NHS

National Treatment Agency
for Substance Misuse

"Nothing about us, without us"

The English user representatives' report from the 2007 International Harm Reduction Association Conference

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In brief

In May 2007, the National Treatment Agency for Substance Misuse (NTA) sponsored eleven service user representatives – referred to as the "team" – from across England, to attend the International Harm Reduction Association's (IHRA) 18th International Conference on the Reduction of Drug Related Harm, hosted in Warsaw. Their intention was to collect information on new evidence-based initiatives on reducing drug-related harm and communicate these messages to the wider service user community. The overall aim was to identify examples of international good practice that could inform and improve harm reduction services in England. This report covers the team's five key areas of learning from conference and they drew the following conclusions on each area.

Blood-borne viruses

Drug users can adhere to HIV and hepatitis C medication, and injecting drug users maintained on substitute prescriptions adhere equally well to antiviral treatment in comparison with the general population.

Awareness must be raised around hepatitis C and the resistance to treatment among the injecting drug user population must be challenged

Harm reduction and needle exchange

The system of needle exchange must be rejuvenated by ensuring the distribution of equipment is only part of a range of harm reduction initiatives delivered through needle exchange services.

Prison services

Drug treatment in prisons has advanced in recent years but there is much room for improvement.

Drug users involved in sex work

Ensuring that this marginalised group receive a full range of drug treatment options remains a challenge, one which service user involvement may help to overcome in the future.

Service user involvement

One of the lasting impressions of the trip was the degree to which service user involvement is now established in England. It encouraged debate over the future direction of user involvement in England.

In conclusion

Overall, the team of NTA-sponsored service users felt the trip to the conference was a great success because:

- It highlighted to the team the progress made in establishing and embedding harm reduction in England, while also highlighting what could be improved
- It demonstrated the NTA's acknowledgement of service user contribution to the continuing development of drug treatment policy, planning and delivery in England
- Team members were able to witness the growing role of service users within drug treatment systems across the world
- It had an energising effect on team members.

The conference

Eleven NTA-sponsored service user representatives from across England joined 1,200 delegates from 80 countries at the International Harm Reduction Association's (IHRA) 18th International Conference in Warsaw, Poland in May 2007. The theme of the conference was "harm reduction coming of age." The range of topics examined included illicit drugs, alcohol, tobacco, sex work, blood-borne viruses, young people and prisons. Service user representatives from Asia, eastern and western Europe and North America joined other speakers from major international organisations and donors (such as UNAIDS and the World Bank), leading academics, policymakers, researchers, advocates, activists and practitioners.

Aims

The team set out to collect information on evidence-based initiatives to reduce drug-related harm, which they could communicate to service users in England. The team attended over two hundred presentations, working on average fourteen hours a day. Breaks between presentations allowed the team to meet service user representatives and drug treatment professionals from Asia, eastern Europe and the US. There was also a meeting between service user representatives from England and Indonesia, the only official delegations present.

Analysis

Team members recorded their observations on a template developed by the team. As well as providing personal perspectives on sessions, team members were encouraged to focus on evidence-based research and policy recommendations that could improve harm reduction services in England. In addition, team members recorded what they felt to be the three major learning points from the conference.

Upon their return, the team delivered a written report of the conference through the service user co-ordinator, with support from an NTA staff member. They agreed on the three steps required to produce the report:

1. Reading team members' templates, it was clear there were strong opinions about the next steps in harm reduction. In order to avoid bias and be systematic, both authors read all templates twice

   a. The first reading produced a list of key themes based on information recorded by the team (such as alcohol and prisons)

   b. On the second read, authors read templates alongside the list of key themes. If they identified a topic in a template, they marked the corresponding key theme once. This scoring approach allowed the authors to be confident about which topics appeared most often.

2. Using this method, the authors produced a list of twenty-two major themes (see Annex 1 for a complete list). The list included issues such as data quality and the wider policy debate around challenging drugs prohibition. After some discussion among authors, the list was reduced to the five major themes that form the basis of this report. The decision was informed by a number of factors:

   a. The authors took the decision to steer away from the larger political or policy issues in the drug treatment field, in favour of more focused and practical issues that were more likely to be relevant to service users across England. This meant that issues such as challenging prohibition – a much wider and longer-term issue with consequences for the future of wider drug policy – were not considered a priority. The authors focused instead on issues that would have an immediate and positive effect on service users and the community, such as barriers to accessing treatment for blood-borne viruses.

   b. The view was that a short, punchy document would have a greater impact and outcome among the service user community and other interested parties.

3. Once completed, team members commented on the first draft of the report. The team was also asked to think of innovative ways to communicate lessons learned from Poland to the service user community in England.

Key conference themes

Five major themes emerged from analysis of the team members' written submissions: blood-borne viruses, the need to reinvigorate harm reduction and particularly needle exchange, prison services, sex work and service user involvement. This report provides an overview of conference content and the team's key learning points from conference presentations covering the highlighted theme. Where appropriate, an outline of the English policy context has also been included.

