UK Harm Reduction Alliance Consultation Exercise

Introduction

The UK Harm Reduction Alliance (UKHRA) was funded by the National Treatment Agency (NTA) to carry out a consultation exercise in March 2005. This consultation aimed to gather the views of key stakeholder organisations on what action is required in relation to drug treatment and harm reduction (HR) to reduce the impact of blood borne viruses (BBVs) and overdose.

This report summaries statements, findings and key themes in response to this consultation exercise

Data collection

53 organisations and/or key individuals[1] were contacted and surveyed using a short structured interview[2]. 28 respondents were interviewed over the telephone and their comments paraphrased within this report. A further 25 people preferred to submit their responses to the same questionnaire via e mail. Feedback from this set of responses has been reproduced directly from these e mails.

Interviewees included a range of DAT coordinators and commissioners, drug treatment and harm reduction service providers, policy and public health centres, drug user groups and other relevant bodies across England.

It should be noted that a number of other organisations were also contacted at the same time in an effort to sample right across the spectrum of key stakeholders. However, due to the consultation timeframe, not being able to reach other possible contacts on the telephone and a small lack of response to e mailed questionnaires[3] only 53 were collected in total.

In the writing of this report there has been no attempt to be selective about the responses published, but rather a concerted effort to provide as comprehensive a summary as possible of respondent feedback on the issues raised by the questionnaire.

Analysis method

A thematic approach was used to analyse the views of all respondents to identify common themes and areas of concern.

Executive Summary

A total of 53 organisations and key individuals working in the field of drug treatment and harm reduction responded to a semi-structured questionnaire in relation to drug treatment and harm reduction.

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[1] Appendix 1 – List of respondents

[2] Appendix 2 – Interview questionnaire

[3] Appendix 1 (a) – Other organisations who were contacted but did not response. This may have been due to appropriate organisational representative not being around to take call. Or the questionnaire was e mailed over to an appropriate person or another colleague to pass on to appropriate person and just not returned for whatever reason.

A number of people felt that over the last five years, several positive things had come out of the current drug strategy. Namely, the linking of the drugs and crime agenda and that harm reduction was now better understood and embodied both within policy and practice.

However, the majority of feedback indicates discontent and criticism of key aspects of the drug treatment sector with particular concerns around the lack of an effective response to increasing rates of blood borne disease.

To elicit views, respondents were asked a total of eight questions:

1. How well do you feel that harm reduction principles are understood and embodied within the government's current drug strategy in England?

Respondents generally agreed that harm reduction principles were understood and embodied but not necessarily implemented or prioritised. Many people expressed concern that emphasis seemed to be around reducing crime related harm rather than improving public health.

Comments included:

- Clear understanding with regard to Adult treatment and Young People agenda. Where it's loses out is under Communities and Criminal Justice System

- Contradictions and tension between Drug Strategy and Community Safely, government policy is at heart driven by the contradiction of pursuing the war against drugs and also a harm reduction approach

- Well understood, however the emphasis is not on health – it is on offending and anti-social behaviour.

- '..in terms of expenditure, the only real policy initiative appears to be crime reduction through treatment'

- One of the problems has been the lack of attention paid at Tier 2 in comparison to Tier 3. This has meant that many DATs have not adequately resourced Tier 2 interventions. The NTA do not even monitor Tier 2 activity which results in less areas paying it attention'.

- Government's drug policy focuses on supply and consumption prevention as the sole HR measure, failing to focus on consumer protection. Debate about HR often confuses these approaches. The Government's Alcohol HR Strategy for England provides an example where consumer protection – balances with consumer rights- is the central focus, The Misuse of Drugs Act concerns drugs misuse, not use.

2. What, if any, do you see as the most pressing current threats to harm reduction?

Respondents most frequently mentioned the 'threat' of the criminal justice agenda, followed by concerns about the influence of USA drug policy and it's anti-harm reduction stance.

Overall feedback identified a number of respondent concerns:

- An over delivery of treatment via the criminal justice agenda
- An apparent anti-harm reduction stance in the USA
- A lack of an effective response to increasing levels of blood borne viruses
- Ignorance in the field and poor training in relation to carrying out harm reduction
- Emphasis on moving people to total abstinence rather than long term prescribing
- The marginalisation of illegal drug users and a climate of vilification as opposed to support and understanding
- Refusal to take harm reduction in relation to crack seriously
- A lack of national consistent drug education messages for young people
- A lack of understanding by the public and politicians of the importance of harm reduction

3. What developments would you prioritise within a national treatment strategy that is based upon harm reduction?

Respondents highlighted a number of issues including the following:

- Increased funding and greater coverage of needle exchange
- BBVs – prevention, testing, vaccination, treatment and support
- The piloting of drug consumption rooms and safer injecting spaces
- Need to reduce injecting risks and greater peer interventions
- Rapid and widest possible access to treatment and drug of choice prescribing
- 'Retox' maintenance treatment for people in prison and the continuation of HCV treatment in prison if already commenced
- The use of supplementary and independent nurse and pharmacist prescribers
- Increased young people treatment services (Tier 3) throughout the country and clear guidance on how to deal with younger drug users

4. With regard to harm reduction, what do you regard as the main gaps and priorities for development within our existing evidence base?

Feedback was varied as to the main gaps but several main themes emerged.

- Needle exchange and need to know more about NEPs and how they best function and what they can be expected to deliver
- Blood borne viruses particularly hepatitis C
- Substitute medication and information on good practice/prescribing
- Gaps in evidence base for stimulant treatment and recreational use
- More focus on young and heavy cannabis users and greater clarify on legal position of working with under 18 year olds
- Research around homeless crack users – how we can change the environment or persuade heroin users not to inject crack. Need evidence to avert risks

5. Overall, what do you feel that the impact of the drugs and crime agenda has been on the reduction of drug-related harm?

Views ranged from 'Disastrous' to 'a good thing in some ways'. Some people felt that it was too early to tell the true effects, while others felt that the linking of the agendas had enhanced services, increased investment and that coercion does work.

Several people had mixed feelings:

- I see crime as a harm to the individual and the community however, it should not be at the expense of BBV and voluntary entry into 'treatment'
- Improved access to substitute prescribing but other areas somewhat neglected. Is it drug users or the victims of crime that anyone cares about?

However, the overall consensus appears to be that overall the linking of the two agendas has a negative impact, particularly in relation to public health.

- From the perspective of the general public, it seems to have re-enforced stereotypes and done nothing for drug-users whose criminal activity is limited exclusively to contravention of the Misuse of Drugs Act
- Where's the real evidence of effectiveness? People don't understand the public health agenda – no community safety if don't have public health agenda
- The reality is that so much money and 'performance management' requirements have been thrown at expanding the criminal justice system, we've inherited a false-commissioning economy where finances and targets ring-fenced for

supposed drug treatment and support, are effectively being used to prop up and achieve criminal justice targets. This, in my experience, has resulted in a commissioning culture that prioritises party-political will over public health issues

6. How adequate do you consider the existing emphasis on the prevention of blood borne virus transmission and treatment within the national strategy?

This issue of blood borne viruses was an area of major concern. An increase over the last five years of HIV and HCV has been seen at both a national and local level and was 'very worrying'. Respondents called for a need to ensure a higher profile for BBVs and a far more effective national response.

