolong sex, thereby increasing the risk of trauma and bleeding. Indeed, there are data to suggest that drug use behaviours (snorting or injecting) that could transmit hepatitis C are highly prevalent among gay men. A report published in 2009 showed that over a third had ever used cocaine, 29% amphetamines, 9.5% methamphetamine, 6.8% crack and 5.7% heroin.30 It is also of note that the 2005 UK Gay Men's Sex Survey found that although only 3% of gay men overall reported use of the drug methamphetamine in the previous year, prevalence of use was 20% among all HIV positive gay men, and 35% of HIV-infected men with 30 or more sex partners a year reported taking the drug.31

Research attention could profitably be devoted to the personal strategies HIV positive gay men are adopting to protect themselves from hepatitis C infection. If anecdotal reports that some individuals are relying on their sexual partners to disclose their infection status prove founded. then there is a clear need for well-focused and targeted information highlighting the unreliability of this strategy.

# Hepatitis C diagnosis and treatment

Prompt diagnosis of hepatitis C infection has both individual and public health benefits. It is possible to cure hepatitis C infection, and increasing rates of hepatitis C detection and therapy were highlighted by the HPA in its 2011 report as being key to control of the epidemic.

Early treatment of hepatitis C in HIV positive individuals has a success rate of up to 80%, much higher than the 30% to 40% seen if therapy is provided during the chronic phase. Because of the growing interest in early therapy, European consensus guidance for the detection and management of acute hepatitis C infection in HIV positive

individuals were issued in 2010,<sup>32</sup> which are generally in accordance with BHIVA guidance.

Individuals who did not respond to hepatitis C therapy, or are unwilling to take such treatment can still benefit from monitoring and care. Co-infected patients have more rapid hepatitis C disease progression, which is probably due to the inflammatory effects of untreated HIV infection. For this reason, early antiretroviral therapy is especially recommended for co-infected patients. Virologically suppressive HIV therapy has been shown to slow the pace of hepatitis C disease progression

and improve the prognosis of co-infected patients.<sup>33</sup>

There is also an obvious information need for co-infected patients concerning newer hepatitis C agents. Telaprevir and boceprevir have been shown to improve treatment response rates in individuals with hepatitis C alone, when used in combination with pegylated interferon and ribavirin. However, there are extremely limited data about the safety and efficacy of these newer drugs in people who have HIV as well as hepatitis C, leading to substantial uncertainty about their role in therapy for co-infected individuals.34

The fact that a significant proportion of individuals successfully treated for hepatitis C are rapidly re-infected suggests that there are needs, recognised or not, which are long-term and which are not receiving appropriate intervention and support.

# Supporting people with HIV and hepatitis C

The needs of co-infected people extend beyond the concerns about antiviral treatment. BHIVA guidelines recommend that the care of co-infected patients should include both an HIV specialist, a hepatologist, and if appropriate other specialists, and the guidance also stresses the importance of clinical networks.35 This shared care model is especially important as hepatitis C infection and its treatment can add to the burden of illness experienced by people with HIV, significantly affecting an individual's overall health. quality of life, mental and emotional well-being and ability to work. The BHIVA audit noted widespread good practice but also some concerns in a minority of cases including delayed or lost referrals, some lengthy travel distances, some high 'did not attend' rates and the need for better communication and strengthened networks.

Stigma associated with hepatitis C can also cause social isolation and a loss of self-worth. One research participant described his reaction diagnosis with hepatitis C thus: "I felt grubby. I felt skanky. I felt isolated. I felt lonely...it's the shame: the shame, secrecy, stigma and everything else." Another participant in the same study highlighted the stigmatising attitudes of other gay men towards hepatitis C: ""Hep C is

not yet owned by the gay community like HIV, and if it isn't owned, then it is outside and more stigmatised... Even within the gay community, and the HIV community too, it has created a 'them' and 'us' type situation."36

Clearly there is a need to support individuals living with the psychological and social ramifications of hepatitis C infection. Moreover, there is a pressing need to address the wider circumstances in which hepatitis C transmissions are occurring. Research has consistently shown high levels of emotional distress as well as anxiety and depression in people with HIV.37 Many infections are in men who have been living with diagnosed HIV for longer periods of time. The significant prevalence of recreational drug use and high numbers of sexual partners reported by large numbers of men diagnosed with hepatitis C could be a coping strategy, suggestive of unmet mental health needs. The fact that a significant proportion of individuals successfully treated for hepatitis C are rapidly re-infected suggests that there are needs, recognised or not, which are long-term and which are not receiving appropriate intervention and support.

There is also a more general need to address the stigma that many gay men with HIV attach to hepatitis C, not least because the fear of rejection

causes individuals to experience shame and fear. leading to silence and nondisclosure. This creates transmission risk in situations where HIV-positive men have sero-sorted to engage in unprotected sexual practices and are relying on their partner's disclosure as a hepatitis C prevention strategy.