Some presentations were less relevant to countries such as England, with more established drug treatment systems, and were less likely to offer new ideas. For this reason, there are sections within the report that just provide a flavour of the debate sparked by certain presentations.

Blood-borne viruses

Key messages

- Drug users can adhere to HIV and hepatitis C medication – injecting drug users maintained on substitute prescription adhere equally well to this treatment as those in the general population
- Urgent work is required to raise awareness about hepatitis C and challenge resistance to hepatitis C treatment among the injecting drug user population.

Conference snapshot – hepatitis C worldwide

Many conference presentations reported continuing worldwide rises in blood-borne viruses among injecting drug users. Particular focus was given to the prevalence of the hepatitis C virus (HCV), the continued rise of tuberculosis and the dangers of co-infection. In his conference presentation, Mauro Guarinieri from the Open Society Institute outlined the scale of the challenge presented by HCV across the world:[a]

Rick Cook (service user Involvement worker, Brighton) and Eliot Albert (London User Forum)

- An estimated 200 million people worldwide are chronically infected with HCV
- Three to four million people are newly infected each year
- Transmission is strongly associated with intravenous drug use
- HCV is the leading cause of chronic liver disease
- Deaths are expected to triple over the next two decades
- Growing worldwide awareness of the issue of co-infection in injecting drug user sub-populations (HBV or HCV viral infection among HIV-positive people). Some conference presentations reported on an improved scientific understanding that co-infection accelerates HCV progression and makes HIV treatment more complicated.[1]

Conference presentations attended by the team suggested that responses designed to tackle HCV should involve a more holistic approach and include:

- Testing and counselling
- Education and outreach to injecting drug users, including steroid-specific advice and improved information on safer preparation of drugs for injecting
- Providing sterile needles and syringes and other injecting equipment
- Opioid substitution therapy
- Work intended to stop people from starting injecting
- Providing vaccination for hepatitis A (HAV) and particularly for hepatitis B (HBV).

The HCV situation in England

While harm reduction interventions in England have been very successful in preventing an HIV epidemic among injecting drug users, they have been less successful in tackling HCV.

Recent figures from the Health Protection Agency help illustrate the scale of the HCV problem in England:

- Ninety per cent of all HCV infections are current or former injecting drug users
- Half of all current injecting drug users are estimated to have HCV

- There are about 6,000 new infections annually[2]
- HIV levels among injecting drug users have increased in recent years – one in 50 in England and Wales are now infected, although this is low compared to other countries. Prevalence rates in London show that about one in 25 injecting drug users are HIV-positive. Elsewhere in England, the prevalence has risen from around one in 400 in 2003, to about one in 65 in 2005.[3]

The team's recommendations on blood-borne viruses

Despite these considerable challenges, there were also reminders in Warsaw that HCV transmission among injecting drug users is preventable and the disease is treatable. The team felt that three areas highlighted at the conference were particularly worthy of attention.

Drug users can adhere to HIV and hepatitis C medication
Several conference presentations supported challenging sections of the medical profession who are reluctant to treat current injecting drug users for HCV and HIV, because they believe they are less likely to adhere to medication than the general population. They reported on the growing evidence base that shows that drug users were similar to controls or comparable groups in their adherence and response to anti-retroviral treatment and highly active anti-retroviral treatment, especially if they were also receiving opioid substitution treatment. [a, 4, 5, 6, 7]

Responding to this, the team were keen to challenge what they saw as an example of opinion-based rather than evidence-based medicine. The team felt this misconception is an unnecessary barrier to blood-borne virus (BBV) treatment, has no evidence base and goes against the notion that doctors treat each individual separately. The team thought this explained why those with the greatest need for HCV care and support are often denied these services. In order to challenge this stigma, the team believed work to strengthen knowledge about the disease in general practice was a priority.

Hepatitis C awareness among injecting drug users
There were repeated calls to increase the quality of HCV information provided to current injecting drug users (IDUs). Some conference presentations echoed existing research evidence suggesting that most IDUs have some awareness of HCV, but it was at best incomplete. Indeed, research in this area also reports a sense of fatalism among IDUs around the inevitability of getting HCV through

Team meeting

the course of an injecting career.[8] In light of this, the team felt it was important that IDUs are made aware of:

- The dangers of co-infection, such as:
  - Infection with both HIV and HCV greatly complicates treatment for both diseases
  - Accelerated progression to end-stage liver disease and death in patients with HCV and HIV co-infection when compared to those infected with HCV alone
- The dangers of alcohol consumption for HCV-positive individuals
- How simple changes to daily lifestyle and diet can reduce symptoms.

