Needle and syringe programmes: providing injecting equipment to people who inject drugs. NICE Public Health Intervention Guidance

Fieldwork report

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Please note that as this report was prepared to provide an account of the views and opinions of professionals in response to draft NICE guidance, data reported should not be considered to necessarily reflect the views of NICE, the meeting facilitators, or the Centre for Public Health, LJMU.

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# Executive summary Introduction

The Department of Health requested that the National Institute for Health and Clinical Excellence (NICE) produce guidance on *Needle and syringe programmes: providing injecting equipment to people who inject drugs.* The target population of the draft guidance was people who inject drugs, including those who inject opioids, stimulants, and other illicit substances. It also included those who inject non-prescribed anabolic-androgenic steroids, and other performance and image enhancing drugs (PIEDS). Organisations and roles tasked to take action included (but not limited to), local strategic partnerships, Drug and Alcohol Action Teams (DAATs), joint commissioning managers, Primary Care Trust (PCT) commissioners, Needle and Syringe Programme (NSP) providers, and public health practitioners.

Based on the findings of an effectiveness review and economic appraisal, five draft recommendations were developed. The Centre for Public Health (CPH), Liverpool John Moores University was commissioned by NICE to field-test the draft recommendations. Four meetings and telephone interviews were held with professionals working within and allied to NSPs in Liverpool, Sheffield, Bristol, and London. These areas were chosen as each comprised city, suburban, and rural areas with a wide socioeconomic profile, and health burden from Blood Born Viruses (BBV). Furthermore, these areas were considered to have historical differences in the development of NSPs, with Liverpool for example, having a longer history of this type of service provision than Sheffield. Fieldwork meetings sought to collect views of professionals on the relevance, usefulness, and feasibility of the draft recommendations.

## Methodology

Field meeting delegates comprised professionals from fields including research, policy, retail supplies, health, social welfare, drug treatment and criminal justice. A matrix of relevant professional roles was constructed and convenience sampling was undertaken across each of the fields, whilst ensuring that independent, voluntary and community sectors were represented.

Discussion was facilitated by CPH and independent facilitators allied to the Department. Each draft recommendation was introduced and delegates were asked to consider 'Given that the evidence suggests that a particular kind of intervention/activity has worked in the following circumstances, and that this should form the basis of a recommendation, what would need to be done to make it work in your local situation? A follow up prompt was 'If this would not work, why not – and what would'? Delegates were asked to identify the possible barriers or facilitators to successfully implementing a suggested intervention/activity, solutions to these barriers, and implications of the intervention in terms of increasing equalities in health and

social inclusion. Three general areas were explored; Relevance of the draft recommendations: What is the current practice of professionals working in the area? Are the recommendations appropriate for these professional groups? Is there evidence, from practice or other sources, that has not been considered in developing these recommendations? Usefulness: How might these recommendations build on or change current practice and/or service provision? What are the implications of this? Are they accessible and clear? Are they appropriate to different client groups? Are they likely to be sustainable? Feasibility: What are the barriers to/opportunities for implementation? What further resources, training or support might be needed to implement them? To which other professional groups might they apply? How might the range of professional groups involved be reached? Discussions were transcribed and themes categorised within and between groups. Furthermore, individual interviews were conducted to record the views of professionals not in attendance at the field meetings. These interviews provided supplementary data on views concerning the relevance, usefulness and feasibility of the draft recommendations, which was used to inform the discussion of the field meeting data.

## Findings

## Recommendation 1: consultation with the community

#### Who should take action?

- Local strategic partnerships, local drug partnerships (including drug and alcohol action teams [DAATs]), drug joint commissioning managers and primary care trust (PCT) commissioners.
- Public health practitioners with a remit for substance misuse.

- Consult with people in the local community (including those who inject drugs) to help assess the need for and to plan – needle and syringe programmes (NSPs).
- Provide local people with information about the purpose of the programme. Acknowledge and respond to any reservations they may have about such a service: for example, specify how any resulting drug-related litter will be dealt with.
- Although the importance of public consultation was recognised, and was a commissioning requirement for many new services, experiences of the process were mixed. A service that was sensitive to local opinions, and communicated the needs of IDUs to the community was believed to gain long term benefit from the good neighbourhood relationship that was fostered. However, many examples were provided of new services that had been delayed or even abandoned because of strong local opposition, usually through co-ordinated protest from local media, or vocal segment(s) of the population. Common community concerns were the fear of crime (e.g. burglary, assault), discarded drug-litter, public injection, and an increase in drug dealing. Some of these concerns were legitimate and community and professional roles should be identified and included in any consultation. There were also some moral objections held by the public towards NSPs such as the view that NSPs promoted the use of drugs, or simply negative perceptions

held of IDUs. Projects that had proceeded despite local opposition required continued effort and resource to respond to ongoing concern and negative media stories.