- A public health disaster – policy makers have presided over a period that has seen an increase in infections, not even managed to contain current infection rate as it was a few years ago

- … other than needle exchange, there are no other nationwide existing services within the national strategy. The availability of products such as filters and stericups within the exchange packs to prevent the spread of viruses through sharing equipment, not only from needles and syringes will vary from DAT to DAT. The supply of information around safe injecting guidelines and good practice also varies depending on DAT

Respondents' priorities for improvement focused on a number of prevention, treatment and support issues:

- Continuous rolling out of HAV and HBV vaccination programmes – and far more proactive in prison; more funding for vaccination A & B clients and more funding for vaccination A & B pharmacists and staff

- Greater coverage of needle exchange. Less emphasis on 'seeing' people rather than just letting them take what they need

- Proper mapping and action research to establish and identify needs assessment amongst marginalised groups; tools for monitoring access for such groups and pick up by preventative/educational agencies

- Increase, dedicated funding and a focus on the transmission of BBVs as a priority, performance management target

- ….testing and support vital to prevent the damage of the disease. More support for affected individuals. Extra advice in relation to alcohol issues

- An integrated hepatitis C strategy which is supported by resources to provide treatment for affected IDUs

7. How adequate do you consider the existing emphasis on the prevention and management of overdose within the national strategy?

There appeared to be slightly less concern here than over blood borne infections. However, the majority of respondents felt that existing policy and practice was inadequate and more could be done to improve the prevention and management of overdose as well as reduce the number of drug related deaths.

Respondents cited inadequate training for drug workers, poor intelligence systems, and a need for much more work to be carry out within prison and on release to reduce overdose and drug related deaths as areas for further development and prioritisation.

Recommendations included:

- Relax supervised consumption as keeps people away from services and therefore dangerous in terms of BBVs and OD
- NHS, DH and NTA should certainly ensure a nationwide OD risk programme is in place in prison
- Proper drug treatment prescribing services within prisons would reduce addict deaths
- Pilot Drug Consumption rooms (DCRs); more peer approaches; targeting of hot spots (such as Brighton) with ring-fenced resources
- Give naxolone to users and carers and all paramedics
- Set up a new expert group/Guidance to look at risks from new drug/poly drug using trends; more scrutiny into the part that alcohol plays in what are described as DRDs

8. How do you assess the government/NTA's progress on drug user and carer involvement in the reduction of drug related harm?

Among respondents in general there appeared to be less certainty, knowledge and awareness of the NTA's progress in relation to user and carer involvement than in any other area.

Again, feedback varied from good "a mega step forward' and 'NTA getting it about right' to 'a poor response that has been 'spun' to create an impression of action'.

Suggestions for improvements included:

- Some qualitative sociological research with carers and users; peer led research to identify determinants around prevention issues at a community level as well as peer promotion of things that could protect
- The NTA should reconfigure the treatment planning process and reduce the current 8 Treatment Planning Grids from 8 to 5 (Tiers 1-4 and Criminal Justice).

They could then pressure DATs to evidence a financial, strategic & operational commitment to Workforce Development, Underserved Groups, Systems & Infrastructure, Users, Carers AND Harm Reduction Initiatives through all 5 Tiers with an 'expected' % spend specified against each one.

- Serious consideration by NTA on protocols around how to enable effective user/carer involvement; would like to know where best practice is; Need to identify the best patient liaison model

Full summary of respondents' views

1. How well do you feel that harm reduction principles are understood and embodied within the government's current drug strategy in England?

Respondents generally agreed that harm reduction principles were understood and embodied but not necessarily implemented or prioritised. Many people expressed concern that emphasis seemed to be around reducing crime rather than improving health.

Respondent views

Very crime strategy focussed and 'protecting the community'. NTA have picked up the health agenda

Current drug strategy updated in 2002 to include HR but in practical terms I do not see it benefiting from any political will to see HR principles actioned robustly and effectively enough to make a positive change to the lives of users or our wider communities..but there is awareness that it is a philosophy and approach that needs to be, at least, acknowledged. Tokenism, basically!

Doesn't really go into what wanted and what agencies should be delivering; not comprehensive or given enough emphasis; embodied in paper format but poorly implemented

Contradictions and tension between Drug Strategy and Community Safely, government policy is at heart driven by the contradiction of pursuing the war against drugs and also a harm reduction approach, a consistent and coherent harm reduction strategy fundamentally endorses the pragmatic and realistic view, based on past experience that in society substances use will always exist and that the war against drugs is totally unrealistic and wasteful of resources.

Understood but not well embodied. Totally missing public health agenda – just pay lip service. No real incentive to implement robust integrated HR services; corrupted as a concept to meet the crime agenda rather than addressing the public health needs of drug users.

Play second fiddle to a policy of oppression of the drug-using community, born out by the latest bill on drugs – which is based on a populist 'tough on drugs' approach

Government's drug policy focuses on supply and consumption prevention as the sole HR measure, failing to focus on consumer protection. Debate about HR often confuses these approaches. The Government's Alcohol HR Strategy for England provides an example where consumer protection – balances with consumer rights- is the central focus, The Misuse of Drugs Act concerns drug misuse, not use.

Government are running with the concept of HR but delivery is poor, commissioning is poor and performance management is poor; no clear programme for refinement, improvement of HR activities. NTA/DH work on injecting and overdoses is marginal and of poor quality. One of the problems has been the lack of attention paid at Tier 2 in comparison to Tier 3. This has meant that many DATs have not adequately resourced

Tier 2 interventions. The NTA do not even monitor Tier 2 activity which results in less areas paying it attention'.

Many workers have no idea of the Government's drugs strategy and no management feedback of new HR recommendations, methadone maintenance effectiveness as a HR tool or any other up to date HR info

More clearly stated and mentioned more in current drug strategy. Government has at least chosen to use HR terminology; getting better – at least says 'Treatment and HR'

Probably no more or less understood by politicians; from a criminal justice perspective it is reasonable. Not however in health shown by poor quality needle syringe exchange and low doses in methadone services

Well understood, however the emphasis is not on health – it is on offending and anti-social behaviour. Enforcements approaches such as the closure of crack houses can have the effect of harm maximisation where enforcement alone is the only intervention

'..in terms of expenditure, the only real policy initiative appears to be crime reduction through treatment'

Well understood but what's embodied is reducing crime rather than public health; Understood academically but don't prioritise it or understand the urgency of HR; Understood by officials, not engaged with by Ministers

Embodied more though people's own initiative at grass root level than government's understanding or direction

HR drives strategy to an extent; Clearly an emphasis on HR and requirement of commissioners to demonstrate at a local level

Clear understanding with regard to Adult treatment and Young People agenda. Where it's loses out is under Communities and Criminal Justice System

Depends on definition and interpretation of HR? Lacks of clarify about what HR is. If truly understood then why do we still have debates about Diamorphine prescribing; no longer contentious to have a HR message

Depends on the drug! Government does not accept HR principles around crack the same way they accept harm reduction in relation to heroin and injecting

2. What, if any, do you see as the most pressing current threats to harm reduction?

Respondents most frequently mentioned the 'threat' of the criminal justice agenda, followed by concerns about the influence of USA drug policy and it's anti-harm reduction stance.