Challenging injecting drug users' resistance to HCV treatment
The team attended a presentation emphasising that work designed to make IDUs "status aware" should ideally be accompanied by work challenging resistance among IDUs who avoid HCV testing and treatment. The team believed that failure to collect test results, or non-attendance at clinical and counselling appointments following a positive result for HCV, happened for a variety of reasons including:

- Fear of discrimination

- A perception that HCV treatment takes time and is not readily available
- Providers who are not specialised in BBVs and dealing with users
- "Ignorance is bliss". IDUs' nervousness about discovering their own BBV status and attendant problems this may cause if a positive test result is received
- One team member was particularly keen to highlight the importance of follow-up testing:

  "So many people have the one HCV test – and then never go back for another test (which determines their genotypes, PCRs). These subsequent tests are essential, as the person may not even have HCV anymore – they may have cleared the virus yet have been walking round for years depressed thinking they are going to die from HCV! I've seen this happen many, many times. Follow up tests give people an insight into how their HCV is doing. This is an important step in getting people to address the issue – look themselves"

Reflecting on this issue and the situation in his local area, another team member highlighted five areas he believed required urgent attention:

- The absence of specialist venepuncture nurses in most services means people with very bad veins have particular difficulties with blood tests, which can be very unpleasant and painful. One possible solution to this is to follow the example in some European countries and increasingly employ swab testing. Areas in England that have adopted this have had a hugely positive response
- Primary care trusts need to promote local awareness, clinical pathways for IDUs and funding for HCV treatment
- Awareness, testing and referral for treatment in primary care needs to increase
- The need for more peer-led support groups and training for service providers and service users alike
- Promoting awareness among those seeking help that HCV treatment can be difficult, unpleasant and trigger depression, but is worth it.

Harm reduction and needle exchange

Key messages

- There is a need to rejuvenate needle exchange by ensuring distribution of equipment is only one part of a range of harm reduction initiatives delivered by needle exchange services
- Groups most in need of harm reduction should be targeted
- Harm reduction through text messaging should be considered.

Conference snapshot – improving needle exchange

Some conference presentations highlighted the lack of government support for needle exchange in parts of the world; other presentations looked at fresh initiatives in countries with established needle exchange programmes. Although these perspectives were useful for the team, they decided only those with direct relevance to established needle exchange programmes, such as those in England, merited inclusion in the report. Needle exchange services have always evolved and calls for further improvements were heard again in Poland. When the team's impressions of presentations about needle exchange were reviewed, two clear messages emerged; that drug treatment systems worldwide needed to do the basics of needle exchange better and there remained a need for fresh evidence-based initiatives to build on existing success.

The team's recommendations on needle exchange

The team wanted to draw attention to five issues around needle exchange highlighted at the conference. These included services using mobile phones to communicate with clients, wound management, peer outreach, drug consumption rooms and targeted interventions to particular vulnerable groups.

Harm reduction by text messaging

There were some new developments within harm reduction presented at the conference. One involved a Finnish needle exchange service that communicates with its clients using an anonymous SMS message service. The service is free of charge, functions seven days a week and does not require face-to-face registration.[b] Registration is simple and anonymous, with service users sending a single text message to their service. Users then received useful

information, including service opening times. One of the biggest challenges to such a service was client concerns about confidentiality and anonymity. Such objections were overcome once service users understood that all SMS messages received and responses sent out by the service were processed using a computer.

Within a drug treatment context, clients could send particular keywords on topics such as overdose, abscesses and deep vein thrombosis, and get instant information back from the service about their areas of interest or concern. Services can send clients SMS messages from a computer and a dedicated software package. In order to comply with the latest EU legislation on mobile phone spamming, services would have to maintain an unsubscribe or opt-out function. If they no longer wanted to be contacted by SMS, service users could send the word "stop" to ensure that they are not sent any further messages. This type of harm reduction text campaign could be free to use (barring the cost of sending the message) for the service user and has no set-up or monthly charges for the drug service. Charges to the agency are only made for the messages sent.

Potential applications of this technology include the possibility for letting clients know about:

- Details of particular clinics, for example a dental clinic or a nurse-led wound management clinic on a particular day
- Days when blood-borne virus testing is taking place
- What alternative therapies are available
- The availability of new products, such as citric acid, water or foil
- Bad batches of heroin
- Basic harm reduction messaging, such as "don't lick the tips of needles and syringes" and "always divide drugs with sterile needle and syringes".

Potential benefits of this technology include:

- Cost-effectiveness
- Confidentiality and anonymity
- Instant messaging to multiple recipients is cheaper and less intrusive than mobile phone calls.

Finally, although this may be a relatively new way of communicating with clients in drug treatment, the practice of using SMS to keep in touch with clients is increasingly common in the UK. For example, doctors' surgeries

already encourage patients to attend their appointments using text messaging, while this cheap and relatively simple technology is already being used by schools as a response to truancy.

