

**SHAPING ATTITUDES.
CHALLENGING INJUSTICE.
CHANGING LIVES.**

**TRANSFORMING
THE UK'S
RESPONSE
TO HIV**



Report: July 2013

HIV and Injecting Drug Use



Contents

Introduction	3
Epidemiology: HIV amongst People who Inject Drugs	5
Changing Patterns in Injecting Drug Use	7
• MSM and Injecting Drug Use	7
• Image and Performance Enhancing Drugs	10
• Getting Ahead of the Curve	12
Commissioning Arrangements for Drugs Services	13
Harm Reduction	16
• Opioid Substitution Therapy	16
• Needle and Syringe Programmes	20
HIV and People who Inject Drugs	23
• HIV Treatment and Care for People who Inject Drugs	23
• Barriers to Effective HIV Treatment and Care	24
Summary of Recommendations	28
Endnotes	32
Glossary	33
Acknowledgements	33
Annex A - Seminar Attendees	34
Annex B - Agenda	35

Introduction

One of the most striking successes of the UK response to HIV has been the continuing low rate of HIV amongst people who inject drugs. This has not been the result of luck but of ethical, evidence-based and effective policies introduced early on during the course of the epidemic. In particular, the provision and roll-out of needle and syringe programmes (NSPs) and of Opioid Substitution Therapy (OST) have reduced unsafe injecting and meant HIV prevalence amongst people who inject drugs is one of the lowest in Europe.

Such success must not, however, encourage complacency. Transmissions of HIV and other blood-borne viruses (BBVs) still occur amongst people who inject drugs and we should be aiming to reduce these rates further. NAT has been especially concerned at a change of tone and substance in the last two or three years in Government drug policy, with a far less positive approach to the provision of OST. It is very dangerous to take for granted the successes in reducing blood-borne virus risk amongst people who inject drugs - and especially dangerous to think changing OST policy will not have a harmful impact on these epidemics.

Another risk of complacency is that you fail to keep up with changing behaviours and new health risks. NAT have heard of worrying trends in injecting newer club drugs amongst men who have sex with men (MSM), as well as injecting more widely of image and performance enhancing drugs (IPEDs) such as steroids and tanning agents. There is a clear risk of the spread of blood-borne viruses amongst populations newly injecting who have not traditionally been targeted by harm reduction interventions.

The need to maintain the successes in HIV prevention amongst people who inject drugs and respond promptly to newer injecting trends prompted NAT to organise a roundtable on HIV and Injecting Drug Use, which took place at City Hall in London in January 2013. The list of participants can be found at Annex A and the Agenda for the day at Annex B.

We explored these issues in the context of the imminent and fundamental changes to the commissioning of drug treatment services in England. On 1 April 2013 the National Treatment Agency (NTA), which had been responsible for commissioning drug services, was abolished and its research, policy and expertise functions rolled in to the newly

established Public Health England (PHE). Commissioning of drug services became a responsibility of local authorities as part of their new public health remit.

We also thought it important to discuss the current provision of HIV treatment and care to people who inject, or have injected, drugs.

This report draws on the excellent presentations and discussion which took place at the roundtable. We do not aim to explore every issue in comprehensive detail - rather we identify the significant current needs around HIV and Injecting Drug Use which require a response and make some key policy recommendations. It has been good to see even in the period since we held the roundtable, that some concrete actions have emerged from the day, including:

- a national survey of Needle and Syringe Programme provision;
- increased focus by key stakeholders on problematic drug use amongst MSM;
- the development by BASHH of a Position Statement on 'club drugs' and sexual health;
- the establishment of a 'national intelligence network' by Public Health England to advise on harm reduction.

Introduction

This report focuses on drug treatment services in England, given the significant changes in policy and implementation over the last year. We were, however, very pleased that Dr Roy Robertson, an Edinburgh GP with great expertise in this field, also joined us at the roundtable. He shared a Scottish perspective on the issues discussed on the day. Many of our recommendations, for example on harm reduction and on services for people who inject drugs, are of course as relevant to Scotland, Wales and Northern Ireland as they are to England.

We trust this report acts as a helpful prompt to both drugs and HIV/BBV sectors to protect and maintain with vigilance the health successes of the last three decades, whilst responding innovatively and promptly to change.



One of the most striking successes of the UK response to HIV has been the continuing low rate of HIV amongst people who inject drugs.



It is very dangerous to take for granted the successes in reducing blood-borne virus risk amongst people who inject drugs

Epidemiology: HIV amongst People who Inject Drugs

Since the start of the HIV epidemic in the UK 30 years ago, the prevalence of HIV among people who inject drugs has remained relatively low. Reporting at the end of 2011, Public Health England data documents 122,000 HIV diagnoses in the UK since the beginning of the epidemic 30 years ago - out of whom only around 5% (5,600 people) are thought to have been infected through injecting drug use.¹

At NAT's roundtable Dr Vivian Hope from Public Health England² presented the current data on HIV prevalence among people who inject drugs. He showed how HIV prevalence among people who inject drugs has remained low though it has increased from around 0.7% in 1996 to around 1.2% today.

He added there is no evidence to show HIV prevalence is increasing further amongst people who inject drugs, although rates continue to be higher than in the 1990s.

In 2011, 1,636 people with HIV were seen for care for whom injecting drug use was reported as the route of transmission.³ This equates to just 2.2% of all people with HIV being seen for care in the UK.

In London, HIV prevalence for people who inject drugs has been around four times higher than elsewhere in England: in 2011, HIV prevalence was around 3.9% in London and 0.9% elsewhere.⁴ In Brighton and in areas in the North West of England there have also been higher rates of HIV amongst people who inject drugs compared with other parts of England.

The majority of people with HIV who inject drugs and who are being seen for care, are white (88%), with Other/mixed ethnicity at 4% and black African at 3%.⁵ Cumulative diagnoses amongst people who inject drugs from the beginning of the epidemic have seen 4,006 men diagnosed with HIV and 1,698 women.⁶ In terms of age, amongst the 1,636 people who inject drugs currently seen for HIV care, 951 are aged between 40 and 54, and 539 aged between 25 and 39.⁷ This suggests a gradually ageing cohort, consistent with the overall epidemiology around opiate and crack cocaine injecting. Over the past decade the vast majority of people who inject drugs diagnosed with HIV are born in either the UK or the rest of Europe (with similar numbers for both groups).



In London, HIV prevalence for people who inject drugs has been around four times higher than elsewhere in England.

Epidemiology: HIV amongst People who Inject Drugs

A significant proportion of people with HIV who inject drugs are also found to be co-infected with hepatitis C. The Unlinked Anonymous Monitoring (UAM) Survey of people who inject drugs⁸ between 2009 and 2011 found 86% of the samples collected in London and the North West had HCV antibodies indicating current or past HCV infection. Of the samples collected outside of London and the North West 46% of people presented with HCV antibodies.⁹ HIV/hepatitis C co-infection complicates each disease, affecting both disease progression and treatment options and effectiveness.¹⁰ A 2010 paper found that 83% of people who inject drugs diagnosed with HIV are co-infected with hepatitis C.¹¹

The risks of health harms amongst people who inject drugs remain worryingly high. The 2011 UAM Survey showed that among those who had injected in the previous month, the proportions injecting crack cocaine and injecting into the groin (associated with a higher risk of deep-vein thrombosis and of wound infection) have remained at around a third. The key risk for HIV and hepatitis transmission – direct sharing of injecting equipment – has declined over recent years. In the late 1990s it stood at 30% of people who inject drugs but by 2011 this had declined to 17%.¹² At the roundtable Vivian explained that this level of sharing is still sufficient to maintain BBV transmission amongst people who inject drugs.

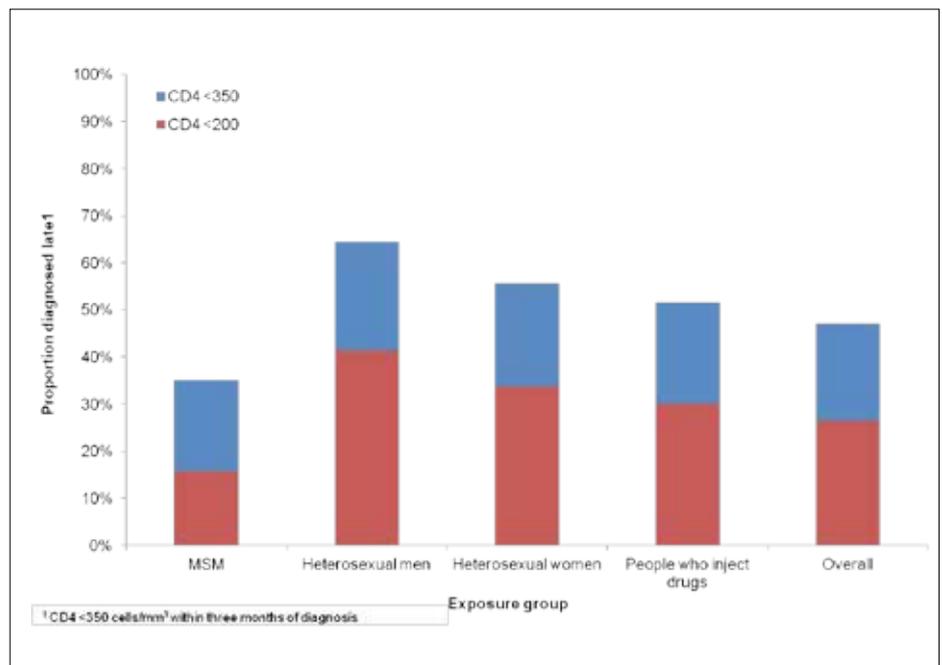
In addition, there continues to be a significant percentage of people who inject drugs diagnosed late – after the point at which they should have started HIV treatment (CD4 count of less than 350 cells/mm³). Overall, in the UK in 2011 52% of people who inject drugs with HIV were diagnosed late. This figure is higher than the overall proportion of people living with HIV diagnosed late (47%). 30% of people who inject drugs who have HIV were also diagnosed very late (CD4 count of under 200 cells/mm³) compared to 26% of all new diagnoses of people living with HIV in that year.