Criminal Justice and commissioning

The Criminal justice agenda; Link with crime has taken us 2 steps back; HR has been sidelined by CJ agenda; Tension between Criminal Justice and Treatment Strategy; the over delivery of treatment via the CJ system – particularly when it is coercive

Depends on definition of HR but criminal justice agenda has led to loss around human rights

Subtext going on all the time – how are we going to get people off drugs? Not how are we going to improve their health?

Implementation of DIP, more emphasis should be placed on ensuring take up of vaccination, blood testing, safer injecting techniques etc not enforced drug testing and structured day care

The current emphasis on treatment outcomes and specifically on Tier 3 services does give cause for concern as this can be interpreted as a drive towards quick 'curing' rather than reduction in harm, potentially over a long period.

The priority to increase the number of drug users in treatment through the criminal justice route combined with other NTA targets means drug services are concentrating on processing clients through treatment rather than looking at the needs of those who are not ready/willing/able to access treatment. This has meant that there is a reduced priority given to developing or maintaining high standard comprehensive harm reduction services

'Treatment and rehabilitation centres are geared increasingly to deal with CJ clients and less able to cope with long-term chaotic users

Change in political will and failure to deliver crime reduction benefits; biggest threat is that poor delivery will not justify the huge sums invested; once picked up by CJIPs then straight to treatment which may not be appropriate for some people and lead to false starts and expectations from individuals. Then services get blamed and funding questioned; potential change in Government/Government emphasis towards an abstinence based approach

Unintended effect from Government challenging money into CJ services and meeting CJIPs targets rather than e.g. Outreach, which commissioners might prefer to commission

..from a commissioning background, I am very aware of the pressure that DATs are under to achieve outputs over outcomes, and to assist the present government in scoring political points

PCT/NHS structure has a set of competing priorities that don't include HR;
the possible threat to ring fencing of drug budgets as a result of the development of local area agreements

USA policy and influence

GW Bush; the American administration and anti harm reduction stance; pressure from the USA and INCB to marginalise interventions that are known to reduce harm; the UK government does not want to disaffect either UN or USA by introducing radical new harm reduction policies; the negative influence of the US upon UN HR initiatives together with the current anti-drugs stance of the tabloid media probably means that HR initiatives have gone as far as is socially acceptable

Externally and internationally, the US pressure against HR and specifically needle exchange including pressure on UNODC, blocking or emasculating all resolutions on health, investigation into 'harm reduction/drug legalisation', pressure on the Global Fund to not fund HR projects and pressure on US/AID to dissociate itself from HR and NEXT. This has implications for UK international work, and also gives ammunition within UK to those against HR

BBVs

HIV/AIDs dropped off the political agenda, hence an undervalued under energised part of the national response to drugs. HCV consequently addressed too little and very late. Clear indications that HCV is not under control and that we may be losing our ability to limit HIV infection. Indicators are rising levels of a) risk behaviour b) HIV incidence in young injectors

HIV has slipped off the agenda with the advert of triple therapy yet sexual behaviour with methamphetamine is particularly high risk; need to get BBVs under control; major problem in local area and need to appoint more staff to raise BBVs with all users as they come though the door; trying to ensure integrated HBV funding is in place and enough vaccination points

Unclear targets in the UK (eg. in relation to needle exchange (Nx Ex) and overdose (OD) that relate to key harms we want to prevent. The less evidence we have on the extent of problems the more difficult to persuade policy makers to do something about them

Education and skilled workforce

Not enough mobile schemes, outreach teams and qualified staff to discuss HR issues with clients; we are poor at moving people to the next stage. For example, injecting to oral methadone. Ignorance in the field and poor training for the delivery of what is highly skilled work

Workers and commissioners should look inward as still not doing HR basics; challenge is to embody it consistently in local service provision

..the lack of education on all types of harm reduction, housing, switching injection sites etc by workers in the field, basically not the obvious reduction techniques known by many, but the more unobvious ones, they only know about OD and Hep C, and that knowledge is patchy

HR itself

Misunderstanding based on a false thinking that HR is in someway at odds with whatever is driving drug treatment. HR is a very sophisticated concept but people don't see it in that way

We could be more ambitious on behalf of drug users. Goals tend to be 'alive and not in prison' so limits to HR is it's own worse enemy

Harm reduction itself by not understanding that it is not someone's right to take drugs if they cannot afford them, even with legalisation

Seems more of an emphasis on moving people to total abstinence rather than prescribing long term

Marginalisation of illegal drug users
At present, drug users are perceived as this country's greatest, visible 'folk devils' and as a result, we are living in a climate where vilification of – as opposed to understanding and support for – drugs users is the norm

Denial that legal drugs are drugs leads to widespread blaming of illegal drugs users for all drug related harm, Stigma attached to consumers and treatment practitioners of illegal drugs represents the greatest obstacle to efficient and fair treatment – both are deterred by stigma

Other key concerns
Crack and methamphetamine use with its tendency to increased risk behaviour;
Not taking crack HR seriously e.g. crack pipe exchange

Comprehensive drug education programme within schools and colleges;
Need national consistent messages via PHSE teachers; lack of needle exchange for young people (U18)

The reliance on pharmacy based needle exchanges has been identified in Shooting Up as a possible cause of the continued high level of sharing – they are transaction focussed, not interaction focussed'; patchy availability of NEX, especially in rural areas – need for more outreach and out of hours services

Legislation regarding drug paraphernalia

Not enough choice in treatment e.g. Lack of heroin, delay of trials

Lack of understanding by public and elected representatives of importance of harm reduction to them.

3. ***What developments would you prioritise within a national treatment strategy that is based upon harm reduction?***

Respondents highlighted a number of key areas.

Needle Exchange
Do what we know works in a sustained and systematic way e.g. Nx Ex - need for greater coverage; robust and well funded needle exchange services that are adequate, equitable, with range of comprehensive, effective and appropriate; increase Nx Ex funding and make this money more clearly identified/allocated; more direction from the Centre to ensure that pharmacies are engaged in Nx Ex; make sure that Nx Ex schemes

are consistent and more than just disposal and supply; pharmacists providing brief interventions work; vending machines; more expansive needle exchange with scope to provide other services such as accommodation, health and employment services ; NTA to produce targets and protocols for NSPs and safe injecting advise and monitor implementation by DATs

BBVs
Prioritise BBVs – prevention, greater education, information and awareness, support services for HCV+ people, prevention of BBVs, expansion of HBV vaccination services; testing and vaccination for all clients coming though the door

Why can't drug workers take blood? Even via dry blood spot test and then if positive for HCV, address alcohol consumption and harm reduction measures with client

Injecting
Pilot drug consumption rooms and safer injecting spaces to use own drugs; injecting rooms for street homeless; walk in clinics; engage with people not going to services; big effort to target injectors and smokers around injecting techniques and safer drug use; at local level DATs should be constantly reviewing local injecting behaviour and assessing the effectiveness of HR services in reducing risk. They don't generally do this because of a lack of expertise and they have no targets related to the risks

Need to reduce injecting risk even before 'treatment' and risk of infection – health education via peer interventions