Target vulnerable groups for harm reduction interventions

The challenge of delivering drug treatment and harm reduction services within budgetary constraints was a common topic at the conference. One of the most cost-effective harm reduction measures is providing HBV vaccinations. Another is to prioritise intensive harm-reduction measures, such as outreach work, at the most vulnerable drug-dependent individuals, particularly those not in contact with services. The most vulnerable groups include (but are by no means exclusively):

- Homeless drug users not in touch with services
- Sex workers at high risk, such as street prostitutes
- Young people not in touch with services
- Socially excluded individuals from minority communities, including migrant workers

The team unanimously endorsed this approach and felt this work was particularly suited to peer-led interventions. One team member's submission stated:

Service user representatives Paul Murphy and Jimi Grieve in Warsaw old town

INPUD representatives Stijn Goossens (Belgium) and Fredy (Indonesia) address the conference

"Most [drug treatment] programmes are for heterosexual male drug users, which can be intimidating … we need to develop programmes and policies that address the issues that exclude women, men who have sex with men and transgender clients."

After attending the session on harm reduction for homeless people, another team member wrote:

"Homeless drug users usually use drug treatment services in times of crisis … there is a need to take the services to the user rather than vice-versa."

On a similar theme, another team member observed:

"Because of institutional boundaries like the fact that homeless people aren't able to access a GP, there is an increasing need for specialised services to be working on the streets … problems are minimised by co-operation across professions and networking with outreach teams and homeless organisations".

Finally, another team member suggested that:

"… the harm reduction grids of local treatment plans should included strategies for marginalised groups [listed in the previous section]"

Targeting the most vulnerable with more expensive initiatives should not mean that harm reduction services fail to serve the needs of other identified populations. Mainstream harm reduction initiatives – whether provided by specialist treatment agencies or by general health and social care agencies – should be accessible to less-vulnerable populations. These more stable groups can include steroid users attending gyms and sex workers in contact with other health and harm reduction services.

Leg ulcer management and prevention of abscesses

Long overdue messages on wound care and the unsafe practices that cause them were heard in Warsaw. Team members attending Marie White's presentation, Wound Care and Leg Ulcer Management for Injecting Drug Use, supported the call to move the issue up the agenda.[c] Although this issue is often low on the list of service priorities, it is important to injecting drugs users. Discussion between some team members reflected anecdotal evidence that ulcers and cellulitis are increasingly prevalent, particularly as the injecting population ages. For older members of the injecting population, circulatory problems such as deep vein thrombosis (DVT) are an increasing concern. Indeed, of the eleven team members who travelled to Poland, at least three had problems with ulcers and DVT issues. The reported rise of femoral injecting simply increases the urgency to educate current injecting drug users about the dangers of poor injecting hygiene that can lead to abscesses, which in turn could result in the loss of a leg or death.

Drug consumption rooms

The team wished to raise awareness around the issue of drug consumption rooms (DCRs), upon hearing evidence about the place DCRs can have within a holistic harm reduction approach. A recent Joseph Rowntree Foundation report defined DCRs as "places where dependent drug users are allowed to bring their illegally obtained drugs and take them in supervised, hygienic conditions". The arguments for and evidence about DCRs are now well rehearsed and there are now an estimated 65 DCRs in eight countries worldwide.[9] Anecdotal reports from Sydney reported that local community funding grew, once positive outcomes of a safer area became more apparent. Supporters claim that the positive impact of DCRs can include:

- The reduction of public injecting and associated drug-related litter
- The promotion of greater knowledge of safer injecting practices
- The reduction of disorder and public drug dealing in the vicinities of DCRs
- Lives saved following rapid overdose intervention
- Reaching the "hard to reach" homeless and transient populations of drug users without a place to inject safely and hygienically.

Expanding and rejuvenating harm reduction

"Most of the practical information we get about injecting is from each other, so sometimes we end up with a few habits that, without realising, could be dangerous to our health. Ingrained habits can be hard to break, but they are just that: habits – and so they can be broken. If you can replace just one unhygienic practice with a safer one, you will be reducing your chances of future infections or complications – complications that can end up life-threatening, and that has to be worth a change."
(Black Poppy magazine)[10]

"Health promotion in its purest form needs peer-driven harm reduction programmes'
(Poland team member)

The team echoed the arguments made in various presentations; that needle exchange services should provide safer injecting information and the exchange of equipment as part of a wider package of information relevant to current injectors. For example, specific safer injecting advice aimed at preventing the spread of BBVs might sit alongside interventions on how to avoid a "dirty hit" and good practice intended to prevent abscesses.

Herman Prescote, Southend User Forum representative

The team also felt there is a real need to promote greater awareness of the symptoms of life-threatening conditions caused by injecting such as septicaemia, endocarditis, gangrene and other serious infections. There is often a standard series of symptoms for these infections, including fever, aches and heated swellings. Often these can be misread and users will just take increasing amounts of heroin believing they are sick. Currently there is virtually no information given out on these types of infections at needle exchanges and work is needed to improve on this.