These high rates of late and very late diagnosis not only have an impact on HIV transmission amongst people who inject drugs but have an impact on their

morbidity and mortality. Late diagnosis reduces life expectancy and very late diagnosis shortens a person's life by at least ten years¹³ compared with somebody who starts treatment at CD4 350 cells/mm³.

Despite high rates of late diagnosis, a relatively low proportion of people who inject drugs have undiagnosed HIV. Only 17% of people who inject drugs who have HIV are unaware of their infection, compared to 24% of the 96,000 people living with HIV in the UK in 2011. Alongside higher rates of awareness of HIV status have been greater uptakes of HIV testing among people who inject drugs. From below 60% in 2002, 77% of people who inject drugs reported ever having had an HIV test in 2011 and over 80% had ever been tested for hepatitis C.¹⁴

Late diagnosis of HIV infection by exposure group UK, 2011



Source: PHE

Changing Patterns in Injecting Drug Use

Between 2005 and 2011 there has been a significant decrease in the number of people using heroin or crack cocaine in England from 332,090 in 2005/06 to 298,752 in 2010/11.¹⁵ Use of heroin or crack cocaine has been particularly reduced among under 25's - from 66,161 in 2005/06 to 41,508 in 2010/11. The decline in the number of heroin and crack cocaine users has similarly been reflected by the fall in numbers entering treatment for dependency. In 2005/2006 there were 64,288 people entering treatment, falling to 47,210 in 2011/12 (although it should be added some question whether the decline in numbers could be an indication not of less heroin/crack cocaine use but of less attractive treatment services.)¹⁶ In addition, the number of estimated injecting drug users has declined from 129,977 in 2005/2006 to 93,401 in 2010/2011. Other public health gains have come from the reduction in the proportion of people reporting sharing needles as described above.¹⁷ Pete Burkinshaw from PHE¹⁸ told the NAT roundtable that 60% of heroin users are also now in treatment compared to 49% in 2005/6.¹⁹

However, measuring current injecting patterns remains problematic - not least because the data collected focuses on the injection of two substances. Vivian explained how the focus on data only around crack cocaine and heroin use was particularly limiting in light of new evidence showing an increasingly diverse group of

people using and injecting newer drugs. Vivian explained these new injecting patterns may mean the number of people injecting drugs is higher than current estimate from the UK Focal Point and the NDTMS statistics.

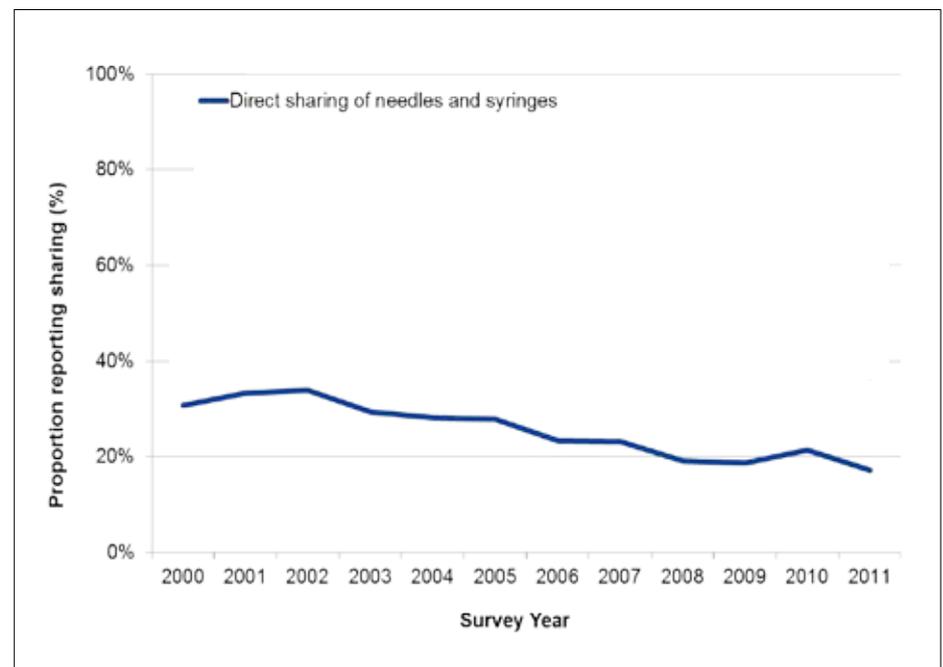
MSM and Injecting Drug Use

One of the new injecting patterns described at NAT's roundtable was primarily connected to the rise in the injection of new psychoactive drugs or 'club drugs' that have traditionally been 'snorted' or ingested. A recent report by the NTA suggests the proportion of club drug users reporting injecting has risen from 6% to 8% in the period 2007/2008 to 2011/2012.²⁰ This rise in injecting has been

particularly connected to higher rates of injection of the drugs ketamine and mephedrone. The injection of mephedrone was first reported in the UK in 2011 and, although localised to a few areas, could have significant implications for HIV prevalence. The recent outbreak of HIV in Romania in 2011 has been associated with the increased rates of injecting of amphetamines such as mephedrone.²¹

There is still little known about this new sub-group of drug users who do not fit the 'traditional' profile of heroin or crack cocaine users. The NTA's report on club drugs shows that 43% of all over-18s treated for club drugs were aged between 18-24 while 70% of methamphetamine users and over half of all GHB/GBL users in treatment were in their 30s

Trends in sharing among current PWID in England, Wales and Northern Ireland



Source: PHE

Changing Patterns in Injecting Drug Use

or older.²²

Of concern to participants at the roundtable was the significant increase in use and injecting of these drugs by MSM. Dr Adam Bourne from Sigma Research drew on evidence from Antidote, the one LGBT drug support service in London, and from the two clinics to provide specialist support for MSM around drug use - the CODE clinic and the Club Drug Clinic - to show the rise in the use of drugs such as crystal methamphetamine ('crystal meth'), mephedrone and GBL/GHB amongst MSM and the rise in the injection of crystal meth and mephedrone (a phenomenon known as 'slamming'). Just before the NAT roundtable a concerned article had appeared in *The Lancet*, 'High-risk drug practices tighten grip on London gay scene'.²³ How quickly drug use can change, and the need to keep up with such trends and provide relevant services, can be seen from the fact that at Antidote, 85% of all people coming for treatment are now using these three drugs. This figure was only 3% in 2005.²⁴

Among the 239 patients seen between 2011/12 identifying as MSM at the Club Drug Clinic in London, 24% had currently injected and 18% had previously injected such drugs. More recently, data from the clinic shows 55% of service users have injected drugs

at some point. At CODE, whilst 30% of patients in 2011 reported the injection of crystal meth and mephedrone, in 2012 this had risen to 80%. At Antidote, 70% of those injecting, and 50% of those injecting at the Club Drug Clinic, reported sharing injecting equipment.

Adam described how these drugs are often being used in highly sexualised environments. At Antidote, users reported between five and 10 sexual partners per drugs episode, often within chill out parties or sex parties where injecting drugs are used to facilitate sex. Within such environments, MSM are engaging in high risk behaviour through the sharing of needles and having unprotected sex.

Seventy-five percent of those accessing the CODE clinic in London or using Antidote's services using crystal meth, GBL or mephedrone are also HIV positive. In addition, out of those who are HIV positive, 60% report not taking their ARVs, possibly increasing their infectiousness and risking the development of drug resistance. The majority of HIV negative service users amongst this group also reported at least one course of PEP in the last year.

The rise in MSM injecting drugs, sharing needles and in the context

of extended sex sessions where there are high rates of unprotected sex clearly means increased transmission of HIV, hepatitis C and hepatitis B as well as other sexually transmitted infections and health harms (for example, serious bladder problems from the use of another club drug, ketamine). Mental health problems have been associated especially with the use of crystal meth and mephedrone. There are also risks from overdose. In 2012 there had been a number of highly publicised drug-related deaths on the London gay scene. With GHB/GBL in particular, there is a significant risk of overdose and of dependency, with expert medical supervision sometimes needed for withdrawal.

Within sexual health clinics, it was reported staff often do not have adequate training or awareness to ask appropriate questions about problematic recreational drug use and provide support. Where there are assessments asking about drug use, the terminology used does not always encourage disclosure. For example, enquiring about whether a person is an 'injecting drug user' may not always solicit a response among people who inject club drugs or image enhancing drugs who do not always view their drug use as problematic, and associate the phrase with opiate use.²⁵

Similarly, traditional drug treatment services, used to dealing with

Changing Patterns in Injecting Drug Use

opiate and crack cocaine users, were said to be less comfortable or knowledgeable around the drug-related needs of MSM. The example was given of providing clean needles with citric acid, important for heroin injecting but useless for those injecting crystal meth or mephedrone. This gives the sense to MSM using such drugs that these drug treatment services are 'not for them'. There may not be the awareness of the specific needs and risks around GHB/GBL use and withdrawal. There may also, both from the provider and from the service user, be discomfort about talking about the use of such drugs in a gay, highly sexualised context.