Work targeting gay men, especially those with HIV, that addresses the community-wide stigma associated with hepatitis C would have benefits for individuals with or at risk of the infection, and also address the misguided prevention strategies adopted by some men which are undoubtedly contributing to ongoing transmissions.

#### Recommendations

A significant proportion of HIV positive people in the UK are co-infected with hepatitis C (approximately 83% of HIV positive injecting drug users and 7% of HIV positive gay men). Hepatitis C is an increasingly important cause of illnesses and death amongst HIV positive people in the era of effective antiretroviral therapy. Addressing HIV/ hepatitis C co-infection must become a strategic priority within health promotion for, and the healthcare of, those groups most at risk.

Comprehensive surveillance and reporting of hepatitis C/ HIV co-infection data should continue to be undertaken and further developed by the **Health Protection Agency** and clinics, with co-infection data regularly reported.

It is striking in particular that that is not as yet an agreed strategic approach explicitly addressing the epidemic of sexually transmitted hepatitis C in HIV positive gay men. Given the continuing incidence of the infection in this group - and the increasing importance of liver disease as a cause of serious illness and death in co-infected patients - the prevention of hepatitis C in HIV positive gay men deserves to be a national priority in gay men's health promotion. An agreed strategic approach must be developed by the Department of Health, gay men's health promotion organisations and

#### relevant clinical bodies.

BHIVA have detailed guidance on hepatitis C screening, treatment and care. Annual screening for hepatitis C is recommended for all HIV positive patients with a risk of the infection but only 66% of clinics reported doing so in the 2009/10 BHIVA audit. It is vitally important that all people diagnosed with HIV are annually screened for hepatitis C infection and commissioners should be requiring this of all relevant services.

Current BHIVA Guidelines recommend more frequent than annual testing for MSM 'at sexual risk' but the nature of such sexual risk is not defined. Prevalence and consistency of 'more frequent than annual' hepatitis C screening does not appear to have been included in the recent BHIVA audit. Given the value of diagnosis during acute infection (a six month period) for treatment success, greater clarity is needed on those at ongoing risk of hepatitis C needing to be screened at least every six months, and also on which behaviours amongst MSM indicate the need for such 'more frequent' hepatitis C screening.

New hepatitis C and HIV infections are also occurring amongst injecting drug users, requiring well-targeted and appropriate prevention

interventions. Comprehensive harm reduction services (including needle exchange, testing services for both HIV and hepatitis C, and opioid substitution treatment) must be at the forefront of hepatitis C and HIV prevention for injecting drug users.

The well-established hepatitis C epidemics in HIV positive gay men have been attributed to a range of sexual risk factors. which include unprotected anal sex, fisting, the use of sex toys, and group sex, especially within the context of recreational drug use. Sharing drug-taking equipment may also be a risk factor. There is currently disagreement about the relative importance of these risk factors, and this may be hampering clear and effective prevention information. Clinical/scientific consensus is urgently needed on key risk factors for sexual transmission of hepatitis C transmission. This is an area where joint work by BHIVA and the British Viral Hepatitis Group would be very useful. **Health promotion** interventions around hepatitis C for gay men with HIV should then be developed as soon as possible in response to such a consensus statement.

More broadly, further health promotion should be resourced and provided to HIV positive gay men which highlights, for example, the ongoing risks for HIV positive men who are sero-sorting of other serious sexually transmitted infections, and the dangers of relying on partners to know or disclose their hepatitis C infection status.

It is important to highlight the risk to gay men of hepatitis C and other blood-borne viruses from the sharing of needles and other drug-taking works and paraphernalia.

**BHIVA Guidance contains** detailed information about the treatment of co-infected patients. Treatment should be available and provided consistently across the country to co-infected patients in full conformity with the BHIVA Guidance. The NHS **Commissioning Board should** ensure commissioning of HIV and hepatitis C services addresses HIV/hepatitis C co-infection according to clear **Quality Standards.** 

It is also important to research the wider social, practical and emotional needs of individuals with HIV and hepatitis C coinfection. Re-infection rates for hepatitis C amongst HIV positive gay men are a serious cause for concern. Further research is needed into the reasons for hepatitis C infection and reinfection amongst gay men, as well as the social and psychological impacts of hepatitis C infection. Intensive support, including as appropriate mental health support, should be made available to help prevent infection and re-infection. This issue could also usefully be further addressed in the next issue of BHIVA Guidance.

**Hepatitis C anti-stigma work** amongst gay men should be planned and resourced, on the basis of relevant research, and with clear outcome-focussed evaluation measures.

Addressing HIV / hepatitis C co-infection must become a strategic priority within health promotion for, and the healthcare of, those groups most at risk.