The needle exchange situation in England

Recent surveys suggest over half of blood-borne virus infections among injecting drug users who believe they follow harm reduction principles – by not directly sharing needles and syringes – are caused by sharing other equipment (such as spoons, water and filters).[11] In addition, there is increasing concern about the rise in other risky injecting practices such as femoral and neck injecting. Also worrying is the rise in crack injecting and speedballing.[3] Clearly, high-risk injecting practices have continued despite a number of local and national prevention initiatives. Reliance upon the exchange of equipment alone is not sufficient to halt the spread of blood-borne viruses.

The call to reinvigorate needle exchange is not new to English audiences. The NTA guidance Models of Care for Treatment of Adult Drug Misusers: Update 2006[12] recommends that harm reduction interventions should ideally include:

- Increasing the availability of clean injecting equipment
- Interventions designed to reduce sharing of injecting equipment
- Attracting drug users to opioid substitution treatment
- Blanket hepatitis B vaccination of drug users
- Interventions encouraging those infected with blood-borne viruses to take action to improve their health, to reduce the risks of transmission of BBVs to others and to link into appropriate medical services.

Similarly, harm reduction was one of two key themes of the joint NTA and Healthcare Commission Improvement Reviews of 2006. More recently, the Department of Health's Reducing Drug-Related Harm: An Action Plan[13] has re-iterated the call to improve delivery of the harm reduction strategy through "provision of training and guidance to service users and carers on how to minimise harm associated with drug use".

Despite these initiatives, it is clear there is room for improvement in how we deliver needle exchange services in England. Recent NTA research, however, found that what was provided under the banner of needle exchange in England was very variable.[14] Despite needle exchange being widely available, there were considerable disparities found across the country in terms of the numbers of needles and syringes given out, the range of paraphernalia available and extent of out-of-hours service provision. We know that some needle exchanges in England do provide a comprehensive service. Less than half the services provide BBV testing on site. Finally, there were differences in the importance placed on communicating harm reduction messages to clients. Some services simply handed out equipment; for others, equipment exchange was part of a wider programme of harm reduction messaging.

Prison

Key messages

- Improving prison drug treatment benefits society and users
- The team recognised the progress made in the provision of drug treatment in English prisons, while also calling for further work to ensure equivalence with community drug treatment options.

Conference snapshot – prison drug treatment

> *"All prisoners have the right to receive health care, including preventive measures, equivalent to that available in the community"*
> World Health Organization[15]

A number of conference presentations described approaches to tackling illicit drug use in prison systems in a range of countries. The overview provided by Baroness Vivienne Stern, in her presentation Harm Reduction in Prisons, succinctly summarised responses from different prison systems to the twin problems of illicit drug use and blood-borne viruses in prison.[d] Some of her key points were:

- Prisons are populated by the poorest people in society who tend to have the poorest health
- One in four prisoners worldwide are imprisoned for illegal substances
- Risky injecting and sexual behaviour are common in prisons, which are often ineffective in changing these behaviours
- Prisons are breeding ground for disease – rates of HIV in prisons are higher than in the general population and HCV rates higher still. The high turnover of inmates make prisons particularly effective disease factories[e, f]
- Outbreaks of HIV in UK prisons have already been documented – at least thirteen prisoners were infected with HIV through use of non-sterile injecting equipment at Glenochil prison in Scotland during the early 1990s.[16]

Baroness Stern described the current situation in English prisons as being characterised by:

- An imprisonment rate of 138 per 100,000 of the general population – the highest in the European Union
- Large turnover and movement of inmates around the prison system
- A patchy national picture in terms of the availability of drug treatment options in prison.

In light of established United Nations and European Union recommendations for countries to ensure equivalence between community and prison healthcare, the team felt that there was still great room for improvement in provision of drug treatment in England.[15,17]

The expansion of prison drug treatment

Baroness Stern's presentation referred to a recent move by the Scottish Prison Service to stop mandatory drug testing within its estate and divert the money earmarked for testing into drug treatment.[d] Although this was not the only development in prison drug treatment that the team heard about, it was particularly welcomed by the team. For some, it was representative of a welcome shift in approach to prison drug treatment in the UK. One team member observed: "Prison drug testing did not and never has acted as a deterrent to my drug use".

The team acknowledged the recent work towards the expansion and quality assurance of treatment in English prisons. Notable successes have included significant increases in the provision of HBV vaccinations to prisoners with a history of injecting drug use, the publication in 2006 of new clinical guidelines (Clinical Management of Drug Dependence in the Adult Prison Setting[18]) and the introduction of the Integrated Drug Treatment System (IDTS). Annual funds of £17m will provide improved licensed detoxification, availability of substitute prescribing and provision of intensive psychosocial support, particularly during the first 28 days of a sentence when drug-misusing prisoners are at their most vulnerable.

The aims of IDTS are to integrate the drug treatment provided by prison healthcare and psychosocial services; expand prison drug treatment options and strengthen the continuity of care for drug users entering, moving between and exiting prisons.