This is a relatively new phenomenon, and fast changing, so there are many things still not known. Whilst absolute numbers being seen for care have increased and are significant, it is hard to know what is the overall proportion of MSM with problematic recreational drug use – are most being seen by services or are they just 'the tip of the iceberg'? Similarly, it would be good to know more as to whether this is still mainly a London phenomenon (granted, men travel into London for clubbing and sex) or whether, and to what extent, it is also common in other parts of the country. As important as further behavioural information, is the need for greater understanding of what

works best to address these needs. NICE public health guidance draws on research to provide evidence of recommended interventions – but for drugs recently on the scene an adequate evidence base may not yet exist. In such cases Public Health England has a vital 'bridging role.'

It was acknowledged at the roundtable that in the past sex may have been assumed as the route of infection for MSM, and the possibility of it being injecting drug use not explored by the HIV clinic. In the new HARS dataset, the reporting process for HIV being rolled out by PHE for clinics, there is a new option for completion on route of infection, 'Men who have sex with men who also have injected drugs'. This is welcome and will both sensitise clinics when discussing behaviour with service users and ensure more accurate data on HIV transmission.

One immediate result of the NAT roundtable and the focus on drug service needs for MSM, was the convening of a further meeting by HIV Prevention England, the national HIV prevention programme funded by the Department of Health. Another outcome was that questions on MSM have been included in the current survey on NSP provision.

NAT also wrote an open letter to the London councils, who had recently decided to undertake a needs assessment of the HIV prevention needs of MSM in London. We emphasised the importance of considering and meeting these substance use needs if any assessment of HIV prevention for MSM was going to be useful and relevant.²⁶ Local authorities have just been given responsibility for both sexual health and drugs service commissioning (see below). This is an opportunity to think holistically about MSM needs and integrate services. But there is also the risk of commissioning being undertaken on too 'local' a footprint. Services should be available across London for MSM. For this to work, given the size and distribution of the MSM population, the important thing is to have adequate services at a London-wide level which are open access, with effective cross-charging arrangements between London councils.

Changing Patterns in Injecting Drug Use

Recommendations

- ▶ There is a health crisis amongst a significant number of MSM who are engaging in problematic recreational drug use and high-risk sexual behaviours. A coordinated, fully funded and effective response from both commissioners and providers is urgently needed.
- ▶ Commissioners in London should integrate sexual health and substance misuse service provision for MSM, with integrated care pathways into specialised support.
- ▶ Open access, appropriate and tailored services across London for MSM with problematic drug use should be commissioned by London councils as soon as possible with the capacity to meet these increasing and complex needs.
- ▶ Commissioners outside London should undertake needs assessments around MSM drug use, injecting and sexual risk to identify the scope for joint commissioning of tailored drugs and sexual health services for MSM.
- ▶ Clinicians and health advisors in sexual health clinics should be trained to ask service users, and in particular MSM, systematically and on an ongoing basis about problematic recreational drug and alcohol use. BASHH should provide guidance to support this process.
- ▶ Generic drug treatment services should be trained to respond sensitively and in a clinically appropriate way to the needs of 'non-traditional' drug users such as MSM, and to the use of newer drugs in addition to opiates and crack cocaine.
- ▶ Further research is needed into problematic recreational drug use and injecting amongst MSM both within and outside London - to meet current and emerging needs and to inform local HIV prevention and health promotion interventions.
- ▶ HIV Prevention England should continue its welcome focus since the NAT roundtable on MSM drug use, in particular drawing on international and local experience to develop relevant health promotion interventions for this group of MSM. They should be supported in this, and in the gathering of further data and evidence, by Public Health England.

Image and Performance Enhancing Drugs

The other main shift in injecting behaviour described at the roundtable has come from the injection of Image and Performance Enhancing Drugs (IPEDs). IPEDs are drugs used by people to change physical appearance and/ or improve performance and strength. In the UK anabolic steroids have typically been the most commonly used and injected IPED. Vivian Hope gave an example of where the injection of anabolic steroids had increased at an agency-based Needle and Syringe Programme (NSP) in Cheshire & Merseyside. From 1991 to 2011 they recorded a huge increase in clients injecting anabolic steroids. Their data showed that while anabolic steroids have been the most commonly injected, other non-psychoactive drugs are being injected for purposes such as muscle bulk, changing appetites or tanning.

Similar trends of increased use of injecting IPEDs have been found in a 2010/11 Unlinked Anonymous Monitoring Survey (UAM) of people who inject drugs.²⁷ In the survey 395 male IPED injectors took part. Amongst the group 86% had injected anabolic steroids and injecting was more common than oral use (57%). Thirty-two per cent had injected Growth Hormones and 16% had injected Human chorionic gonadotropin (hCG). More than 5% also reported injecting insulin and melanotan I/II.

Changing Patterns in Injecting Drug Use

A significant proportion of respondents reported that they had either shared a needle (9%) or were injected by someone else (17%). There were also high levels of psychoactive drug use which can enhance risk taking behaviour. Nearly half (46%) of participants had used cocaine and 12% amphetamine. A small number (5%) also injected a psychoactive drug. Most of the men also reported having high levels of sexual activity and poor condom use - only 20% always used a condom for anal or vaginal sex.

Despite the high risk of acquiring HIV from sharing injecting equipment and having unprotected sex with multiple partners, less than a third of men had ever had an HIV test. Less than 20% had used a GUM/sexual health clinic in the previous year. The survey found that the HIV prevalence within this group was around 1 in 65, similar to the prevalence found in people who inject psychoactive drugs. MSM within this group had higher levels of HIV (1.5%) than the predominantly heterosexual male cohort (0.8%). Prevalence of hepatitis B and hepatitis C were also high: around 10% of respondents had hepatitis B and around 6% had hepatitis C.

For people injecting IPEDs, HIV transmission rates through sharing of injecting equipment may not as yet be comparable to those amongst people injecting opiates. However, it is vital that recognition is given by harm reduction initiatives and other drug treatment programmes to the high-risk behaviour accompanying these new injecting patterns which can leave people at particular risk of HIV and hepatitis B and C transmission. Even when taking sexuality into account there is clearly elevated blood-borne virus risk in this group.

NICE have recently called for evidence to identify effective harm reduction measures for those who are injecting IPEDs. It was pointed out at the roundtable that many users of these drugs will not have heard the harm reduction messages around needle sharing which have been provided to opiate and crack cocaine users. When NAT commissioned Ipsos MORI to survey public knowledge and attitudes around HIV in 2010, only 45% of the general public knew that HIV can be transmitted by sharing needles or syringes.²⁸ It will be important to ensure adequate coverage of NSPs for those who inject IPEDs, innovative measures to reach them and promotion of harm reduction measures for these groups. Both NICE and Public Health England can support local authorities by recommending needs assessment methods for IPED use and appropriate harm reduction interventions.

Recommendations

- ▶ **There are risks of blood-borne virus infection to people who are injecting IPEDs. Local authorities should ensure the health needs of IPED users are known and met in their local area, drawing on advice from NICE and Public Health England.**
- ▶ **Local authorities should commission interventions to advise newer communities injecting drugs of the risks of sharing injecting equipment, and the importance of sterile equipment, as well as of where to go to access NSP services. These communities include steroid users, young women injecting tanning agents, and MSM injecting crystal meth and mephedrone. Social media and newer settings should be considered (Twitter, gyms, tanning salons, gay clubs etc).**

Changing Patterns in Injecting Drug Use

Getting Ahead Of The Curve

The discussions at NAT's roundtable show a rapidly changing drug landscape. As heroin and crack cocaine use declines, a new generation of drug users may increasingly inject and consume a diverse range of other drugs.

There also continue to be gaps in the data collected on people who inject drugs that prevent drug treatment services from knowing more about these new injecting patterns and the risks they pose. Specifically, most data collected in the UK on injecting drug use only looks at people in drug treatment services, with a focus on drug use deemed 'problematic,' i.e. opiate and crack cocaine use. This is inadequate as it neglects the significant proportion of people who are injecting club drugs or IPEDs, who are not in treatment (indeed there may be few services for them) and who need different harm reduction and prevention efforts. It is also less good at capturing emerging drug use issues and reflects the 'bias' of service configuration. More needs to be done to get a full picture of drug use in the UK.

Recommendations

- Agencies which collect drug monitoring data in the UK should broaden their data collection to ensure it captures emerging drug trends, for example the injection of amphetamines such as crystal meth and mephedrone and the injection of IPEDs.



The discussions at NAT's roundtable show a rapidly changing drug landscape. As heroin and crack cocaine use declines, a new generation of drug users may increasingly inject and consume a diverse range of other drugs.

Commissioning Arrangements for Drugs Services

From 1 April 2013 there have been new commissioning arrangements for drug services in England. It had previously been the case that the National Treatment Agency (NTA), a national special health authority, commissioned drug treatment services locally via Drug Action Teams (DATs). Now local authorities have the responsibility for the commissioning of these services within their new public health remit, and have been provided with a ring-fenced public health budget from which to fund such services along with all other local public health interventions (including sexual health services). The NTA has been one of the bodies abolished and amalgamated within the functions of Public Health England, the new national body charged with providing expertise, data, advice and support to local authorities and Directors of Public Health, as well as undertaking national public health interventions.

At the NAT roundtable concern was expressed at the fact that local authorities are not 'mandated' to provide drug services - in other words, there is no legal requirement for them to do so when they commission public health interventions. This contrasts with sexual health services which are one of the very few interventions which are mandated under the new

system. Is there a risk that a local authority will de-fund drug services altogether? Or compete in a 'rush to the bottom' of minimal services of poor or erratic quality? Or only fund services which chime with the particular ideological persuasion of a few councillors with strong views, for example only abstinence services being made available?