# Further information and sources of support

#### **NAT (National AIDS Trust)**

#### www.nat.org.uk

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.

#### **British HIV Association (BHIVA)** www.bhiva.org

BHIVA has become the leading UK professional association representing professionals in HIV care. Founded in 1995, it is a well-established and highly respected organisation with national influence committed to providing excellence in the care of those living with and affected by HIV.

BHIVA produce consensus guidelines for the treatment and care of patients with HIV. These include specialist hepatitis guidelines, which were last updated in 2010.

#### NAM

#### www.aidsmap.com

A leading provider of HIV treatment information, NAM produces a number of resources concerning HIV and hepatitis C co-infection. Regular news reports on hepatitis C risk factors and treatment developments appear on its website.

#### **iBASE**

#### www.i-base.info

HIV i-Base is a treatment activist group, HIV positive led and committed to providing timely HIV treatment information to HIV positive people and to health care professionals. It produces a booklet on HIV and hepatitis C co-infection.

# **Hepatitis C Trust**

#### www.hepctrust.org.uk

The Hepatitis C Trust is the national UK charity for hepatitis C and has been operating since 2001. It is a patient-led and patient-run organisation and almost all of its Board, staff and volunteers either have hepatitis C or have had it and have cleared it after treatment.

# **Terrence Higgins Trust**

#### www.tht.org.uk

Terrence Higgins Trust is the UK's largest HIV and sexual health charity with centres across England, Scotland and Wales. THT provides information and advice, campaigns for better sexual health and the rights of people with HIV and offers a wide range of services including sexual health checks, counselling and support groups. THT has provided information about hepatitis C in its sexual health promotion interventions to gay men.

### Sigma Research

#### www.sigmaresearch.org.uk

Sigma Research is a social research group specialising in the social, behavioural and policy aspects of HIV and sexual health. Sigma is part of the Faculty of Public Health and Policy at the London School of Hygiene & Tropical Medicine. Sigma undertake significant research into gay men's sexual behaviour and other relevant behaviours in the UK.

#### **GMFA**

#### www.gmfa.org.uk

GMFA is the UK's leading gay men's health charity. We utilise the skills and experience of our volunteers to produce a broad range of online, mass and small media resources and face to face interventions. We reduce health inequalities within the gay community by increasing the control that gay men have over their own lives, their health and, specifically, their sexual health. GMFA is part of the Health Equality and Rights Organisation. GMFA has developed small and mass media resources to provide HIV positive gay men with information on hepatitis

#### **End notes**

- 1: HPA, Hepatitis C in the UK: 2011 Report.
- 2: Shooting Up Infections among Injecting Drug Users in the United Kingdom, 2009.
- 3: "The prevalence of hepatitis C virus (HCV) infection in HIV positive individuals in the UK - trends in HCV testing and the impact of HCV on HIV treatment outcomes", Journal of Viral Hepatitis, Vol 17 Aug 2010.
- 4: "Incidence of hepatitis C virus and HIV among new injecting drug users in London: prospective cohort study", BMJ, Vol 330, Jan 1 2005.
- 5: HPA 2011 Report.
- 6: IAS: Hepatitis C clusters reveal international transmission among HIV positive gay men, http://www.aidsmap.com/IAS-Hepatitis-C-clusters-reveal-international-transmission-among-HIV-positive-gay-men/ page/1427944/.
- 7: Little evidence of sexual transmission of HCV amongst HIV negative gay men in largest study yet. http://www.aidsmap.com/Little-evidence-ofsexual-transmission-of-HCV-amongst-HIV-negative-gay-men-in-largeststudy-yet/page/1420267/.
- 8: BHIVA: No evidence of hepatitis C epidemic in HIV negative gay men, http://www.aidsmap.com/BHIVA-No-evidence-of-a-hepatitis-C-epidemicin-HIV-negative-gay-men/page/1430200/.
- 9: "Lack of evidence of sexual transmission of hepatitis C among monogamous couples: results of a 10-year prospective follow-up study", American Journal of Gastroenterology, Vol 99, May 2004.
- 10: Management of Coinfection with HIV-1 and Hepatitis B or C Virus, BHIVA, 2010 (http://www.bhiva.org/HepBC2010.aspx).
- 11: As note 3.
- 12: HIV and Hepatitis B/C Co-infection Audit, BHIVA 2009-10, http:// www.bhiva.org/NationalAuditReports.aspx.
- 13: "Survival of persons with and without HIV infection in Denmark, 1995-2005", Ann Int Med, 146, Jan 16 2007.
- 14: Hepatitis C still increasing in German gay men with HIV, reinfection common. http://www.aidsmap.com/Hepatitis-C-still-increasing-in-German-gay-men-with-HIV-reinfection-common/page/1541682/.
- 15: High rate of HCV reinfection after treatment of acute infection in Amsterdam gay men. http://www.aidsmap.com/High-rate-of-HCVreinfection-after-treatment-of-acute-infection-in-Amsterdam-gay-men/ page/1690938/.
- 16: Correspondence, Dr Sanjay Bhagani, September 2011.
- 17: "An 'elephant in the room': stigma and hepatitis C transmission among HIV-positive 'serosorting gay' men", Culture, Health and Sexuality 10, Aug 2008.
- 18: Barebacking the sole common risk factor in London's sexually transmitted hepatitis C epidemic. http://www.aidsmap.com/Barebackingthe-sole-common-risk-factor-in-Londons-sexually-transmitted-hepatitis-C-epidemic/page/1416879/.
- 19: "Hepatitis C virus in the semen of men coinfected with HIV-1: prevalence and origin", AIDS 19, Nov 2005.
- 20: Hepatitis C in semen unlikely to explain transmission. http://www. aidsmap.com/Hepatitis-C-virus-in-semen-unlikely-to-explain-transmission/page/1438576/.