This valuable work will only involve one-third of English prisons during 2007/08. The team felt that English prisons were short of realising the WHO policy recommendation that prison drug treatment should replicate what is available in the community. The team members' written submissions from prison presentations illustrated a real sense that prison drug treatment in England was the area with the greatest potential for improvement.

Needle exchange

> *"Having spent some years being imprisoned, having shared injecting equipment (in prison) until the point that the needle bounced off your arm, then having contracted four strains of hepatitis C, then endured a years worth of treatment and one can only imagine how many of the other prisoners on that wing are in the same situation! Surely it would be far more cost effective to provide needle exchange for those who need it and far safer for injecting drug users."*
> (Team member)

Fully realising WHO recommendations requires prison systems to provide opioid substitution therapies and other drug treatment; supply condoms and other measures to prevent sexual transmission; provide care, treatment and support for those testing positive for BBVs; and supply harm reduction advice and education (such as overdose prevention). Of these range of options, the team believed that providing harm reduction options was the furthest from being realised within the English prison estate. This is not the case in other parts of the world. Speakers from Poland, Iran, Ukraine, Switzerland and Scotland reported that needle exchange in prisons is increasingly a reality in their parts of the world.

Team members heard about:

- A needle exchange project in Ukraine's only women's prison, run by prisoner volunteers[g]
- A needle exchange pilot in Iranian prisons
- A planned pilot in the Scottish prison estate.

A presentation by Annette Verster[f] reported that a WHO review of harm reduction interventions in prison settings found that where needle exchange was available in prisons, there was no evidence to suggest that people were using needles as weapons against the prisons staff, as routinely feared and predicted by opponents of prison needle exchange.

Drug users involved in sex work

Key messages

- The team thought that enabling drug treatment services to meet the complex needs of drug users involved in sex work is an urgent priority

- The team recognised that user involvement could play an important role in this work, particularly in terms of engaging with this hard-to-reach population.

Background

Sex work was the fourth major theme reported by team members. There were presentations on sex work issues from the UK, Indonesia, Ukraine, China, Canada, Australia and Scotland.[h, i, j, k, l, m, n]

Issues facing the average polysubstance user pale into insignificance when compared to the risks and harms faced by the average sex worker on each shift. Sex workers' lives are often affected by a complicated mesh of factors ranging from sexually transmitted infections (STIs), unwanted pregnancy, low self-esteem, stigma and discrimination, physical, emotional and mental abuse, sexual exploitation, and social isolation to name a few. Despite geographical differences, the team heard that sex workers worldwide experienced similar problems and barriers to drug treatment including:

- Services that are generally male dominated
- Restrictive opening and waiting times
- Discrimination (whether real or perceived)
- A postcode lottery of services
- The inability of mainstream service providers to respond to their specific needs.

Some countries have found that specific sex worker services need to be adequately equipped to deal with a wide range of issues. The conference heard that countries such as Ukraine, Indonesia and Canada have managed to implement a range of educational programmes, which equip female sex workers to deal with stigma and criminalisation. The team suggested that the effectiveness of these programmes should be reviewed and if necessary presented as good practice for the UK.

Reflecting on some of the sex work presentations they attended, one team member with an interest in this area highlighted the need to look in more detail at the admission policies of safe houses for victims of domestic violence. Currently, many safe houses in the UK will not accept women on methadone scripts or women who are sex workers.

The team recognised that service provision specific to sex workers is a hugely challenging area that needs to be improved. There was also a feeling within

the team that user involvement needs to step up to the challenge, with peer-led interventions and work alongside service providers, and sex worker champions to identify, design and deliver sex worker interventions.

Service user involvement

Key messages

- The conference put down a marker that service user involvement is now established within the English drug treatment system
- The team's attention turned to reflection about the next steps needed to further develop service user involvement:

"We don't demand privileges; we just want to be treated as normal"
Milena Naydenova (Bulgarian user activist)[o]

"Sometimes users have to do things first, it's not always appropriate to wait for policy to be made and laws to be passed"
(Team member)

Many presentations in Poland reflected a trend of growing service user involvement in drug treatment across the world. There was agreement within the team that service user involvement has become a standard and essential component of the drug treatment system in England in the last couple of years.

International Network for People Who Use Drugs

The team attended an opening session run by the International Network for People Who Use Drugs (INPUD). Now in its second year, the network represents the first steps towards creating an international service user organisation. INPUD has made some progress in its first year, with a member now sitting permanently on the IHRA committee, representing service users in the detailed running of the IHRA and its annual conference.

Reflecting on the INPUD session, team members held a range of views about the concept behind the organisation and the session itself. Overall, the team supported the principle of improving service user networks nationally and internationally. It is also fair to report that most of the team were underwhelmed by most of the content of the INPUD session.

The team applauded the fact that service users from across the world were able to network and recognised that establishing an international service user network would take time and be challenging. One team member wrote that in time, INPUD had the potential to be a "source of more information and knowledge that will provide users with vital support around harm reduction issues".