- It was suggested that in keeping with the history of harm reduction activities in the UK, new services should be introduced and the general public provided with information about its activities retrospectively. This was justified from a public health perspective if local research indicated that there was an urgent health need for the service, and an evidence based intervention was introduced. Local groups would be invited to sit on project boards and workers would meet with the community to discuss any concerns and respond to any issues related to the work of the NSP (e.g. such as drug related litter). These mechanisms would also provide a means of describing the benefits and advantages of NSPs to local populations in an attempt to address some of the negative or misinformed beliefs they may hold against drug users and drug treatment services.
- In contrast, all delegates agreed that consultation with (potential) client groups was essential when establishing a new service. It was recognised that it was not an easy process and multiple creative methodologies would be needed to access the views and opinions of the most hidden populations of IDU. Some types of IDU, such as anabolic-androgenic steroid users would not self-identify as typical NSP clients and so these would need to be accessed in gyms and sports centres. An initial period of hard work (plus ongoing consultation) would provide important insights into need, service preferences (e.g. opening hours, equipment carried), injecting and drug taking behaviours, and location of public sharps bins. The responsibilities of clients regarding use of the service could also be established during this period, particularly around expectations of reducing drug related litter and public injection.
- It was thought that consultation on pharmacy based NSP provision would be more straightforward. Although there was always the expectation of local opposition, this was considered easier to address as NSP could be provide alongside other health services, and was not the main activity of the organisation. This allowed many pharmacies to provide NSP without the awareness of the majority of customers.

## **Recommendation 2: accessibility and distribution**

## Who should take action?

- NSP providers (specialist drug services and retail pharmacies).
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.
- Public health practitioners with a remit for substance misuse.

#### What action should they take?

• Commission a range of services to ensure needles and syringes are widely available and meet local need within the area covered by the local strategic partnership. This should include:

- outlets that distribute needle and syringe packs (for example, pharmacies)
- specialist NSPs that offer or refer people to, additional harm reduction services (for example, treatment for Hepatitis C) and other specialist services
- needle and syringe disposal, in line with 'Tackling drug related litter' (Department for Environment, Food and Rural Affairs 2005).
- Use local data on disease prevalence (for example, hepatitis C), populations (for example, the number of sex workers, crack injectors and homeless people in an area) and geography (for example, whether it is an urban or rural location) to ensure there is a balance of services, based on local need. Services should include a mix of:
  - pharmacy-based distributors and specialist NSPs within the PCT/local strategic partnership area, and
  - generic and targeted services (the latter should meet the needs of particular groups, such as people who are homeless).
- Ensure specialist drug services that offer opiate substitution therapy also distribute needles and syringes.
- Coordinate the provision of needle and syringe programmes to ensure a service is available for a significant period of time during any 24-hour period. As an example, PCTs could ensure that needle and syringe services form part of the 'necessary enhanced services' offered by '100–hour' pharmacies.
- Ensure people who use NSPs are provided with sharps bins and advice on how to dispose of needles and syringes safely.
- Ensure plans are in place to deal with any drug-related litter that may result from extending the opening times and locations of NSPs.
- Audit and monitor services to ensure they meet the needs of people who inject drugs.
- Consider providing and evaluating schemes to distribute needles and syringes:
  - via vending machines, mobile vans and non-pharmacy outlets (for example in sports venues for PIED users).
  - To people who have left prison and who are injecting drugs.
- There was a general consensus that the range of services specified in the recommendation was already being provided. NSPs were less successful in attracting

and retaining some populations of IDU (including anabolic-androgenic steroid users, and homeless individuals), working closely with, a range of other health and drug treatment providers, or providing services that were *widely available* and met *local need*.