Although substance misuse funding allocations account for about a third of the calculation of the new ring-fenced public health budget, there is no distinct identification of a substance misuse component nor any 'protection' for substance misuse funding within the overall public health budget. This risks diverting funds historically spent on drug services to other local public health priorities.

Pete Burkinshaw spoke at the NAT roundtable on the new commissioning arrangements and was confident, where local authority commissioning appeared to be failing around drug services, that a system would be in place to address any such worrying trends. In particular, PHE will be asking local authorities to provide them with annual breakdowns of expenditure by sub-categories which will include greater detail on precisely what services local authorities are commissioning for drug users.

Whilst amounts of funding are clearly important, as, if not more, important is the quality of services provided and the impact on outcomes. The Public Health Outcomes Framework (PHOF) sets out key outcome indicators which will be published for each local authority and which will enable assessment of performance and progress. The key indicator, in two parts, relevant to drug treatment is found within the Health Improvement Domain. Indicator 2.15 (i) is successful completion of drug treatment by opiate users and indicator 2.15 (ii) is successful completion of drug treatment by non-opiate drug users, where successful completion means not returning to treatment within the next six months.

There is an indicator (2.16) in the Health Improvement Domain of 'People entering prison with substance dependence issues who are previously not known to community treatment', which will usefully incentivise treatment services which are attractive and accessible to people who inject drugs. There is also a placeholder indicator (2.18) for alcohol use - alcohol-related admissions to hospital.

Commissioning Arrangements for Drugs Services

Drugscope have commented on the fact that whilst there are only three indicators (out of 66) around drug and alcohol use in the PHOF, 34% of the overall public health funding formula is influenced by historical funding to meet substance misuse need.²⁹ Pete Burkinshaw from PHE did, however, point out that substance misuse treatment contributes to over half of all PHOF indicators. It will be important to cite these more generic indicators when making the case for drug services at a local level. Nevertheless, more indicators focusing on drug services are needed given the necessary share these services should have of the public health budget.

With new politicians and local government officials having such commissioning responsibilities it is very important to communicate effectively why drug services are important and what good quality looks like. The NTA, as it then was, had been developing resources for local authorities to assist them in their new role, for example a guide for commissioners on how to take account of drug-related need in the Joint Strategic Needs Assessment (JSNA). The JSNA is a key document since the local Joint Health and Well-being Strategy (JHWS) will be based on it and all local commissioning plans need to pay due regard to the JSNA's content.

It remains immensely important that PHE invest in research, promotion of good practice and the development of useful resources and advice for local authorities in relation to drug treatment and harm reduction. There should be no disinvestment from the resources dedicated to these issues under the NTA - if anything, further support from PHE is needed for local decision-makers given the many people who will have new responsibilities for drug services.

Participants at the roundtable discussed outcomes from good quality drug treatment services which might incentivise local authorities to invest in good quality services. Sadly, the needs of the service users themselves will not always be sufficient given prejudice and judgemental attitudes still far too prevalent in sections of society.



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Commissioning Arrangements for Drugs Services

A number of people made the link between effective drug treatment services and reductions in levels of crime. Statistics from the National Audit Office 2010 report 'Tackling Problem Drug Use' were cited - that every £1 invested in drug treatment saves £2.50 later on; that there was an annual cost in 2003/04 of £13.9 billion attributable to drug-related crime; that between a third and a half of acquisitive crime is drug-related. It will be important to engage the new Police and Crime Commissioners (PCCs) on the public health agenda around drug services since they can at a local level be powerful advocates for high quality drug treatment.

Police and Crime Commissioners have control of the Community Safety Fund which, according to the Home Office, can support local priorities such as 'tackling drugs and crime'.³⁰ The overall sum for the Community Safety Fund in 2013/14 is £90 million, which is distributed according to the levels of crime, drugs and existing community safety fund grants across police force areas. This overall sum consolidates in 2013/14 to a number of separate funding streams previously available for drug services (such as the Drugs Intervention Programme) but it should be noted that the Community Safety Fund is not ring-fenced for particular services or

interventions - so the case will need to be made for PCCs to invest their monies in drug service initiatives to reduce crime. It is expected that PCCs will work collaboratively at a local level on drugs and alcohol issues, engaging in particular with Directors of Public Health and local Health and Well-being Boards.

Recommendations

- ▶ **Drug treatment services should be part of the mandated services required by law of local authorities' public health commissioning.**
- ▶ **Public Health England should continue to fund central resources dedicated to supporting drug treatment services. The amounts of funding should be similar to or greater than that invested by the National Treatment Agency.**
- ▶ **Police and Crime Commissioners should engage with local Directors of Public Health and Health and Well-being Boards to ensure adequate and evidence-based local investment in drug treatment services, including harm reduction, these being an essential and cost-effective means to reduce crime. Consideration should be given as to how the Community Safety Fund might be used locally to leverage improvements in drug treatment services.**

Harm Reduction

The epidemiology of HIV amongst people who inject drugs in the UK is one of the strongest justifications for a policy of harm reduction – which prioritises reducing health harms from injecting drugs above ethical or legal opposition to drug use. The introduction of needle and syringe programmes ensured people did not share injecting equipment and thus transmit blood-borne viruses such as HIV and hepatitis C. The provision of methadone or buprenorphine as Opioid Substitution Therapy enabled people dependent on opiates such as heroin to move away from heroin use and injecting with the attendant health risks. In countries which have opposed harm reduction, for example Russia, prevalence of HIV amongst people who inject drugs is extremely high.

Opioid Substitution Therapy

Given the evident success of these public health measures, it is surprising that some of the recent policy statements from the Government have undermined confidence and commitment to these interventions. NAT, along with a number of other professional and voluntary sector bodies, was especially alarmed by the

publication in March 2012 of 'Putting Full Recovery First', which was endorsed by eight government departments. Since its publication, and its critical reception, there have been attempts by officials to distance Government policy from this document, referring instead to the Drugs White Paper.

We do not wish to discuss 'Putting Full Recovery First' in detail and extend its shelf-life. But some sense of its content gives an insight into a strong lobby within Government and their view of harm reduction – a view which should be robustly challenged on the basis of evidence.

Central to this view is the concept of 'full recovery' which sees as the core purpose of drug treatment 'full independence from any chemical'³¹ and depicts maintenance on Opioid Substitution Therapy in negative terms - the Government speaks of 'the current drift of far too many people into indefinite maintenance, which is a replacement of one form of dependency with another'³² - 'people on substitute prescribing will also be expected to engage in effective recovery activities to ensure they move towards full recovery as quickly and as appropriately as they are able to'.³³ 'Putting Full Recovery First' commits the Government to

'ensure that open-ended substitute prescribing in the community is only used where absolutely necessary, and only on the basis of a rigorous, multidisciplinary review of a patient's ongoing needs and even so with recovery as the eventual goal'.³⁴ Its abstinence bias can be seen in such statements as 'It is self-evident that the best protection against blood-borne viruses is full recovery'.³⁵

Whilst there have been attempts to sideline this Government document it must be pointed out that the document has not been withdrawn and many of its central tenets are found elsewhere in official policy. For example, the National Treatment Agency (NTA) website defines successful completion of treatment as being free from dependency and this means that clients cannot be on substitute prescribing.³⁶

A more evidence-based and balanced approach to the use of OST in harm reduction is found in the report 'Medications in Recovery' published by the Government-appointed 'Recovery Orientated Drug Treatment Expert Group' in July 2012. Framed within the agenda of supporting service-user 'recovery', the report used evidence to reach some key findings, for example:

Harm Reduction

- Coming off OST or exiting treatment prematurely can harm individuals, especially if it leads to relapse [Exec Summary 2]
- Recovery is an individual process or journey rather than a pre-determined destination [para.2.7]
- It may be only a minority of people who are able sustainably to overcome all dependence on drugs or OST [Exec Summary 5].

We highlight these conclusions not to be pessimistic about the impact treatment can have – some people with well-resourced and individualised support may well be able to end both drug use and the need to access OST, and for some people abstinence-based approaches may well offer preferred treatment choices. The conclusion to be drawn from ‘Medications in Recovery’ is that treatment options, choices and outcomes need to be evidence-based, clinically appropriate and individualised, and that, specifically, exiting treatment is not the only acceptable goal or outcome of OST. Some people will be maintained long-term on

OST and if this enables them to be free of harmful drug dependency, avoid blood-borne viruses and other drug-related ill-health, build social and family relationships, avoid crime, maintain good quality housing and enter employment, then this for them is effective recovery, and should be welcomed and supported.

Dr Thomas McLellan, newly appointed as the Drugs Recovery Adviser by Public Health England, commenting on the ‘Medications in Recovery’ report, put it very well – ‘it is neither the presence nor the absence of an opioid medication that defines recovery – it is other important qualities of the lifestyle’.³⁷ In the same article he adds ‘Recovery status is best defined by factors other than medication status ... Recovery status instead hinges on broader achievements in health and social functioning – with or without medication support’. He makes clear that there is not just one acceptable treatment goal and that there is scope for services and practices which can increase ‘the likelihood of recovery within opioid maintenance treatment’. We welcome these comments and trust PHE advice on OST going forward will be fully, explicitly and consistently in line with these views.