Other comments about the INPUD session included: "[a] lack of clarity about the structure of the session", "translation is essential to ensure INPUD materials reaches a multitude of users who don't speak English" and "being 'activist' and 'oppressed' is not enough on it's own, failure of past groups indicates that we haven't learnt enough [from past mistakes]".

Improved results through better networking and organisation

One of the most striking themes of the conference was the many international examples of service user involvement contributing towards innovation in service delivery and influencing policy development.[p] Most impressive were those examples of user network self-sufficiency producing tangible results in countries where governments had little or no sympathy to harm reduction principles. Two of the most striking examples were:

- Indonesian user networks now contributing to national drug policy
- The user network in Nepal that, without any central funding, managed to establish a permanent seat at the national health committee during a civil war.[q]

These examples of service user involvement illustrated what is possible when anger and desire to effect positive change is channelled into constructive activism. The whole team was inspired by these stories; however, in the debate that followed (which was also reflected within the teams' written submissions) contrasting viewpoints emerged about what next steps were required to strengthen the service user movement in England.

Service user involvement – debating the next steps

Examples of international service user achievement encouraged reflection among the team and there was a range of views expressed about the next steps in service user involvement in England. Some team members recognised the inherent instability of reliance upon a "brave few". For these individuals, there was a sense that the service user movement must move beyond activism into an era of more effective action through increased professionalism and better organisation. Others felt that in some areas of England, service user

groups have become complacent, absorbed into the mainstream and diverted from following up unpopular or unpalatable issues. These team members subscribed to the view that the torch needed to be kept burning by independent service user groups. Those who held this view noted with interest the suggestion presented at conference that the user movement could perhaps learn from the approaches developed by lesbian, gay, bisexual, and transgender men and women in response to the AIDS crisis in the 1980s and 1990s.[r]

Where there was consensus, however, was around the belief that continued funding in particular areas was crucial to consolidating the recent growth and effectiveness of the UK service user movement. One of these areas was the practice of formally employing service users through DAAT teams. Proponents within the team argued that this funding ensures users' perspectives are embedded in the process of planning and monitoring of drug treatment services. It also helps foster professionalism, continuity of expertise, advocacy and ultimately the sustainability of services user groups. The team thought another area that required financial support was for a national umbrella organisation such as the National User Network. The team believed this has the potential, in time, to become a valuable resource for service groups and individuals across the country. Finally, continued local funding and training was identified by some team members as vital in the context of proposed changes in the structuring of local healthcare.

Service user involvement in training and advocacy

Finally, the team thought it was important to stress that no person or organisation can talk and act on behalf of service users like their peers, which is why peer-led outreach and advocacy continue to have an important role in the drug treatment system. There are several types of advocacy – all vital – including peer, group, individual, formal and legal advocacy. Conference presentations showed that all can be effective and the team thought there is a strong case for funding these approaches accordingly.

Service users, including many team members, are already involved in training for drug and alcohol workers, social workers, prison officials and others. This type of involvement is particularly useful in training on drug misuse issues among the following groups:

- Harm reduction centred training for police, prison staff and judges
- Prisoners, who often have minimal knowledge of their rights – making them an important target audience for better harm reduction information.

Conclusion

Team members returned home tired but reinvigorated by their Warsaw experience. For many, the trip was a fresh reminder of why they had worked in the service user movement in the first place, often for little financial reward. Overall, the team felt that the trip was a great success because:

- It highlighted the progress made in establishing and embedding harm reduction in England, while also showing where improvements could be made
- It represented the NTA's acknowledgement of the effort that service users had made over the years and the difference their involvement had brought to policy, planning and delivery in England
- Team members were able to see first hand the growing role of service users within evolving drug treatment systems across the world
- It had an energising effect on team members.

Finally, the team agreed that although we have come a long way in establishing harm reduction in England, there remains room for improvement and this must be achieved with service users at the heart of the process – "nothing about us, without us".

Members of the team will launch this report in October 2007, at the National Conference on Injecting Drug Use in Glasgow.

Acknowledgments

This document was written by a team of user representatives and Alex Fleming (NTA) and is intended primarily for a service user audience.

The authors would like to like to thank the team: Jimi Grieve, Paul Murphy, Sharyn Charlton, Oliver Brain, Simon Craig, Herman Prestcote, Rick Cook, Sally Cook, Erin O'Mara, Eliot Albert, Viv Galvagna, Robert Hickson, Hugo Luck and Alex Fleming.

The team would also like to thank conference organisers in Poland, especially Paddy Costall, Jamie Bridge and Joanna Szostakowska.

Editing and typesetting by Paul Brookes, National Treatment Agency.

Annex 1

Table of scored IHRA Poland key themes

The method for the scoring system is explained on pages 6–7.