Substitute prescribing
Rapid and widest possible access to treatment and wide scale drug of choice prescribing; treatment properly delivered at optimum levels; Cocaine and cocaine substitutes and diamorphine prescribing; Being able to prescribe benzodiazepines on a blue script for daily pick up**;** greater treatment slots and more people exiting into abstinence programmes; Services opening out of hours; More funding and access to detox beds, rehab and aftercare; develop national protocols for fast track prescribing services;

Prisons
Retox' and maintenance treatment for people in prison; expansion of treatment options and HR provision in prison and wider criminal justice system; Harm reduction within prison – increase in drug related deaths after release; immunisation programme within prisons; prisons and communication between treatment services and prisons both on entry and on discharge. Focussing especially on medication, hepatitis vaccinations and blood borne virus results. Also continuation of hepatitis C treatment in prison if already commenced; male and female prison estates to develop methadone and subutex treatment

Other Health issues
Health issues – more skilled workers engaging with users on specific health issues e.g. Endocarditis, HCV related issues, peer education; training of both workers and users around sexual health and STIs and BBV prevention issues;

Greater emphasis on wound care and primary care advice and specific low threshold centres providing wound care

Pharmacists

Use of supplementary and independent Nurse and Pharmacist prescribers. Much more integrated working and recognition of professional expertise of others. Use of Minor Ailment Schemes available as part of new pharmacy contract; build on existing services available through community pharmacy, to provide holistic care to this customer group. There are many services currently only available at specialised clinics or centres, which if available through community pharmacy would reach a wider audience. Examples of this could include: screening for blood borne viruses and vaccinations.

Young people

Young People treatment services (Tier 3) throughout the country; Young people don't necessarily use Class A drugs but rather alcohol, cannabis and ecstasy in large quantities. Therefore, at risk of overdose and issues of heavy use impacting on school and family relationships; more HR approaches in schools; the consistent use of the word 'drugs' to mean all drugs, the definition used in the Misuse of Drugs Act and taught to all children at school by law

The current policy document – Models of Care, although currently being reviewed, is for adult services only, not for those under 18 years. We would encourage future policies to contain clear guidance on how to deal with the younger population who require help and treatment

Other comments

Setting of clear objectives for harm reduction services and interventions together with the development of appropriate monitoring systems to identify benefits and best practise.

Base the strategy on harm reduction – if the government has the courage to do this with the alcohol strategy – likewise it can/should for the drugs strategy; … like to see an integration of the alcohol and drugs strategies. Also – the alcohol harm reduction strategy could learn a lot from what we know about how to influence drug-using populations; more joined up thinking between alcohol and drugs and how they inter-relate. Alcohol and drugs should not be separated

Police and Ambulance universal protocol to ensure no 'ambulance chasing'; better responses from A & E depts; acceleration of action research into activities designed to reduce overdose deaths (including consumption rooms) and widespread implementation of promising activities

Look at other social issues that affect drug users

Training staff, making clear expectations and reducing the influence of the medical model which is all about the engagement with clients becoming a debate about how much methadone to prescribe where are you going with your life and how can we help you

Focus on reducing harms of older generation of users i.e. 'silver users' in their 60s and 70s still on scripts.

Discrimination of possession; take drug policy lead away from Home Office and move to Department of Health

Drive on cannabis harms – research-based info on dangers of using cannabis if history of schizophrenia; particular dangers of different types of use

Pilot drug testing – street/club etc; trials of pharmacological interventions for crack cocaine use – using those drugs that could conceivably be used as 'maintenance'

Peer approaches aimed at reducing health problems/deaths

Specific research in primary care as an effective place for treatment

Keep users involved and consulted regarding development of services

Destigmatisation is the key. We need to make all part of the NHS work to reduce harm e.g. every GP and every A & E should have needle exchange facilities and every NHS employee should be award of the issues

4. With regard to harm reduction, what do you regard as the main gaps and priorities for development within our existing evidence base?

Needle Exchange

Not enough robust needle exchange research – need to know lot more about NEPs – how they function best and what they can be expected to deliver; community based Nx and Syringe disposal sites; national guidance on 'disposal and exchange'; need to target pharmacies; main gap is in the evidence base for preventive work. In particular the evidence for needle exchanges and outreach work and some clearer indications of what would be considered best practice; ring fenced budgets for harm reduction – targets for needle exchange provision and expansion of Hepatitis services; not much done to increase Nx Ex returns

There should be an increase in nurse led Harm Reduction Services that offer the full range of paraphernalia, opportunistic blood borne virus screening, immunisation, overdose awareness training and health checks. Too many needle exchange schemes just providing basic needle exchange i.e. needles and syringes only.

What works in terms of encouraging service users to return used works for safe destruction? How to optimise NEX for opiate, stimulant and steroid service users. Review supply of condoms as part of NEX. Sound advice on supply of injecting equipment/harm reduction advice to under 16s

BBVs

Still uncertainly around HCV – should be at the forefront; Main gap is in the provision of services. We should be doing much more to integrate HCV therapy into the harm reduction service. There are some wonderful models and wonderful examples but they are the exception not the rule; the failure to deliver the HCV strategy and action plan. The increasing incidence of HIV in the general population means that the failure to keep harm reduction as a priority provides an opportunity for BBVs to establish a greater

incidence among drug users, particularly new injectors, if the promotion of comprehensive harm reduction strategies are not continually promoted

We know quite a lot about prevalence and infection levels. No question that bacterial infections have gone up, high levels of risky injecting behaviour, HBV, HCV and HIV are higher than 5 years ago as an indirect result of lack of attention to BBVs.

Substitute medication

Information on good practice methadone prescribing not disseminated widely enough; too much 'opinion based' prescribing; an end to catchment until the provision of prevention, care and treatment in line with ACMD report on treatment and rehabilitation (circa 1986), which envisages the availability of a broad range of treatment options in all regions and localities. Drug users have always been a highly mobile population who naturally tend to gravitate towards agencies which provide them with what they think they need; prescribing options and making sure that doctors feel more supported so they can take on greater number of patients; guaranteed access to therapeutic doses of substitute medication nationally that removes post code prescribing

Gap in evidence base for stimulant treatment and recreational use: HR around drugs other than heroin; crack pipe distribution to get more people into services to talk about HR

Young drug users

More focus on young heavy cannabis smokers; need to know more about the comparative harms of different methods of taking various drugs – especially cannabis; Greater clarity around what treatment agencies can do with U18s because legal position is so unclear

Big need to look at underlying issues of drug use in U18s and possibly government needs to look at parenting and the result of earlier childhood experiences in drug users

Other comments

Research around homeless crack users – how can we change the environment or persuade heroin users not to inject crack? We need this evidence to avert risk

Lack of evidence regarding the impact on heath of criminal justice approaches to drugs

Lack of evidence relating to benefits including any cost/benefit analysis for harm reduction strategies – 20 years on - the basic work around cost/benefit of SES has not been conducted

Gap in the analysis rather than the base – drugs don't cause crime – prohibition does

Not so much gaps, but the way the evidence is used. Compare the way the alcohol harm reduction strategy is evidenced and argued, with the way the drug strategy is presented. We need to get back to a more technical rather than moral and polemical analysis of the problems.