The 2010 Drug Strategy remains, we are repeatedly told, the key relevant policy document from the Government and whilst it does place an emphasis on recovery, it states that this is ‘an individual, person-centred journey, as opposed to an end state, and one that will mean different things to different people. We must therefore put the individual at the heart of any recovery system and commission a range of services at the local level to provide tailored packages of care and support’.³⁸ The Drug Strategy also states that ‘Prevention of drug-related deaths and blood-borne viruses’ as a best practice outcome for a recovery-oriented system - although there could usefully have been much more content on harm reduction in the Strategy document. It does not state explicitly that the goal of freedom from drugs and alcohol requires an end to maintenance on OST.

Of course the pre-existing guidance from NICE on drug treatment is wholly in line with the approach set out in ‘Medications in Recovery’. But many of those attending the NAT roundtable raised concerns at the tone and content of some recent Government statements on harm reduction, and on OST in particular. Of particular concern

Harm Reduction

are the 'incentives' in the system to prioritise exit from treatment over the health of people who inject drugs. We noted above that the main Public Health Outcome Indicator relating to drug use is treatment exit, despite the evidence set out in 'Medications in Recovery' and elsewhere, that such exit is often a difficult and unpredictable process, with serious risks of harm and relapse. If the exit treatment indicator is to remain in place there should at the very least be other indicators to 'balance' that one, focusing on important harm reduction outcomes such as drug-related deaths and BBV transmission - that way, a clinically inappropriate pressure to exit treatment will be evident from poorer health-related outcomes.

Similarly, financial incentives have been used to prioritise treatment exit under the Government's 'recovery' agenda. A number of Payment by Results (PbR) pilots have been in place some of which involve greater funding to the provider on the basis of how many service users exit treatment.

More generally, the pooled treatment budget from central Government for local drug treatment services last year (2012/13) earmarked 20% of the overall £466.7 million allocation to

be based on the numbers locally who successfully completed a programme of treatment and did not return within six months (most of the remaining funding is linked to numbers in treatment, and some also linked to local social deprivation). This is a significant proportion of drug treatment monies linked to what the 'Medications in Recovery' report makes very clear is just one model of recovery, often very difficult to effect in a safe and sustainable way. It appears that this funding model has also been used to calculate the relevant element in the overall ring-fenced public health budget for 2013/14 and 2014/15. Just as in the Public Health Outcomes Framework itself, funding incentives should be re-balanced to reflect other possible benefits of treatment, including social integration, reduction/ending of problematic drug use, and avoidance of health harms.



If the exit treatment indicator is to remain in place there should at the very least be other indicators to 'balance' that one, focusing on [...] drug-related deaths and BBV transmission.

Harm Reduction

Recommendations

- ▶ Public Health England should set out formally an evidence-based, ethical position on the provision of OST, and advise local authorities to commission services on that basis. This position should reflect the evidence as set out in the report 'Medications in Recovery' and make clear:
 - that all people dependent on opiates seeking drug treatment should have OST as an available option where clinically appropriate
 - that there should be no pre-determined time-limits to the provision of OST
 - that exiting from OST should only be with the full, informed consent of the service-user as part of a treatment plan s/he has been an equal partner in developing
 - that for a proportion of people who have been dependent on opiates the clinically appropriate treatment will be to be maintained on OST and not to exit this treatment
 - that for some people successful and 'full' recovery means ending problematic drug use, and forming satisfying and productive social, work and emotional relationships, whilst on OST
 - that exiting from OST should not be regarded as the only measure of treatment success or service performance.

All PHE documents should reflect these principles. These principles do not contradict the current emphasis on regular review of how well a service user is doing on OST, and further consideration of other treatment and support options, including treatment exit.

- ▶ Public Health England should promote a strong harm reduction agenda to local authorities, in particular around reducing drug-related deaths, overdoses, and transmission of blood-borne viruses such as HIV and hepatitis C. NAT welcomes the establishing of the 'National Intelligence Network on the health harms associated with drug use' as an essential element of this work.
- ▶ Current policy and financial incentives around drug treatment outcomes inappropriately and dangerously focus solely on treatment exit. The Public Health Outcomes Framework needs at the very least to balance the treatment exit indicator with indicators around drug-related deaths and HIV and hepatitis C transmission.
- ▶ The recent linking of 20% of funding to numbers exiting treatment is a perverse incentive in relation to evidence-based care and should not be continued after 2014/15.
- ▶ The use of PbR by commissioners of drug treatment services should not focus solely on treatment exit but look also at wider evidence of success, such as ending problematic drug use, ability to remain in stable accommodation, avoidance of overdose or BBV transmission, establishing effective social and/or working relationships, to give just a few examples.

Harm Reduction

Needle and Syringe Programmes

In his introductory overview of epidemiology, Vivian Hope said that there had been an increase in the number of needles and injecting equipment provided by NSPs but it is still inadequate. In England less than two thirds of people with HIV received a greater number of needles than the number of times they injected. In Scotland, whereas there had been an increase in needles/syringes distributed from 3.6 million in 2004/05 to 4.7 million in 2009/10, that still meant the number of needles per person with HIV was about 200, which was less than the average 465 injections a year.³⁹

Jamie Bridge led a discussion at the NAT roundtable on harm reduction and the current provision of Needle and Syringe Programmes (NSPs). The recommendation in 1988 by the Home Office's Advisory Council on the Misuse of Drugs (ACMD) to introduce NSPs to address the spread of HIV was important and effective. The last audit of NSP coverage and provision in England was some time ago, in 2006. With the creation of Public Health England and the transfer of public health and drug treatment responsibilities to local government a new audit is urgently needed, as

a baseline for current provision. Furthermore, it will ensure we build and develop on what we currently have and do not allow this essential service to decline.

At the time of the 2006 audit, 80% of NSPs were pharmacy-based, the remainder being mainly specialist centres. The audit suggested something of a 'postcode lottery' as to the range of services offered at NSPs. For example, within Drug Action Team (DAT) NSPs in the 2006 audit 50% did not provide BBV testing; 40% did not provide immunisations; and 33% did not provide safer injecting advice.

Jamie raised concerns as to what the move to local authorities of drug treatment and harm reduction services might mean, especially in a time of austerity. He was also concerned that cuts might reduce staff training and specialism, reducing NSPs to simple needle distribution centres (a version of a level 1 service, to use the NICE categorisation).

Current NICE Guidance on NSPs makes clear at Recommendation 3 that there should be in a local area 'a balanced mix' of Level 1, 2 and 3 NSP services. It will be important in the current review by NICE of its NSP guidance (see below) to ensure that there is sufficient

advice to assist commissioners in determining what a 'balanced mix' is in practice, and that Public Health England gathers on a regular basis information on the commissioning of level 1, 2 and 3 NSPs from local authorities.

Whilst, as we have seen above, late HIV diagnosis rates and the proportion undiagnosed amongst people who inject drugs compares favourably with other groups at risk of HIV, this is not an excuse for complacency and late diagnosis remains too high in this group also. It is striking that only 50% of DAT NSPs provided BBV testing in the 2006 NSP audit. In the NICE public health guidance on NSPs and its description of the different levels of NSP, BBV testing is only mentioned in relation to level 3 'Specialist NSPs' and even then it is to offer testing 'or help people to access'. This recommendation needs to be reviewed and revised in light of changes in testing technology, in particular the use of Point of Care Testing (POCT), and a more recent and far greater emphasis on HIV testing in a wide range of healthcare settings.

The other concern was the extent to which NSPs are equipped and ready to meet the changing patterns of injecting. NSPs are still geared towards opiate injectors – but what about those who are, for example, injecting mephedrone?

Harm Reduction

The roundtable had already heard about young girls injecting tanning agents and people injecting steroids and other IPEDs, as well as a new wave of injecting practice amongst MSM. These new injecting patterns challenge current NSP practices – a point taken up in the subsequent roundtable discussion.

One question is whether these new injecting communities are being reached with health promotion and harm reduction messages, especially around the need not to share injecting equipment and the services available to provide clean equipment. There is a new health promotion challenge – these are not ‘traditional drug users’ who have heard these messages already.

Then there is the importance, should such newer clients attend NSPs, that the service is trained and ready to meet their specific needs – again, the example was cited of citric acid being given to someone injecting crystal meth. This is partly about understanding the particular drugs being used and injecting patterns, and providing appropriate advice, but also about relating to the service user’s context, whether a young girl worried about her tan, a bodybuilder wanting to bulk up, or a gay man using drugs to facilitate extended sex sessions.

A commissioner present gave an example from her area of how pharmacy-based NSPs can be very effective – 15 pharmacies provide needle exchange services and there is a needle exchange forum every couple of months for staff. This forum brings back to drug services important information from and about clients, including new drugs and injecting patterns. There are more referrals to drug treatment services from the pharmacy NSPs than from GPs. They have a steroid worker, case workers trained to deliver a range of services so avoiding the need to refer on to the harm reduction nurse, a pilot planned with the Hepatitis C Trust for dried blood spot testing, and consideration of a safer injecting site pilot. This is an example of how, with commissioner commitment, pharmacy-based NSPs can provide effective and innovative services when within a strategic and wider network of interventions, supported by resources for staff training. Importantly, a pharmacy service need not be just a level 1 service.

One important outcome of the NAT roundtable has been a decision by NICE, Public Health England and the National Needle Exchange Forum to cooperate on a new survey of NSP provision. This is welcome and we trust will provide a useful baseline around coverage, the quality of services and the needs for further development of the national NSP network. Vivian Hope from the HPA emphasised that harm reduction interventions such as NSPs depend on a very high level of coverage if they are to be effective. With the fragmentation of commissioning responsibility to 151 local authorities, with no mandatory requirement that NSPs are commissioned at all, the risks to coverage are obvious. At the very least we need accurate information on current provision so failings and gaps can be challenged.