- NSPs were set equipment returns targets (typically 70%) by commissioners, but because
  of unofficial distribution policies that did not contain the expectation of equipment return,
  these targets were rarely met. Delegates preferred to be issued with targets on coverage,
  although acknowledged that this would mean service performance would be harder to
  monitor. NICE were requested to provide advice on standardise auditing of services so
  that it was conducted in a systematic and consistent manner.
- The majority of delegates used epidemiological data in planning, commissioning and delivering NSP services, but required further support to collect, access, and interpret local information sources. Current data on BBVs provided by the Health Protection Agency for example was valued but did not provide insight on the health of local sub populations of IDU such as steroid users. In the absence of statutory local data, practitioners sought anecdotal information from service users which provided insight into emerging practices, such as new drugs, administration routes, and local prevalence. In contrast, many providers had negative views on data monitoring systems. These were perceived as being time consuming, of little reciprocal benefit to services, disruptive to the practitioner-client relationship, and representative of 'target driven' drugs treatment culture, which they did not approve of.
- Several locations and professional roles were suggested that should be encouraged to
  provide a low level NSP services (i.e. non pharmacy or agency NSP). These included
  vending machines, gyms, custody suites, and A & E departments. At a minimum all
  equipment distributed through these means should be accompanied by basic harm
  reduction advice and contact information for a range of drug services.
- Discussion of co-delivery of OST with NSP focussed on treatment compliance and client confidentiality. Service users preferred separate provision as they were concerned that key workers would discover that injection still took place despite oral methadone prescription. Both NSP providers and drug treatment workers emphasise that in such cases they would emphasise harm reduction and would not penalise service users by withdrawing their methadone prescription.
- One hundred hour pharmacies were deemed just one of several means of providing significant access to NSP service during a 24 hour period. Delegates preferred that the objective was prioritised rather than the precise means of delivery. Extended opening hours were not thought to increase client numbers but to make access more convenient

for existing service users, particularly those with the most chaotic lifestyles. As experience (and research) indicated that many IDUs were unwilling to travel far to NSPs it was important that local data was used for optimal siting of services.

 Special consideration was requested for drug users leaving prison. Delegates believed that the wording of the final statement in this recommendation was unclear and rather than ex-prisoners, the focus should be on those leaving prisons. It was suggested that all prisoners in contact with prison drugs services should be issued with syringe packs upon release, and if they were known to be injectors and likely to recommence drug use, encouraged to use alternative routes of administration than injection.

#### **Recommendation 3: accessibility and distribution**

#### Who should take action?

 Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Do not restrict the number of syringes/packs an injecting drug user can receive at any one time (within reason).
- Ensure syringes and needles are available in a range of sizes in locations sited across the area covered by the local strategic partnership. (They should only be provided in venues where safer injecting advice and information is available). In addition, other legally permitted injecting equipment associated with illicit drugs should be made available. (This includes, for example, filters, mixing containers and sterile water.)
- Ensure syringe identification schemes (involving, for example, the use of coloured syringes) are available. Encourage people who inject drugs to use easily identifiable syringes to prevent their injecting equipment inadvertently getting mixed up with someone else's.
- Allowing unrestricted distribution to injecting equipment and paraphernalia was normal practice for most NSPs. Return of used equipment was encouraged but this was not a service use requirement. Anecdotal examples were given of some pharmacies where it was believed that staff would only give out one syringe pack per visit, or insisted on oneto-one exchange. However, the veracity of these claims could not be tested.
- Despite unrestricted provision agency based NSP staff were encouraged to discuss injection advice if large numbers of packs were taken by clients and it was believed a long time would elapse until their next visit. Delegates stated that harm reduction paraphernalia should never be distributed without initial or reminder advice.
- Pick and mix approaches were supported by delegates, whereby clients specific on a standardised form the size and number of syringes/needles required. This approach had the advantage of reducing wastage, ensured that the equipment was tailored to administration needs (e.g. correct size of needle for femoral injection), and allowed time for the NSP worker to offer brief advice whilst the order was being prepared. However it was acknowledged that not all types of NSP would have the storage space or staff time to

dedicate to individual requests, especially if the transaction was taking place in a busy commercial environment.