The extent to which Tier 2 interventions impact on reducing harm. Nationally data is not collected by the NTA so it's difficult to monitor its impact and make comparison across the country

The provision of comprehensive harm reduction services that do not require clients to enter treatment in order to be measured as successful

Gaps are around pharmacies – commissioners need to be working more positively with improving quality of premises (no observed consumption should be done in public – paraphernalia exchange should not be done in public); Dynamise the training for pharmacists

The effectiveness of targeted, sustained peer-interventions

No evidence base in relation to what is 'effective information'

Sexual and reproductive health of female stimulant users; make links with sexual health and overall healthy lifestyles

Harm caused to families in relation to drug use

Supervised injecting sites and better injecting techniques

Young People and HR

Research around 'multi drug resistant TB – the next big one!'

Access to and education of users in the ethnic minorities – especially the South Asian community, who seem to shelter their opiates users and possibly deny them help from harm reduction initiatives

Clear health warnings identifying boundaries between reasonably safe drug use, drug use likely to harm the consumer (health risk) and drug use likely to harm others (crime risk). Consumers should not be blamed if they have been deprived of information by Government's failure to regulate illegal drugs.
Underlying stresses fuel drug dependency and must be tackled alongside reduction in drug dependency – alternate stress relief strategies are needed.

Public health HR is reasonably well evidenced however, HR is a far wider process including crime reduction, familial reparation, using time productively, and gaining a sense of progress and direction. The evidence is thinner here from a HR perspective

More outreach – important to address needs of rural areas, islands etc

Overdose – we know approx how many O/D related deaths but need clear evidence in order to target interventions, fuller toxicology reports from coroners would assist, need to establish some kind of other surveillance and evidence that estimates mortality

A longitudinal study of effects of retoxification programmes on the death rates of current and ex drug users leaving custody

5. Overall, what do you feel that the impact of the drugs and crime agenda has been on the reduction of drug-related harm?

Views ranged from 'Disastrous' to 'a good thing in some ways'. However, the consensus appears to be that overall the linking of the two agendas has a negative impact, particularly in relation to public health.

Too early to tell
Too early to tell the true effects; difficult to quantify – ASBOs seem to just displace people across boundaries, some of whom are vulnerable and had just begun to make contact with local services; early indicators suggest has a place in HR as more people engaged in treatment so will have an effect

Positive
Where people are receiving proper evidence based substitute upload treatment the impact is greater whether coming from criminal justice system or not. Too many areas not offering quality evidence based prescribing; overall the impact of the drugs and crime agenda has been positive. More resources have become available and more services have either opened or expanded as a result. However it is important that drugs and crime are not so closely linked that the only way to get fast service provision is through the criminal justice system and where possible criminal justice clients should be mainstreamed into the wider community provision

Apart from the real fear that it takes attention away from public health and means ministers and officials are only interested in meeting crime targets..the crime agenda is the reason why the country has a treatment led strategy.. the funding of that sector has more than doubled in 5 years, much of which new funding goes to HR initiatives

There's evidence that coercion does work; prison is better than before in terms of treatment

The two go hand in hand – crime agenda has put 'community' back into the equation

Quite positive – has enable investment in all sorts of services – more drug workers working with more users

Not necessarily a disaster – focus of policy makers and media has been on crime. This is a good thing in some ways

Mixed feelings
Both negative and positive. Positive in that people in prison now have some access to harm reduction and treatment services. Negative in that the means of accessing treatment outside of prison is increasingly tied to a criminal justice agenda

I see crime as harm to the individual and the community however, it should not be at the expense of BBV and voluntary entry into 'treatment'

In some areas working quite well. But whether it's had a local knock on effect on crime - not sure

Improved access to substitute prescribing but other areas somewhat neglected. Is it drug users or the victims of crime that anyone cares about?

Might have reduced drug related crime – which is HR – and coercion has made people engage with treatment. Problem is in the minds of commissioners and policy makers at local level i.e. too obsessed in hitting DIP targets rather than public health

Government can't decide if users are 'patients' or 'problems'

Acted as distraction

Some impact on communities. Main concern is what happens regarding though care, waiting lists and follow-up 3 – 6 months later. 'DTTOs' – same people offending so treatment doesn't work for them anyway

Don't appear to be accessing number of people into treatment that was originally envisaged

To be quite honest, almost zilch as any experienced member of front-line staff, as distinct from managers, can tell you.

<u>Negative</u>

Disastrous!

Models of Care was introduced to ensure there is an equity in access to treatment for users, however in some areas the drugs and crime agenda have resulted in clients having less access to treatment due to the extra pressures placed on services. Despite the introduction of Models of Care, DIP has in some places compounded the inequity of access to treatment. Also, depending on the commissioning and local implementation of MoC, it has the potential to create 2 treatment 'systems', which is most unhelpful.

The focus is on positive crime reduction outcomes rather than positive public and individual health outcomes; the focus on criminal justice, with rapid growth in a short time span, has meant that services, through micro-management, are concentrating on the process and outcome solely in criminal justice terms. Harm reduction is seen as reducing the harm on communities from drug users by coercing into treatment and complying with rigid standardised responses through the imposition of national standards. This has meant that harm reduction is introduced as part of an overall treatment response, through group work for instance, to clients who can be resistant to receiving messages however well intentioned,

The number of injectors has increased. Crack use has become so common – no thinking has been done on how to prevent this. Must be something that can be done to try and prevent even wider spread of crack use and people using/injecting both heroin and crack

Putting drugs into the crime agenda was a serious mistake from a public health point of view, because it belied the importance of health issues, and led to more coercive (rather than facilitative) relationships between agencies and affected populations – which in turn makes delivery of public health projects difficult. It also pandered to public fears, in turn further marginalising people who are already on the margins.

Health and HR is overlooked with regard to proper commissioning. Waiting list priorities centre around criminal justice clients 'fast tracking' them treatment. Any client injecting

should be prioritised to reduce harm, clients who frequently overdose should be prioritised

HR seems to be being put to the bottom of the pile with the new crime agenda..
all users are being pushed towards abstinence because of CJ orders, this seems to be all going against the drugs strategy that puts its biggest focus on HR

It limits harm reduction. The concept that self-harm is a crime is irrational and unfair when applied to only non-traditional drug using minorities. Prohibition may reduce consumption but that reduced consumption becomes more harmful through a lack of consumer protection measures. Lack of credibility: tobacco addicts kill 11,000 others every year, but this is not yet a crime. Compliance with law depends on a consistent proportionate response to all drug risks and a clear distinction between voluntary risks and imposed risks – as required by Government guidance on risk assessment and better regulation.

From the perspective of the general public, it seems to have re-enforced stereotypes and done nothing for drug-users whose criminal activity is limited exclusively to contravention of the Misuse of Drugs Act

Taken quality staff away from HR services as better wages in DIPs

Its increased drug related harm – 'Mopping up the bathwater as it overflows the bath'!

100% gone backwards - public health used to be central pre-Hellawell. However, some good things from crime agenda i.e. police now have greater understanding and more people talking to each other

Got more people in prison. Coercive treatment on a group of people suffering can't really make it better when drug is a coping mechanism anyway so like taking a security blanket off a child

Where's the real evidence of effectiveness? People don't understand the public health agenda – no community safely if don't have public health agenda

Still not enough understanding of the treatment agenda – get drug users to stop immediately, get them to stop over time, or if not, move to prison or another area

The reality is that so much money and 'performance management' requirements have been thrown at expanding the criminal justice system, we've inherited a false-commissioning economy where finances and targets ring-fenced for supposed drug treatment and support, are effectively being used to prop up and achieve criminal justice targets. This, in my experience, has resulted in a commissioning culture that prioritises party-political will over public health issues

6. ***How adequate do you consider the existing emphasis on the prevention of blood borne virus transmission and treatment within the national strategy?***

This issue of blood borne viruses was an area of major concern. An increase over the last five years of HIV and HCV has been seen at both a national and local level and was 'very worrying'. Respondents called for a need to ensure a higher profile for BBVs and a far more effective response.