One question is whether these new injecting communities are being reached with health promotion and harm reduction messages.

Harm Reduction

In addition, NICE is reviewing its public health guidance on NSPs, with a consultation planned for the last few months of 2013. This will be an important opportunity to ensure NSPs address changing drug use trends, new injecting populations, the need for consistently offered BBV testing, as well as high quality advice and signposting to further services.

Whilst not explicitly discussed at the roundtable, NAT has for some time been arguing that a needle and syringe programme should be piloted in prisons to see whether it reduces drugs-related health harms. We have made the case for this elsewhere but simply note here that such NSPs in prisons are recommended in international guidelines;⁴⁰ when introduced have no negative consequences for prison discipline and do not increase drug use; reduce BBV transmission as well as a range of injection-related infections; and can mean people still using drugs in prison are better supported into treatment and care.

Recommendations

- ▶ NAT welcomes the new survey of NSP provision in England, arising from recommendations made at the NAT roundtable, which should identify coverage, the range of services provided, where there are gaps and deficiencies, and how best to develop services in the future.
- ▶ On the basis of the NSP survey results, Public Health England should engage with relevant local authorities and Directors of Public Health to remedy gaps and deficiencies in service provision.
- ▶ Public Health England should from now on gather on a regular basis from local authorities information on NSP services, their coverage and provision.
- ▶ NICE should review and update their public health guidance on NSPs to take account of new injecting patterns, new drugs and altered commissioning arrangements. Level 3 services should all be offering on site HIV testing, with extension of a recommended HIV testing offer to levels 1 and 2 services.
- ▶ Where the public health challenge is so recent that there is inadequate research on which to base a NICE recommendation, Public Health England should provide advice to local authorities on how to address need with appropriate NSP services.
- ▶ There should be pilot NSPs in some prisons in the UK to identify any possible benefits to prisoner health.

HIV and People who Inject Drugs

HIV Treatment and Care for People who Inject Drugs

For people who inject drugs and who are also living with HIV, complementing drug treatment and harm reduction programmes such as OST and NSP with effective HIV treatment and care pathways remains vital. Sara Croxford from Public Health England⁴¹ compared key quality of care indicators for people who inject drugs living with HIV, with overall outcomes for people with HIV.

In the UK, linkages into HIV care for people who inject drugs have typically remained strong. In 2011, 86% of people who inject drugs diagnosed with HIV were linked

into care after diagnosis (defined as a CD4 count being taken within one month of diagnosis) - broadly similar to the number of people overall with HIV linked into care (88%). There is also a high retention of new patients in care (86% twelve months after diagnosis, the same as for new patients overall) and once given HIV treatment their viral load outcome is comparable to the wider population on anti-retroviral therapy (ART), with 86% of patients having an undetectable viral load (87% overall). It is encouraging to see that outcomes for people who inject drugs are comparable to those of other people living with HIV - but we should add that we must do more overall to improve further these outcomes.

The main difference is that only 69% of people who inject drugs seen for HIV care in 2011 had a CD4 ≥ 350 cells/mm³ after at least twelve months in care, significantly lower than the average of 83% for all people with HIV in care. Sara Croxford said there was little information to explain why such a disparity exists.

Despite the high coverage and effectiveness of ART for people who inject drugs, the mortality rates in 2008 among people who inject drugs and who are living with HIV were shockingly high. Public Health England data showed the mortality rate of a person injecting drugs and living with HIV was 20 times higher than the general population, and four times higher

Quality of care indicators for adult HIV patients infected through injecting drug use, UK 2011

Indicators	Overall	PWID
Late diagnosis	47%	52%
Linkage into care	88%	86%
Retention in care - new patients	86%	86%
Retention in care - all patients	96%	94%
Viral load outcome - ART effectiveness	87%	86%
ART coverage	88%	87%
CD4 outcome - immunological status	83%	69%

Source: PHE

HIV and People who Inject Drugs

than all people living with HIV. However, Sara explained that HIV or an AIDS diagnosis is not the most common cause of death amongst this group. Other factors, such as overdosing on drugs or trauma play a bigger role. In fact, if one looks only at deaths caused by HIV, the mortality rate for people with HIV who inject drugs is the same as the overall rate for people with HIV.

Pete Burkinshaw in his presentation at the roundtable said that people who use heroin have a mortality rate ten times higher than the general population. Whilst further analysis of these separate data sources is needed, this suggests that even amongst people who inject drugs, mortality rates may be higher for those also living with HIV, even if HIV itself is not a cause of death. It may, for example, be the case that HIV is associated with greater clinical and social need amongst people who inject drugs.

A similar story was heard from Dr Sarah Creighton from the GUM/HIV clinic at Homerton Hospital in Hackney who spoke of her experiences of losing patients to illnesses other than HIV, such as cardiac failure, lymphoma or surgical complications.

Recommendations

- More research is needed in order to understand why there are poorer CD4 outcomes for people with HIV who inject drugs compared with the wider population of people living with HIV. More detailed analysis of the data by Public Health England will be an essential first step to identify possible causes, and any recommendations for further research or action.

Barriers to Effective HIV Treatment and Care

At the roundtable there was considerable concern that the high mortality rates among people with HIV who inject drugs were linked to the lack of communication between services, including drug treatment programmes.

Sarah Creighton gave a clear example of an individual's treatment suffering precisely because of a lack of services working together. She described a 41 year old woman in Hackney diagnosed with HIV in 2009 who wanted to turn her life around so was re-housed, but out of the local area, and was then lost to follow up. She then came back to the HIV clinic several years later virtually dead, with a CD4 count of just 11 and weighing only 30 kilos. It was discovered she had been found by the drug gangs and had no support from other agencies outside of Hackney. She has now been in hospital for six months. Sarah explained her ART fell apart due to her drug support falling apart. In other words, adherence to ART was impossible without support around drug use.

HIV and People who Inject Drugs

Part of the difficulty of developing effective HIV and drug treatment care pathways relates to the extremely vulnerable situations that people who inject drugs find themselves in - many of whom are affected by homelessness, poverty, social isolation and imprisonment. In 2010/11 59% of drug users presenting to treatment in England, Scotland and Northern Ireland were unemployed and 80% of problem drug users in England in 2006/07 were in receipt of state benefits.⁴² 71% of people who inject drugs have spent some time in prison and 77% have at some point been homeless.⁴³

Sarah Creighton gave a number of further case studies, all of which demonstrated the need for intensive, flexible and integrated support across a number of agencies to meet need. As in the first case mentioned above, moving someone out of area and away from support services was a trigger for deterioration in another case. Whilst HIV services are 'open access' and so available to someone no matter where they live, drug services are not, so insensitive or inflexible housing decisions can risk interruptions to services and to integration with HIV care.

A number of the cases required home visits and in one instance, the obvious concern for the care of the individual using the service prompted others living there to access treatment and care. In another instance a 17 year old survivor of child abuse, living with HIV, was disowned by her mother and introduced by 'friends' to heroin. Sarah spent a week sorting out services for her, making a large investment in getting her social support. In 2012 she was in college with a CD4 count of 842.

From the perspective of the HIV clinician, their patient doing well on HIV treatment is dependent on a wide range of other services playing their part to ensure stability, support and helpful social networks. Clearly Sarah Creighton, and many other HIV clinicians go to great lengths personally to support their patients. When Sarah started at the Homerton in 2005, there were 38 individuals who were substance users – 12 were homeless, 18 sex workers, nine were in prison, 12 had a CD4 count of less than 200 and 14 were lost to follow up though known to other services such as A&E or GPs. Sarah realised that a single point of contact was needed to coordinate services for this vulnerable group of people. The key to this was the establishment

of a blood-borne virus team who provided phlebotomy services, hepatitis B vaccines and hepatitis C testing, adherence support, side-effect management, sexual health services, delivery of medication and liaison with the HIV clinic. Now there are 47 HIV clinic service users who are people who inject drugs, and from the 14 who were lost to care in 2005, there are now only three.

A particularly vulnerable group discussed at the roundtable were prisoners. Sarah mentioned how one woman in her 20s actually found prison a place to stabilise her life but was treated there for asthma with fluticasone, which is contra-indicated as a medication for people who are on ART. The result was diagnosis with iatrogenic Cushing's and brittle diabetes. She died after leaving prison from an insulin overdose - it was unclear whether or not it was intentional. This underlines the importance of all relevant services for people who inject drugs and have HIV being properly trained, including prison health services.

HIV and People who Inject Drugs

Sophie Strachan from Positively UK (a charity that provides peer support for women and men with HIV, including in prison) drew on her experiences and Positively UK's research report 'HIV Behind Bars' of people with HIV in prison whose care was poor - a high proportion of people with HIV in prison will have acquired HIV through injecting drug use. The report identifies a number of failings in healthcare experienced in prisons, including interruptions to treatment, long waiting times to see clinicians, breaches of confidentiality, and exacerbated levels of stigma, which can result in bullying and ostracism.⁴⁴ Sophie also raised concerns that prisoners were receiving very little support once leaving prison. This lack of support resulted in people struggling to reintegrate into society and find housing and employment, often leading to relapses. Of course there is also good practice but Positively UK's experience and research demonstrates there is a lot more to do to secure high standards of care across the detention estate.

Peer support from HIV support organisations such as Positively UK was greatly appreciated and made a real difference. One prisoner was quoted as saying 'prison does not cater for the health needs of people living with HIV, peer support was a vital lifeline [...] and they were there to help me as I was preparing to leave prison, they have continued to support me ever since.' However, Sophie explained that the care of prisoners injecting drugs and living with HIV was not something Positively UK could do by themselves. It was imperative organisations continued to work in partnership.