Theme	Score
1. Service user involvement	50
2. Blood-borne viruses	47
3. Stigma	28
4. Prison	24
5. Access to treatment	24
6. Data quality and monitoring	22
7. Training and education	22
8. Targeted interventions	20
9. Re-invigorate needle exchange	19
10. Sex work	17
11. Peer-led education and training	16
12. Prohibition vs harm reduction	16
13. Women	14
14. Young people	14
15. Advocacy	13
16. Alcohol	11
17. Drug consumption rooms	8
18. Public health	8
19. Tuberculosis	7
20. Technology	6
21. Homeless	5
22. Tobacco	3

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Conference presentations

The abstracts for all the sessions listed below are available at www.harmreduction2007.org

a. Guarinieri M, program officer, IHRD, Open Society Institute (2007) *The Silent Epidemic: Viral Hepatitis and HIV*. IHRD, Open Society Institute (1149/ M4/Tuesday 15 May 2007/11.00-12.30)

b. Schafranek M (2007) *How to use Mobile Phones in Low Threshold Customers' Health Counselling*. Poster presentation – IHRA conference, May 2007, Warsaw, Poland
http://www.eoph.fi/en/ehkaiseva-paihdetyo/telemaattinen/mobiilivinkki.html

c. White M (2007) *Wound and Leg Ulcer Management for Injecting Drug Users* – (761/C1-7/Monday 14 May 2007/14.00-15.30) IHRA conference, May 2007, Warsaw, Poland

d. Stern V (2007) *Harm Reduction in Prisons* – (1167/P2/Monday 14 May 2007/09.00-10.30) IHRA conference, May 2007, Warsaw, Poland

e. Reyes H (2007) *Harm Reduction in Prisons: The Role of the International Committee of the Red Cross* – (1174/P2/Monday 14 May 2007/09.00-10.30) IHRA conference, May 2007, Warsaw, Poland

f. Verster A (2007) *Evidence for Action: A Review of Harm Reduction Interventions in Prison Settings* – (817/P2/Monday 14 May 2007/09.00-10.30) IHRA conference, May 2007, Warsaw, Poland

g. Pintilei L (2007) Harm Reduction in prisons of Moldova – (1169/M1/ Monday 14 May 2007/11.00-12.30) IHRA conference, May 2007, Warsaw, Poland

h. Farley M (2007) *Bridging the Gap – Fast Track Prescribing* – (161/C1-1/ Monday 14 May 2007/14.00-15.30) IHRA conference, May 2007, Warsaw, Poland

i. Abigail S (2007) *Issues Facing Female Addicts in YAKITA Recovery Centre, Bogor, Indonesia* – (517/C1-1/Monday 14 May 2007/14.00-15.30) IHRA conference, May 2007, Warsaw, Poland.

j. Kurpita V (2007) *Increased Prevalence of Stigma and Discrimination Among HIV-Positive Hepatitis B and C and HIV in Sex Workers Who Inject* – (380/C3-6 /Tuesday 15 May 2007/14.00-15.30) IHRA conference, May 2007, Warsaw, Poland.

k. Bright V (2007) *The Prevalence of Stigma and Discrimination among HIV Positive and Negative Women Engaged in Survival Sex Work* – (561/C3-6/ Tuesday 15 May 2007/14.00-15.30) IHRA conference, May 2007, Warsaw, Poland.

An overview can be found at www.highwayoftears.ca and also list hundreds of women who have gone missing while engaged in sex work)

l. Yanlan R (2007) *Drug Use, Sexual Behaviors and Practices among Female Sex Workers in Yunnan Province, China* – (636/C3-6/Tuesday 15 May 2007/ 14.00-15.30) IHRA conference, May 2007, Warsaw, Poland.

m. Smith E (2007) *Harm Reduction in the Context of Criminalisation: Risks Faced by LGBT Sex Workers in the 'Prostitution Free Zones' of Washington DC* – (997/M9/Wednesday 16 May 2007/11.00-12.30) IHRA conference, May 2007, Warsaw, Poland.

n. Cusick L (2007) *Defining Sex Work as Work for Human Rights and Harm Reduction* – (404/M9/Wednesday 16 May 2007/11.00-12.30) IHRA conference, May 2007, Warsaw, Poland.

o. Naydenova M (2007) *Recent Developments in User Organising Around the World and Where to go From Here* – (1157/P4/Wednesday 16 May 2007/ 09.00-10.30) IHRA conference, May 2007, Warsaw, Poland

p. Friedman S (2007) *User Activism and Harm Reduction in an Age of Socioeconomic Change* – (542/M5/Tuesday 15 May 2007/11.00-12.30) IHRA conference, May 2007, Warsaw, Poland

q. Pandey B (2007) *Networking Among Drug Users and Drug User Urganisations* – (1147/M5/Tuesday 15 May 2007/11.00-12.30) IHRA conference, May 2007, Warsaw, Poland

r. Gonslaves G (2007) *The History of Collaboration Between Drug Users, PLWHAs, Gay Men and Women Around HIV/AIDS* – (1161/P4/Wednesday 16 May 2007/09.00-10.30) IHRA conference, May 2007, Warsaw, Poland

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