Respondent feedback
Terrible! Rubbish!; Inadequate lip service

It is welcome that it is mentioned but the delivery has been hampered both by the concentration on increasing the numbers in treatment and the failure to implement the HCV action plan in any meaningful way.

Not enough, however the emphasis needs to be around treatment generally – not just harm reduction – abstinence based approaches should be available as part of a wide range of options to suit the specific needs/wishes of the drug user

Not as good as could be. Need to focus on other routes as well as injecting e.g. heroin users using crack.

It is totally inadequate – too many users are still getting infected and the rise in HIV and new HCV infections is a major concern

No money, no real monitoring of what people doing at a local level, no targets

Appears in many national strategic documents however much more energy seems to be going to into criminal matters. Therefore the emphasis is not as high as should be

All drug agencies should provide vaccines for their clients and more support to those affected by the virus. Need for pre and post test counselling

In relation to Young People, there's not much impact in terms of PHSE education so people may be aware of HCV but not really HAV or HAB

Prevention strategy has failed although still need to keep trying and not enough in terms of testing and treatment

Emphasis is within the guidance but not in the public consciousness or implemented at a local level

All very well to have a national plan but PCTs need to carry strategy forward and take issues on board. GPs have a pivotal role but they appear to assume that DATs will take care of this

Information seems readily available to those in treatment, but there continues to be a surprising degree of ignorance regarding the nature of BBV contagion amongst the wider drug-using community

It's virtually non-existent because main emphasis is on busting people. When was the last time we heard Tony Blair talking about BBVs!

It is not adequate at all, workers do not have a clue about Hep C or OD. We were in the local prison two weeks ago delivering a Hep C session and the workers in there were telling us about clients they have had who have left now who were down saying they would not be able to have a relationship or live a normal life now they know they are Hep C +. The workers confirmed this to them, giving them completely wrong info and the prisoners left prison with no help re Hep C, no support offered or info on outside Supp groups or any help whatsoever other than never mind, you will be OK!!!!!!!!!!!!!!!!

Extremely inadequate, very little reference to it in fact. Little mention even less funding to support this. The recently published action plan also lacks funding and resources

A public health disaster – policy makers have presided over a period that has seen an increase in infections, not even managed to contain current infection rate as it was a few years ago

Not adequate – dropped in here and there. On the whole information is very limited and basic and seems to just address initial transmission but not follow up issues like how to cope with the symptoms and illness

Inadequate. The research evidence indicates a need to increase needle distribution in order to limit the spread of HCV infection

Poor – other than needle exchange, there are no other nationwide existing services within the national strategy. The availability of products such as filters and stericups within the exchange packs to prevent the spread of viruses through sharing equipment, not only from needles and syringes will vary from DAT to DAT. The supply of information around safe injecting guidelines and good practice also varies depending on DAT

What would be your priorities for improvement, if any?

<u>Prevention</u>
Continuous rolling out of HAV and HBV vaccination programmes – and far more proactive in prison; more funding for vaccination A & B clients and more funding for vaccination A & B pharmacists and staff

Greater coverage of needle exchange. Less emphasis on 'seeing' people rather than just letting them take what they need

Proper mapping and action research to establish and identify needs assessment amongst marginalised groups; tools for monitoring access for such groups and pick up by preventative/educational agencies

Explicit targets for prevention and treatment with incentives e.g. stick on a PCT star!

Be inclusion of wider issues rather than just info on general fatigue etc. Want more specific information as people with BBVs need to be empowered with knowledge to prevent passing on

Adequate funding and partnership targets between sexual health – treatment and HR

Expansion of NEX, but also a reinvigoration of outreach, peer education, 'micro media' health campaigns – delivered in a non-coercive context.

More work with high risk groups that do not normally access services; What is frequently forgotten is that there are a number of marginalised populations – crack users, visible minorities, refugees and asylum seekers etc.- who slip through the net because the net allows them to

Allowing DATs to spend cash on local priorities e.g. needle exchange, OD & BBVs rather than meet national 'cash linked' targets

Alternatives to injecting

Focus on homeless hostels as a risk environment and homeless drug users as a high risk population and look at ways to address these risks

Ideally all paraphernalia and water for injection BP to be available in all needle exchange packs and not a post code lottery for the clients depending on what the local DAT wants to fund

To see clear HR targets and possibly ring fenced funding for HR

HR practices need to be more widely disseminated – especially through the popular media and TV

Greater innovation in prevention activities

Greater assistance and interest in users groups; more peer interventions

<u>Treatment</u>
To use all the available resources to increase the size of the 'treatment bubble' and remove the distinction between criminal justice and other users. Within this single entity concentrate on providing individual care-planned responses that meet individual needs and are not subject to onerous national targets designed to show that numbers in treatment are increasing and concentrate on substitute prescribing rather than achieving the wider health picture.

Massive increase in availability of treatment for HCV & HIV

More cooperation between liver services and drug treatment with both providing within each other's services

We are poor at integration for instance, how much BBV work is done in rehabs or DTTOs? How much offending behaviour work is done in Nx Exs? We need much more joined up approaches

Move drug brief from HO to DH

Discrete funding for immunisation and screening should be made available to all drug services. Also standardised Patient Group Directives, pre & post-test discussion formats, protocols etc would make these interventions easier to implement

Drug use, in itself, should not influence decisions on who is given access to treatment for HCV

Increase, dedicated funding and a focus on the transmission of BBVs as a priority, performance management target

Prioritise advice and support at needle syringe exchange to prevent. But testing and support vital to prevent the damage of the disease. More support for affected individuals. Extra advice in relation to alcohol issues

An integrated hepatitis C strategy which is supported by resources to provide treatment for affected IDUs

Treatment is orientated to over 18 year olds. So real struggle to get treatment for U18 injectors

7. How adequate do you consider the existing emphasis on the prevention and management of overdose within the national strategy?

There appeared to be slightly less concern here than over blood borne infections. However, the majority of respondents felt that existing policy and practice was inadequate and much more could be done to improve the prevention and management of overdose as well as reduce the number of drug related deaths.

<u>Training</u>
Not adequate at all, there needs to be a National programme of training for staff and users, separate training provided by different agencies does not ensure all are saying the correct thing to users, this needs to be coordinated properly and pushed more often, training need to be delivered to service workers too, they should have to complete training on HR before they take up a post.

Over emphasis on Recovery Position and not enough on Mouth to Mouth

It is improving and locally there are incentives to pay IDUs to attend OD training. However, there are still many myths about dealing with an overdose

<u>Intelligence</u>
Intelligence systems relating to overdose remain poor so assessment in the reduction of overdose deaths and 'near misses' is inadequate.