A number of policy developments should be noted as relevant. In terms of commissioning, NHS England has taken over responsibility for commissioning healthcare in prisons - a national approach may be an opportunity to secure greater consistency and better care across all prisons. Dr Eamonn O'Moore, consultant in public health at Justice Health, responsible for advising NHS England on prison health commissioning arrangements, was at the NAT roundtable and committed to addressing some of the deficiencies Sophie raised. He said her examples were simply people not doing their job as they should - we needed better accountability mechanisms in prisons and a reinvigorated commitment to good quality clinical care.



Whilst HIV services are 'open access' and so available to someone no matter where they live, drug services are not, so insensitive or inflexible housing decisions can risk interruptions to services and to integration with HIV care.

HIV and People who Inject Drugs

NAT has also been concerned recently at changes to housing policy which give much greater discretion to local authorities to determine priority for social housing. Stringent and extended residency requirements within a local authority area could militate against housing for someone who injects drugs and has spent time in prison or residential treatment outside of the area, or who simply has lived a more chaotic or transitory life across local authority boundaries. Whilst temporary accommodation, such as in a hostel, might be available to address immediate street homelessness, the move into permanent, stable, and secure local authority social housing may well prove more difficult for people who inject drugs, particularly because authorities are now much more able to implement different housing allocation policies.

Recommendations

- ▶ The high mortality rates amongst people who inject drugs should be a cause for immense concern. Whilst most HIV-related quality of care indicators are good, there are clearly broader threats to life and well-being which need to be addressed by multiple services working effectively together.
- ▶ Public Health England should collect and publish data on overall mortality rates, locally disaggregated, amongst people who inject drugs, in addition to data on those deaths relating directly to drug use. Such mortality rates are the best indicator of how services are together meeting the needs of this group. These rates should be included in the next Public Health Outcomes Framework.
- ▶ It is especially important that NHS transition and new arrangements do not allow people who inject drugs to 'slip between the gaps' in care. All local authorities should ensure single points of contact and coordinators, with outreach capacity, for the multiple service needs of people who inject drugs, and especially those living with HIV. Good practice examples should be promoted by Public Health England.
- ▶ NHS England, as it begins to commission healthcare in prisons should consult on its service specification, take account of evidence of failings in care, establish a proactive programme to address stigma around both HIV and drug use, ensure access to prisons for HIV clinical specialists and peer support, and that generic healthcare services in prisons all operate with an appropriate and up-to-date understanding of HIV and its treatment.
- ▶ People who inject or have injected drugs should be a priority group for social housing and receive ongoing support to remain in such housing - local residency requirements should include some explicit flexibility to acknowledge the specific circumstances of those with chaotic lives, and those who have been out of area for treatment or when in prison.

Summary of Recommendations

Epidemiology: HIV amongst People who Inject Drugs

- There is a health crisis amongst a significant number of MSM who are engaging in problematic recreational drug use and high-risk sexual behaviours. A coordinated, fully funded and effective response from both commissioners and providers is urgently needed.
- Commissioners in London should integrate sexual health and substance misuse service provision for MSM, with integrated care pathways into specialised support.
- Open access, appropriate and tailored services across London for MSM with problematic drug use should be commissioned by London councils as soon as possible with the capacity to meet these increasing and complex needs.
- Commissioners outside London should undertake needs assessments around MSM drug use, injecting and sexual risk to identify the scope for joint commissioning of tailored drugs and sexual health services for MSM.
- Clinicians and health advisors in sexual health clinics should be trained to ask service users, and in particular MSM, systematically and on an ongoing basis about problematic recreational drug and alcohol use.
- Generic drug treatment services should be trained to respond sensitively and in a clinically appropriate way to the needs of 'non-traditional' drug users such as MSM, and to the use of newer drugs in addition to opiates and crack cocaine.
- Further research is needed into problematic recreational drug use and injecting amongst MSM both within and outside London - to meet current and emerging needs and to inform local HIV prevention and health promotion interventions.
- HIV Prevention England should continue its welcome focus since the NAT roundtable on MSM drug use, in particular drawing on international and local experience to develop relevant health promotion interventions for this group of MSM. They should be supported in this, and in the gathering of further data and evidence, by Public Health England.
- There are risks of blood borne virus infection to people who are injecting IPEDs. Local authorities should ensure the health needs of IPED users are known and met in their local area, drawing on advice from NICE and Public Health England.
- Local authorities should commission interventions to advise newer communities injecting drugs of the dangers of sharing injecting equipment, and the importance of sterile equipment, as well as of where to go to access NSP services. These communities include steroid users, young women injecting tanning agents, and MSM injecting crystal meth and mephedrone. Social media and newer settings should be considered (twitter, gyms, tanning salons, gay clubs etc).
- Agencies which collect drug monitoring data in the UK should broaden their data collection to ensure it captures emerging drug trends, for example the injection of amphetamines such as crystal meth and mephedrone and the injection of IPEDs.

Summary of Recommendations

Commissioning Arrangements for Drugs Services

- Drug treatment services should be part of the mandated services required by law of local authorities' public health commissioning.
- Public Health England should continue to fund central resources dedicated to supporting drug treatment services. The amounts of funding should be similar to or greater than that invested by the National Treatment Agency.
- Police and Crime Commissioners should engage with local Directors of Public Health and Health and Well-being Boards to ensure adequate and evidence-based local investment in drug treatment services, including harm reduction, these being an essential and cost-effective means to reduce crime. Consideration should be given as to how the Community Safety Fund might be used locally to leverage improvements in drug treatment services.

Harm Reduction

- Public Health England should set out formally an evidence-based, ethical position on the provision of OST, and advise local authorities to commission services on that basis. This position should reflect the evidence as set out in the report 'Medications in Recovery' and make clear:
 - that all people dependent on opiates seeking drug treatment should have OST as an available option where clinically appropriate
 - that there should be no pre-determined time-limits to the provision of OST
 - that exiting from OST should only be with the full, informed consent of the service-user as part of a treatment plan s/he has been an equal partner in developing
 - that for a proportion of people who have been dependent on opiates the clinically appropriate treatment will be to be maintained on OST and not to exit this treatment

- that for some people successful and 'full' recovery means ending problematic drug use, and forming satisfying and productive social, work and emotional relationships, whilst on OST

- that exiting from OST should not be regarded as the only measure of treatment success or service performance.

All PHE documents should reflect these principles. These principles do not contradict the current emphasis on regular review of how well a service user is doing on OST, and further consideration of other treatment and support options, including treatment exit.

- Public Health England should promote a strong harm reduction agenda to local authorities, in particular around reducing drug-related deaths, overdoses, and transmission of blood-borne viruses such as HIV and hepatitis C. NAT welcomes the establishing of the 'National Intelligence Network on the health harms associated with drug use' as an essential element of this work.

Summary of Recommendations

- Current policy and financial incentives around drug treatment outcomes inappropriately and dangerously focus solely on treatment exit. The Public Health Outcomes Framework needs at the very least to balance the treatment exit indicator with indicators around drug-related deaths and HIV and hepatitis C transmission.
- The recent linking of 20% of funding to numbers exiting treatment is a perverse incentive in relation to evidence-based care and should not be continued after 2014/15.
- The use of PbR by commissioners of drug treatment services should not focus solely on treatment exit but look also at wider evidence of success, such as ending problematic drug use, ability to remain in stable accommodation, avoidance of overdose or BBV transmission, establishing effective social and/or working relationships, to give just a few examples.
- NAT welcome the new survey of NSP provision in England, arising from recommendations made at the NAT roundtable, which should identify coverage, the range of services provided, where there are gaps and deficiencies, and how best to develop services in the future.
- On the basis of the NSP survey results, Public Health England should engage with relevant local authorities and Directors of Public Health to remedy gaps and deficiencies in service provision.
- Public Health England should from now on gather on a regular basis from local authorities information on NSP services, their coverage and provision.
- NICE should review and update their public health guidance on NSPs to take account of new injecting patterns, new drugs and altered commissioning arrangements. Level 3 services should all be offering on site HIV testing, with extension of a recommended HIV testing offer to levels 1 and 2 services.
- Where the public health challenge is so recent that there is inadequate research on which to base a NICE recommendation, Public Health England should provide advice to local authorities on how to address need with appropriate NSP services.
- There should be pilot NSPs in some prisons in the UK to identify any possible benefits to prisoner health.

HIV and People who Inject Drugs

- More research is needed in order to understand why there are poorer CD4 outcomes for people with HIV who inject drugs compared with the wider population of people living with HIV. More detailed analysis of the data by Public Health England will be an essential first step to identify possible causes, and any recommendations for further research or action.
- The high mortality rates amongst people who inject drugs should be a cause for

Summary of Recommendations

- immense concern. Whilst most HIV-related quality of care indicators are good, there are clearly broader threats to life and well-being which need to be addressed by multiple services working effectively together.
- Public Health England should collect and publish data on overall mortality rates, locally disaggregated, amongst people who inject drugs, in addition to data on those deaths relating directly to drug use. Such mortality rates are the best indicator of how services are together meeting the needs of this group. These rates should be included in the next Public Health Outcomes Framework.
- It is especially important that NHS transition and new arrangements do not allow people who inject drugs to 'slip between the gaps' in care. All local authorities should ensure single points of contact and coordinators, with outreach capacity, for the multiple service needs of people who inject drugs, and especially those living with HIV. Good practice examples should be promoted by Public Health England.
- NHS England as it begins to commission healthcare in prisons should consult on its service specification, take account of evidence of failings in care, establish a proactive programme to address stigma around both HIV and drug use, ensure access to prisons for HIV clinical specialists and peer support, and that generic healthcare services in prisons all operate with an appropriate and up-to-date understanding of HIV and its treatment.
- People who inject or have injected drugs should be a priority group for social housing and receive ongoing support to remain in such housing - local residency requirements should include some explicit flexibility to acknowledge the specific circumstances of those with chaotic lives, and those who have been out of area for treatment or when in prison.