- An apparent contradiction existed between this recommendation and recommendation 2. In the previous recommendation increased availability was prioritised regardless of support offered, whereas this stated that equipment should only be available where safer injecting advice and information is available. It was believed that only trained specialists could offer advice about safer injecting, but any NSP staff member could provide information (e.g. leaflets). Information/advice on the risks of sharing paraphernalia were often overlooked, and should form part of any information provided.
- Delegates were in favour of syringe identification schemes, but wanted to recommendation to reflect that there were multiple ways of delivering this, and that provision should be always be accompanied by safer injecting information and advice. There was also some concern that provision of such syringes might falsely assure IDUs that they were protected against the risks of sharing, simply by using such equipment. Practical concerns were also raised; for example, the environment in which the syringes were used (e.g. lighting levels), the likelihood of reuse, and colours favoured by a particular group (e.g. supporters of a football team).

## **Recommendation 4: pharmacy-based NSPs**

#### Who should take action?

- Retail pharmacies that run an NSP.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Commissioners should ensure a range of pharmacy-based NSP services is available including:
  - distribution of needle and syringe packs
  - distribution plus harm minimisation advice and information
  - distribution plus harm minimisation advice and referral to specialist services.
- Pharmacies and commissioners should ensure staff who dispense needles, syringes or packs receive appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion, to respect the privacy of people who inject drugs and to treat them in a non-stigmatising way. Staff in pharmacies that provide more than just needle and syringe packs should be trained to provide health promotion advice, in particular, on how to minimise the harm caused by injecting.
- Pharmacy staff should be able to provide information about agencies offering further support to people who inject drugs (this includes details about local DAAT services).
  - Delegates supported the proposed tiered structure of pharmacy provision. Although
    there was some criticism of the current level of training that pharmacy staff receive,
    and the perception of the level of ability of some retail staff, delegates valued the
    services that pharmacy NSPs provided and commissioners acknowledged that they
    would not be able to provide adequate coverage to IDUs without their support.
  - Even those pharmacy staff working at the lowest proposed tier (distribution of injection equipment) would require specific training on the principles of NSP and harm reduction. This would provide them with the basic skills to respond to any client questions. Access to a range of information sources and contact details for specialist NSP services would be sufficient response to more detailed questions.
  - Although many pharmacies would like to offer more specialised services they would have to renegotiate local contracts.
  - Pharmacy staff often requested good quality training, but this was not always available, and was rarely standardised and quality assured. It was suggested that organisations such as PCTs and the Centre for Pharmacy Postgraduate Education could provide specialist harm reduction training programmes for pharmacists, coordinated and accredited by local pharmaceutical committees and Harmonisation and Accreditation Groups.

## **Recommendation 5: agency-based NSPs**

#### Who should take action?

- NSPs based within a specialist drug service.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Ensure a selection of individual needles, syringes and other injecting equipment is available (in addition to preprepared needle and syringe packs).
- Ensure NSPs based within a specialist drug service offer comprehensive harm reduction services, including advice on safer injecting practices, assessment and treatment of injection-site infections and help to stop injecting drugs.
- Ensure NSPs based within a specialist drug service provide access to:
  - hepatitis B vaccinations and boosters
  - testing for hepatitis B, hepatitis C and HIV
  - opiate substitution therapy
  - primary care services (including dental care and general health promotion advice)
  - secondary care services (for example, for Hepatitis C and HIV treatment)
  - welfare services, for example housing and legal advice.
- Commissioners should ensure people who inject drugs receive integrated care for all their health needs.
  - There was broad agreement with the objectives of this recommendation. Many of these services were already in place but NICE guidance was believed to support a co-ordinated approach towards delivery. However, delegates suggested two changes in wording. The first, "Ensure NSPs, as part of specialist drug services...", would emphasise the importance of NSPs in the spectrum of drug treatment services. The second, "...alternatives to injecting" rather than "...help to stop injecting drugs" was suggested as injection cessation support was a specialist skill, and although not covered in NICE guidance, there was an understanding that many NSPs distributed foil in order to persuade IDUs to reduce their number of injections.
  - Delegates were unclear about the precise meaning of 'integrated health care' in this recommendation. Clarity was requested on whether this referred to high quality referrals from NSPs or that NSPs were expected to provide or be attached to a wide range of health services.
  - In addition to the specified interventions, suggested additions included items related to wounds care, sexual health, smoking cessation, alcohol harm reduction, mental health, nutrition and diet, social welfare, GP access, and early years development support for the children of IDUs.