Overdose definition too narrow – should focus on all drug related death i.e. causes of death which have occurred due to the health or behaviours of the individual as a consequence of their drug use; not enough work on different types of OD i.e. cocaine OD, seizures

Better than BBVs but again tends to focus on particular drugs but we need a better understanding of poly drug use and risks associated with drug combinations

Pharmacists, ambulance and police

The prevention and management of overdose does not currently feature in any community pharmacy service in England. There needs to be a clear, consistent approach by all DATs for withholding treatment if the client presents intoxicated with drugs and/or alcohol in the pharmacy. National guidelines for the pharmacist on how to proceed/respond to this situation should be available

Promotion of information by pharmacists involved in methadone schemes and NEX

Protocols between ambulance service and the police service regarding attendance at suspected overdose are welcome, but need to be far more widely publicised to achieve the desired effect

It's been pretty much left to chance - what about naxolone with every ambulance crew?

Prison

OK but much more work could be done in prisons particularly a recognised qualification for users to become future peer educators on release

Some of the measures designed to address overdose are being undermined by criminal justice interventions, which are likely to see number of users in prison increasing. These are also likely to be for shorter periods thereby minimising in the users eyes their risk of OD on release. Number of ODs in period following release needs to be counted and published

Other comments

Little within the actual strategy. However the NTA guidelines are good. Easy to apply the national plan to a regional and local level

Still unacceptable. Significant budget allocation by the NTA in 2002 to the development of measures that could impact on OD rates. 3 years later all we have is a few leaflets

Too much time spend on policy – not enough on practice

Fairly big commitment from DH to get strategy in place and lots of education and advice to users and workers

Confusion over stimulant OD – too opiate over orientated

Locally quite adequate – nationally can't really think of many things that Centre really done

No national agreed criteria for DRD e.g. coroner could attribute cannabis in bloodstream as DRD – problems around tracking and monitoring and need effective data in order to target most vulnerable populations

U18s not able to access OD training/awareness at treatment services

What would be your priorities for improvement, if any?

Overdose training and raising awareness
The DAT should provide education to the user/ their family/ friends/ carers on what to do in case of overdose. If the users are supplied with Naloxone, they should know how and when to use it, and how to follow this up

More emphasis on 'mouth to mouth' because if ambulance not turned up and person not breathing then need to breathe for them

Improved training for staff; Improved training for service users and possibly involving them in the delivery of that training

Peer education

Extra funding for overdose awareness raising, also make the NTA guidelines a must do rather than a set of good practice guidelines

Widely publicised protocols for police attendance at suspected overdoses

More training for users on for example, the impact of drinking alcohol

Accreditation for completing OD awareness training – could be useful starting point for user/ex user work CV

Needles exchanges could offer OD and HCV training for young people U14 – U18s, also bring this type of education into youth clubs

Prison
More direct overdose work with clients that are currently using within the community as well as better links with CARAT teams to reduce the risk of overdose on release from prison.

Don't lock people up for short periods of time – no real data on inmates OD on

Retox prior to release if they are planning to use and then can be taken over by CDTs

Relax supervised consumption as keeps people away from services and therefore dangerous in terms of BBVs and OD

NHS, DH and NTA should certainly ensure a nationwide OD risk programme is in place in prison

Proper drug treatment prescribing services within prisons would reduce addict deaths

Seamless treatment for people leaving prison

Other comments
Re-establishing public health primacy as goal of drug strategy with other aspects falling underneath.

More focus on Tier 2 interventions and better KPIs which focus on HR generally so responsibly is placed in DATs etc

Improving the intelligence related to drug related deaths (including overdose). Multi-agency research and monitoring strategy to provide comprehensive evidence of causes, characteristics, risk factors.

Pilot DCRs; more peer approaches; targeting of hot spots (such as Brighton) with ring-fenced resources

Give naxolone to users and carers and all paramedics

Carry out regular risk assessment as part of client care plan

Set up a new expert group/Guidance to look at risks from new drug/poly drug using trends; more scrutiny into the part that alcohol plays in what are described as DRDs

Injecting rooms/drug consumption rooms – could 'wallpaper' with information and have medical help on hand

Funding for a drugs related deaths worker within DAT

Work with Health Directorate – NTA should work more closely with HD

8. How do you assess the government/NTA's progress on drug user and carer involvement in the reduction of drug related harm?

Among respondents in general there appeared to be less certainty, knowledge and awareness of NTA's progress in relation to user and carer involvement than in any other area.

<u>Poor</u>
A poor response that has been 'spun' to create an impression of action

They don't know what they're doing! I think they're TRYING to do the right thing, but they're still getting hung up on 'service user' involvement and haven't really understood or expressed the difference between user involvement and user representation, and the potential that effective user involvement has for delivering the effective HR interventions that DATs/services don't have the capacity/ability to do.

I think it is very politically correct but essentially useless. A user on a group represents themselves not a group. They tend not to be chaotic but quite together and do not face the issues that so many of my clients have. The very organised in employment do not have the time either

If NTA can't even give expertise or guidance on user/carers involvement how can DATs?

In my DAT area user and carer forums is quite poor and partly functional. Again, pressure to deliver on targets elsewhere or fund another post e.g. nurse; compromise around achieving challenging targets but not at expense of user/carer involvement

Pretty abysmal. User involvement is very difficult to do anyway and then groups not usually representative

Not involving workers half the time let alone users!

Lip service – if people don't want to be involved in service user group then seems to be a black mark against the service but they could just be happy with the service

Fundamental barriers of discrimination prevent any real co-operative relationship

I think that the progress on drug user involvement in reduction of harm has been tokenistic and very badly done. User groups are rarely consulted on developments and are mostly sidelined.

Mixed feelings
It does appear to have improved from where it was 10 years ago – but it is still largely tokenistic

Yes on government agenda but last on the list

In principle a commitment – in practice doesn't really happen

NTA's involvement has been good but not passing down to the DATs. Lots of user groups are just there to tick boxes – paid an offensively small amount

Slow but getting better

The momentum of the NTA's early work on user and carer involvement seems to have dissipated although progress at DAT and service provider level while mixed has been encouraging

Not too bad to date in this region, but not everywhere. DAAT's should not be receiving green lights for just having a meeting about a DRD strategy; they should have a RED light until they have a training programme in place and active. Drug users have expert knowledge and our group's OD projects evaluations prove that users respond better to ex users when receiving harm reduction advice

Again this is a welcome development but more needs to be done in nurturing and supporting users in becoming more actively involved. Many areas will experience difficulties in developing, maintaining and sustaining meaningful involvement of users. User involvement also needs to recognise that there are at least 3 constituent user voices —those not in treatment, those in treatment, and those who have completed treatment -–for whom tensions will exist if user involvement doesn't recognise these different perspectives. Meaningful analysis by the NTA of what is happening on the ground is also required if tokenistic responses are to be avoided. I am uncomfortable with the term carer used in this context, especially for adult drug users, as it reinforces a notion of dependency upon individuals who by and large do not require being cared for. This does not remove the fact many care about drug users within a family but the term carer when used in other contexts has this notion of dependency attached.