- 21: "Behavioural predictors of subsequent hepatitis C diagnosis in a UK sample of HIV positive men who have sex with men", Sex Transm Infect, 82 Aug 2006.
- 22: Evidence to support belief in transmission of hepatitis C by sharing drug-sniffing equipment. http://www.aidsmap.com/Evidence-to-supportbelief-in-transmission-of-hepatitis-C-by-sharing-drug-sniffing-equipment/ page/1431678/.
- 23: Most hepatitis C infections amongst gay men in Sydney linked to injecting drug use. http://www.aidsmap.com/Most-hepatitis-Cinfections-amongst-gay-men-in-Sydney-linked-to-injecting-drug-use/ page/1436569/.
- 24: Characterisation of an outbreak of acute HCV infection in HIVinfected men in New York City. 16th Conference on Retroviruses and Opportunistic Infections, Montreal. Poster abstract 802, 2009.
- 25: Multiple Chances: Findings from the United Kingdom's Gay Men's Sex Survey 2006. Sigma, 2008.
- 26: Tactical Dangers: Findings from the United Kingdom's Gay Men's Sex Survey 2008. Sigma, 2010.
- 27: http://www.hepctrust.org.uk/Get+Involved/Get+Tested/ About+Get+Tested.
- 28: http://www.tht.org.uk/mediacentre/pressreleases/2005/may/thtlaunchhepatitiscampaign.htm.
- 29: "The new epidemic: HIV and hepatitis C infection in gay men. HTU 815, April 2009.
- 30: Wasted Opportunities: Problematic Alcohol and Drug use Among Gay Men and Bisexual Men. Sigma, 2009.
- 31: Consuming Passions: Findings from the United Kingdom's Gay Men's Sex Survey 2005. Sigma, 2007.
- 32: "Acute hepatitis C in HIV-infected individuals recommendations from the NEAT consensus conference", AIDS 25, Feb 2011.
- 33: Prognosis of HIV/HCV co-infected patients may be better than previously thought. http://www.aidsmap.com/Prognosis-of-HIVHCV-coinfected-patients-may-be-better-than-previously-thought/page/1430677/.
- 34: For a discussion of the issues raised by the advent of new antihepatitis see agents, see New hepatitis C drugs pose many questions, http://www.aidsmap.com/New-hepatitis-C-drugs-pose-many-questions/ page/1757210/.
- 35: Management of Coinfection with HIV-1 and Hepatitis B or C Virus. BHIVA, 2010 (http://www.bhiva.org/HepBC2010.aspx).
- 36: "An 'elephant in the room'? Stigma and hepatitis transmission among HIV-positive 'serosorting' gay men", Culture, Health and Sexuality 10, Aug 2008.
- 37: What Do You Need? 2007-2008: Findings From a National Survey of People Diagnosed with HIV. Sigma, 2009.

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.



25 YEARS OF

# SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

# **Our vision:**

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

# Our strategic goals:

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV
- early diagnosis of HIV through ethical, accessible and appropriate testing
- equitable access to treatment, care and support for people living with HIV
- enhanced understanding of the facts about HIV and living with HIV in the UK
- eradication of HIV-related stigma and discrimination.

# www.NAT.org.uk

www.lifewithHIV.org.uk - a resource for HIV positive people www.HIVaware.org.uk - what everyone should know about HIV

NAT, New City Cloisters, 196 Old Street, London EC1V 9FR T: +44 (0)20 7814 6767 F: +44 (0)20 7216 0111 E: info@nat.org.uk

National AIDS Trust is a Registered Charity No. 297977 and a Company Limited by Guarantee (registered in England and Wales), No 2175938.

Registered Office: NAT, New City Cloisters, 196 Old Street, London EC1V 9FR

© 2012 National AIDS Trust

All rights reserved. No part of this publication may be copied or transmitted in any form or by any means without NAT's permission.