## **Conclusions & Recommendations**

A summary of major topics emerging from discussion of each particular recommendation is outlined below:

## **Recommendation 1**

- Consultations have the potential to develop services that are sensitive to local concerns.
- Consultation provides a rare opportunity for the views and needs of IDUs to be expressed.
- Objections from local residents have the potential to delay or cancel implementation of NSPs.
- Information provision and education is preferred to direct public consultation.
- Consultation with IDUs and other service users were critical for successful service implementation and development. This is acknowledged as being difficult to achieve especially with sub populations such as anabolic-androgenic steroid users.
- Consultation with IDUs should be bi-directional, and establish service userresponsibilities with regards to public concerns such as drug related litter, and unacceptable social behaviour (e.g. public injecting).

## Recommendation 2

- Although existing NSPs provide the range of services specified in the recommendation, there is currently less than optimal co-ordination of activities with a range of other health and dug providers.
- *Coverage* needs to be clearly defined in the recommendation to help support establishment of local targets.
- The majority of NSPs already provide unlimited access to injecting equipment
- Epidemiological data was useful for planning and commissioning of services, but this needed to be combined with anecdotal data and intelligence from service users and drugs workers to properly inform service provision.
- NSPs require guidance on standardised ways to monitor and audit services that is beneficial to both commissioners and providers. NSPs view existing statutory monitoring systems negatively as they do not perceive a derived benefit from participation.
- Combining or co-locating NSP within OST was welcomed, although there were some concerns with treatment compliance and client confidentiality
- One hundred hour pharmacies were just one way of ensuring significant access to services during a 24 hour period. Twenty four hour opening of NSPs was not required. The overall objective was more important than specific mechanisms, which would have to be planned locally.

- Although client responsibility was important, NSPs would look to establish string partnerships with local Environmental Services to more effectively respond to drugrelated litter. Careful consultation and consideration of the location of public 'sharps bins' would help to reduce litter.
- More work is needed to attract and retain AAS users in services. The use of other performance and image enhancing drugs was perceived to be on the increase. Providers need to be able to deliver opportunistic interventions and NSP attendance by these populations could be infrequent.
- There was overall support for vending machines, but the lack of research supporting their introduction was noted. Findings from pilot schemes suggested strong local opposition and the need for a sophisticated and secure access mechanism.
- Priority should be placed on the needs of illicit drug users leaving prison. Discharged prisoners should be provided with harm reduction packs (including information and syringe packs), and contact details for local services.

## **Recommendation 3**

- Guidance specifying unrestricted distribution of syringes/packs would promote consistency across different types of NSP.
- NSP practitioners should be encouraged to engage with clients (according to their personal training and skills) during all transactions, and encourage frequent visits.
- Limiting equipment may be appropriate where young people are concerned in order to encourage revisit.
- Legal restrictions means that NSPs are only legal able to provide sterile water in 2ml glass ampoules. Other types of packaging and delivery are in breach of MHPRA conditions.
- Investigation of the uses and the effectiveness of foil as an alternative to injecting should be included in NICE research recommendations. Despite currently being proscribed by the Misuse of Drugs Act, there was informal distribution of foil, often with the tacit approval of police. If found to be effective, the legal status of foil should be reviewed.
- Clients should be offered a choice of syringes and needles. Non-specific syringe packs should be avoided where possible.
- Syringe identification schemes were viewed positively but should be used in parallel with more detailed risk reduction advice and information.

## **Recommendation 4**

- The proposed tiered structure of pharmacy NSP provision was supported.
- Pharmacy based NSPs were valued as they enabled commissioners to provide adequate coverage for IDUs. However, there was the perception held by some agency based NSP staff, that many pharmacy staff did not have the required skills to

deliver NSPs. It was noted that this was an issue of current training provision rather than the inherent skills of pharmacy staff. Staff working at all of the proposed tiers of pharmacy NSP provision require standardised and accredited/quality assured training.

 Most pharmacy staff already have good attitudes and working practices towards IDUs. However, advice on confidentiality and client respect should still be included in basic staff training.

# **Recommendation 5**

- NSPs should be part of the core spectrum of drug treatment services, and not considered as standalone entities.
- Persuading clients to cease injecting was difficult. Promoting alternatives to injecting was more achievable.
- Many of the services classed under *integrated care* are currently available to IDUs.
   Good referral systems should be developed and where possible NSP clients treatment in mainstream services to avoid stigmatisation.
- Dental care is a priority for NSP clients.