“ It is especially important that NHS transition and new arrangements do not allow people who inject drugs to ‘slip between the gaps’ in care. ”

Endnotes

- ¹Please see Sara Croxford's presentation cited in NAT's minutes of the HIV and Injecting Drug Use Roundtable.
- ²Then with the Health Protection Agency
- ³HPA (2012) Shooting Up Infections among injecting drug users in the UK 2011. An update: November 2012.
- ⁴HPA (2012) 'Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People who Inject Drugs'
- ⁵HPA (2011) 'Survey of Prevalent HIV Infections Diagnosed (SOPHID)'
- ⁶HPA (2012) 'People who inject drugs: United Kingdom New HIV Diagnoses to end of December 2012'
- ⁷For more information on the UAM survey of people who inject drugs please click here
- ⁸HPA (2011) 'Survey of Prevalent HIV Infections Diagnosed (SOHPID)'
- ⁹HPA (2012) 'Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs'
- ¹⁰See NAT's report: NAT (2012) 'Hepatitis C and HIV Co-infection'
- ¹¹Turner, L et al. (2010) '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, p.569-577
- ¹²Please also see Pete Burkinshaw's presentation at NAT's HIV and Injecting Drug Use Roundtable.
- ¹³UK CHIC (2011) 'Impact of late diagnosis and treatment on life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) Study', *BMJ*, 343:d606
- ¹⁴HPA (2012) Data tables of the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs.
- ¹⁵Hay G et al. (2012) 'Estimates of the Prevalence of Opiate Use/ or Crack Cocaine Use 2010/11: Sweep 7 report.'
- ¹⁶NTA (2013) 'Falling Drug Use: The Impact of Treatment'
- ¹⁷Please see Pete Burkinshaw's presentation at NAT's HIV and Injecting Drug Use Roundtable.
- ¹⁸Then at the National Treatment Agency for Substance Misuse (NTA)
- ¹⁹Please see Pete Burkinshaw's presentation at NAT's HIV and Injecting Drug Use Roundtable.
- ²⁰NTA (2012) 'Club Drugs: Emerging Trends and Risks'
- ²¹HPA (2012) 'Shooting Up Infections among injecting drug users in the UK 2011. An update: November 2012'
- ²²NTA (2012) 'Club Drugs: Emerging Trends and Risks'
- ²³Kirby T and Thorner - Dunwell M (2013) 'High-risk drug practices tighten grip on London gay scene' *The Lancet*, Vol 381, Issue 9861, p.101-102
- ²⁴See Dr Adam Bourne's presentation at NAT's Roundtable, and also, for much of the information in this section, Stuart, D (2013) 'Sexualised drug use by MSM: background, current status and responses,' *HIV Nursing*, Spring 2013
- ²⁵Stuart, D (2013) 'Sexualised drug use by MSM: background, current status and responses,' *HIV Nursing*, Spring 2013
- ²⁶see NAT's 'Open Letter to London Councils'
- ²⁷Please see Vivian Hope's presentation at NAT's HIV and Injecting Drug Use Roundtable
- ²⁸NAT (2011) 'HIV: Public Knowledge and Attitudes, 2010' p.11
- ²⁹Drugscope (2013) 'The Public Health Reforms: What they mean for drug and alcohol services'
- ³⁰See for more detail: Drugscope (2012) 'Police and Crime Commissioners - A briefing for the drug and alcohol sector'
- ³¹HMG (2012) 'Putting Full Recovery First' p.4
- ³²Ibid p.3
- ³³Ibid p.6
- ³⁴Ibid p.11
- ³⁵Ibid p.18
- ³⁶<http://www.nta.nhs.uk/facts.aspx>
- ³⁷McLellan T and White W (2012) 'Come together' Druglink
- ³⁸HMG (2010) 'Drug Strategy 2010' p.18
- ³⁹Please see Vivian Hope's presentation at NAT's HIV and Injecting Drug Use Roundtable
- ⁴⁰Policy Briefing (2013) 'HIV prevention, treatment and care in prisons and other closed settings: a comprehensive package of interventions' UNODC, ILO, UNDP, WHO, UNAIDS June 2013
- ⁴¹Then at the Health Protection Agency (HPA)
- ⁴²PHE (2011) UK Focal Point on Drugs 2011 Edition pp 141
- ⁴³Please see Vivian Hope's presentation at NAT's HIV and Injecting Drug Use Roundtable
- ⁴⁴Positively UK 'HIV Behind Bars' 2013

Glossary

ACMD	Advisory Council on the Misuse of Drugs (ACMD)
ART	Anti-Retroviral Therapy
BBVs	Blood Borne Viruses
BASHH	British Association of Sexual Health and HIV
DATs	Drug Action Teams
HPE	HIV Prevention England
HPA	Health Protection Agency
IPED	Image and Performance Enhancing Drugs
JHWS	Joint Health and Well-being Strategy
JSNA	Joint Strategic Needs Assessment
MSM	Men who have Sex with Men
NDTMS	National Drug Treatment Monitoring System
NICE	National Institute for Health and Clinical Excellence
NSP	Needle and Syringe Programme
NTA	National Treatment Agency
OST	Opioid Substitution Therapy
PbR	Payment by Results
PEP	Post Exposure Prophylaxis
PHE	Public Health England
PHOF	Public Health Outcomes Framework
POCT	Point of Care Test
UAM	Unlinked Anonymous Monitoring

Acknowledgements

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We are also immensely grateful to all of the participants and their contributions at NAT's roundtable (listed in Annex A). Particular thanks go to those presenting and to those who provided feedback on the drafting of this resource.

NAT remains solely responsible for the content of this HIV and Injecting Drug Use report.

Annex A - Seminar Attendees

Attendees

Dr Adam Bourne	Sigma Research, LSHTM
Andrew Langford	British Liver Trust
Andrew Tippett	Nurse Practitioner, BBV team, Mile End Hospital
Becky Hug	Hep C Trust
Carole Sharma	Federation of Drug and Alcohol Professionals (FDAP)
Dr Chris Ford	Clinical Director, International Doctors for Healthy Drugs Policies (IDHDP)
David Badcock	Addaction
David MacKintosh	GLA Senior Health Policy Officer on Alcohol and Drugs
Dr Eamonn O' Moore	Offender Health, DH
Dr Eliot Albers	International Network of People who Use Drugs
Elsa Browne	Substance Misuse Management in General Practice (SMMGP)
Emily Grundy	Commissioner NHS Blackpool
Dr Fortune Ncube	HPA
Dr Helen Walters	GLA Health Team Manager
Jamie Bridge (IDPC)	National Needle Exchange Forum (NNEF), International Drug Policy Consortium
Joe Murray	Senior Policy Officer, Health, GLA
John McCracken	Drugs Programme Manager, Department of Health
Councillor Jonathan McShane	Local Government Association
Kate Halliday	SMMGP
Lisa Power	THT
Dr Marcus Roberts	Drugscope
Maria Phelan	Harm Reduction International
Dr Mike Kelleher	South London and Maudsley NHS Foundation Trust (SLAM)
Niamh Eastwood	Release
Dr Patrick French	HIV clinician, Mortimer Market Clinic, UCL
Pete Burkinshaw	National Treatment Agency
Dr Roy Robertson	General Practitioner, Edinburgh
Dr Sarah Creighton	HIV clinician, Homerton Hospital
Sara Croxford	Health Protection Agency (HPA)
Shaun Watson	National HIV Nurses Association
Sophie Strachan	Positively UK
Dr Valerie Depech	HPA
Viv Evans	Adfam
Dr Vivian Hope	HPA
Dr Yusef Azad	NAT

Observers

Hannah Bate	NAT
Sally Thomas	NAT

Annex B - Agenda

**HIV AND INJECTING DRUG USE
NAT ROUNDTABLE
Monday 14 January 2013
Committee Room 4, City Hall, The Queen's Walk, London SE1 2AA**

AGENDA

- 10.00 am** **Welcome and introduction**
- 10.15 am** **Current trends in injecting drug use in the UK:** Dr Vivian Hope, Health Protection Agency
- Reflection: Injecting Drug Use and Prisons,** Dr Eamonn O'Moore, Justice Health, DH
- Reflection: Injecting Drug Use and Men who have sex with Men,** Dr Adam Bourne, Sigma Research, London School of Hygiene and Tropical Medicine
- Discussion**
- 11.30 am** **The new commissioning arrangements for drug treatment services in England:** Pete Burkinshaw, NTA
- Discussion**
- 12.30 pm** **Lunch**
- 1.15 pm** **Harm Reduction in the UK: current issues in policy and service delivery:** Dr Marcus Roberts, Drugscope, and Jamie Bridge, National Needle Exchange Forum and International Drug Policy Consortium
- Discussion**
- 2.00 pm** **Current epidemiology of HIV and other BBVs amongst people who inject drugs:** Dr Sara Croxford, HPA
- 2.30 pm** **HIV treatment and care issues for people who inject drugs:** Dr Sarah Creighton, HIV Consultant, Homerton Hospital, London, and Sophie Strachan, Positively UK
- Discussion**
- 3.30 pm** **Concluding remarks: policy and service needs over the next few years**
- 4.00 pm** **Close**

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.



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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

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