Improving – the progress is still patchy depending on the DAT, some have a very good user/carer group and involvement, but this is not nationwide

Good
A mega step forward but perhaps too Stalinist in its approach. If proper information is to reach the top from below then stop appointing party commissars. Let user groups (and groups of front-line staff, who are often nearer to users) organise and set their own agenda without shutting out the voices you don't want to hear

Seems impressive – people gather in larger numbers. But users who are involved seem enthusiastic rather than skilled

NTA getting it about right

Other comments
NTA needs an 'injection of reality' – all these things are usually left to local partnership to develop user/carer groups which can be challenging and time consuming

..Not really qualified to assess this – but have noticed increased user involvement references in NTA docs

User and carer involvement is all about how much people are prepared to do about it at a local level. Agenda around user employment, housing, further education is not being addressed anywhere

Have concerns that up until now drug users and carers views have not been adequately canvassed. In many cases user/carer representatives only have a mandate to represent their own views. By definition, chaotic, problematic drug users will be those with the highest stakes in effective harm reduction but also the least likely to provide their opinions

What would be your priorities for improvement, if any?

Separate users and carers – different issues

A much greater level of investment into user led organisations

Some qualitative sociological research with carers and users; peer led research to identify determinants around prevention issues at a community level as well as peer promotion of things that could protect

The NTA should reconfigure the treatment planning process and reduce the current 8 Treatment Planning Grids from 8 to 5 (Tiers 1-4 and Criminal Justice). They could then pressure DATs to evidence a financial, strategic & operational commitment to Workforce Development, Underserved Groups, Systems & Infrastructure, Users, Carers AND Harm Reduction Initiatives through all 5 Tiers with an 'expected' % spend specified against each one.

Equal treatment for all drug consumers, irrespective of tradition/law. Where this is possible (always?) legal challenges by consumers and carers should be encouraged as proof of genuine co-operation

Compulsory consultation between DATs and these groups on annual spending and priorities

Need more active user network

Debrief people after user meeting and use link person with service to support

Needs lot more coordination and user training in areas such as presentation skills and confidence building

'Think out of the box', spend money, separate users and carers, employ a worker at arms length from the DAT – 'service user mentor'

Needs to be given increased priority and investment; more money to pay users for their time

Make it mandatory that services have to take users' views into account regarding service planning and delivery

Get users onto interviewing panels and central to any discussion

It would be useful to possess one single document outlining the government's drugs strategy in full

Clearer understanding of how service users can be involved, and not merely "consulted"

Need for continued growth in peer interviewers (Indigenous Fieldworkers/Privileged Access Interviewers) to ascertain views of PDU in and out of treatment. However it requires significant investment and management if the findings are to be reliable

If people want things to materialise then need to not just provide a meeting venue, but food and training otherwise always going to be driven from top down

Potential for greater peer education in HR not really utilised. A lot of the time we think we know what users are thinking and want - but do we?

Not enough support and under use of groups to cascade peer education down to users not in contact with treatment services

How can you have good user involvement if not taken HR on board? Punters want HR!

Ensuring that there is realistic well-funded support for user involvement through a supported user development worker independent of the provider agencies who has the authority to engage with clients within the system as well as outside of it

If there is a genuine commitment to service user involvement it should be given a far higher priority and proper training and support should be in place for it to take place

effectively. If it is only about ticking boxes and been seen to do the right thing then it should not be undertaken as it is both patronising and unfairly raises expectations

Need information on 'How the NTA and your DAT can support you' and need to get across to users on the street and in clinics what the NTA is doing. New bridges are starting to be created and it's crucial to know how it works and how to get your views across

Accredited courses for users and carers

National service user feedback questionnaire

Young people (U18) specific
Make sure that NTA get involved with Children's Trust and that DATs are also linked in.

Carer specific
Increased emphasis on carer involvement – with stimulants the prognosis is usually massively improved if family are involved. Also, family tend to be the main referrers to services and we then refer back to the family

I think the only way you get carer information is through an audit and info to NTA should be given in this way

In terms of the carer aspect, drug agencies should be directed to look more closely at the possibility of involving a wider social network when working with drug users. Identifying available resources within family/community are likely to provide better results than solely focussing on the individual.

Need for a 'family pack' – a factual information with contacts and strategies for dealing with rather than excelerating a drug-using situation

Helpful if serious consideration by NTA on protocols around how to enable effective user/carer involvement; would like to know where best practice is; Need to identify the best patient liaison model

Appendix 1

Respondent list

User/Carer Groups
The Alliance
Users Voice
Calderdale Users Forum (CUF)
Parents Against Lethal Addictive Drugs
Oxfordshire User Team (OUT)
Black Poppy

Service providers
Kaleidoscope
E's Up – (Young People's substance misuse treatment service)
The Stockwell Project, South London
Manchester Drug Service
The Piper Project
Harm Minimisation Service, Durham
East Sussex Community Pharmacy Nx Ex scheme
Addaction HR Service (Bethnal Green, London)
Addaction Head Office
SMMGP
Lifeline
Mainliners
RAPT
Twenty Four: 7 Drug & Alcohol Services, Newcastle
Cranstoun Drug Services
Release
Cheshire & Wirral Partnership NHS Trust
KCA
Barts and The London Queen Mary's School of Medicine
Coventry CDT

Pharmacists
PharMAG
RPSGB
Lloyds Pharmacy

Research, education & policy
Centre for Public Health, Liverpool John Moores University
Centre for Research on Drugs & Research Behaviour
International Harm Reduction Association
Transform
COCA
HIT
Drugscope
Independent Consultant in Health Education
T3E (UK) Ltd
Joseph Rowntree Foundation

Drug Action Teams
North Yorks & York DATs
Bristol DAT
Torbay DAT
Sefton DAT
Plymouth DAT
Coventry DAT
Blackburn with Darwen DAT
Hillington DAT
Gateshead DAT
Blackpool DAT
Luton Drug & Alcohol Partnership
Lewisham Council

(NB: Working though a database of DATS, the above responses were collected by the appropriate person within the DAT being around to response to the questionnaire either on the telephone or when e mailed).

Appendix 1 (a)

List of Non-respondents

A number of other organisations (see below) were also contacted during the time of the consultation exercise but no response was gained. This may have been due to the fact that those contacted by e mail simply did not want to response to the questionnaire/take part in the consultation. However, most of the organisations contacted said that the person with the relevant expertise was simply not being around on the day of being telephoned and that the questionnaire would be passed onto them when e mailed.

National Addiction Centre
Turning Point
The Federation (BME professionals working in the drug & alcohol field)
Variety of DATs

Appendix 2

Interview questionnaire

NAME……

ORGANISATION……..

1. How well do you feel that harm reduction principles are understood and embodied within the government's current drug strategy in England?

2. What, if any, do you see as the most pressing current threats to harm reduction?

3. What developments would you prioritise within a national treatment strategy that is based upon harm reduction?

4. With regard to harm reduction, what do you regard as the main gaps and priorities for development within our existing evidence base?

5. Overall, what do you feel that the impact of the drugs and crime agenda has been on the reduction of drug-related harm?

6. a) How adequate do you consider the existing emphasis on the prevention of blood borne virus transmission and treatment within the national strategy?

   b) What would be your priorities for improvement, if any?

7. a) How adequate do you consider the existing emphasis on the prevention and management of overdose within the national strategy?

   b) What would be your priorities for improvement, if any?

8. a) How do you assess the government/NTA's progress on drug user and carer involvement in the reduction of drug related harm?

   b) What would be your priorities for improvement, if any?