## 1. Introduction

[This section is adapted from the systematic review of Jones et al., 2008. Please see this report for a more detailed overview of relevant policy and epidemiology]

## 1.1.1 Prevalence of injecting drug use

National estimates for 2005/06 suggested that there were around 129,977 (95% CI: 125,786 to 137,034) injecting opiate and/or crack cocaine users in England (Hay et al., 2007), approximating to 3.90 per 1,000 of the population aged 15 to 64. Data also suggest that injecting drug use prevalence has increased over time (HPA 2007a) and it has increased substantially since the 1986 Advisory Council for the Misuse of Drugs (ACMD) estimate of 37,000-75,000 IDUs for England and Wales (ACMD 1988).

The prevalence of injecting drug use varies across regions, ranging from around six per thousand in Yorkshire and the Humber to around three per thousand in London, the East of England and the South East. Although data on the number of amphetamine injectors is not readily available, according to the 2007 British Crime Survey, 0.2% of 16-24 year olds and 0.1% of 16-59 year olds in the United Kingdom have used anabolic steroids in the last year. Of these, a high proportion inject, with around 60% of anabolic steroid users reporting that they inject the drug (Koria & Stimson 1993).

## 1.1.2 Morbidity and mortality- blood borne viruses

Injecting drug users (IDUs) experience high levels of morbidity and mortality. In 2006, there were 1,469 deaths relating to drug misuse in England including those who died as a result of accidental overdose, intentional self-poisoning and from drug abuse and drug dependence (ONS 2007). In addition, IDUs may experience poor health from a range of conditions including infectious diseases and injection site infections (HPA 2007a).

Although HIV and AIDS remain a concern in the UK, infection among IDUs is relatively uncommon. One hundred and ten new diagnoses (2% of total) of HIV were thought to have occurred as a result of injecting drug use in 2007 (HPA 2007b) with a cumulative total of 4,790 HIV diagnoses reported in the UK up to the end of 2007 (HPA 2007b). Of greater concern is the increasing prevalence of Hepatitis C (HCV). The majority of the 62,424 reported laboratory diagnoses of HCV infection in England reported up to the end of 2006 were probably acquired through injecting drug use and over 90% of those diagnoses with risk factor information reported injecting drug use as the route of infection (HPA 2007a). Among participants in the Unlinked Anonymous Prevalence Monitoring Programme (UAPMP) survey, the prevalence rate prior to 2001 was 11%, but has increased to – although remained stable at – 21% in the period 2001 to 2005. The UAPMP survey reported a HCV prevalence rates as for 1998, although absolute numbers of infections have decreased since then. The UAPMP

survey also found increased prevalence of HBV among IDUs. Rates of infection have risen from 3.4% in 1997 to 10% in 2006. In 2006, within London the prevalence of hepatitis B among IDUs was 34% and 18% outside of London. Whereas HCV prevalence appears to have remained relatively stable, HBV prevalence among IDUs outside of London has decreased since 1996 (from 23% to 18%) but continued to rise among London IDUs (from 22% to 34%).

## 1.1.3 Morbidity and mortality- Overdose

Data on the number of drug-related deaths in England have been reported since 1993. After a general increase in the number of deaths up to 2001, followed by a general decline and then an increase in 2004, currently drug related deaths are at their lowest since 1995. In 2006, 1,782 male and 788 female drug related deaths were recorded (ONS 2007). Although the number of heroin-related deaths has decreased over the years, it remains the largest cause of drug-related deaths and there continues to be a long term upward trend in deaths involving cocaine. In a study of drug-related overdose deaths in London in 2003, Hickman et al., (2006) found that the majority of deaths were among people with a history of dependent drug use and injecting drug use.

## 1.1.4 Morbidity and mortality- injecting site infections

IDUs are also at risk of wound site infections resulting from injecting contaminated drugs and/or non-sterile injecting equipment. Thirty-five percent of IDUs participating in the 2006 UAPMP survey reported experiencing an abscess, sore or open wound, or possible symptoms of an injecting site infection during the previous year. Elevated levels of wound site infections appear to be associated with homelessness, injecting in the legs, injecting in the hands and injecting crack cocaine within the previous four weeks.

Wound site infections to which IDUs are particularly vulnerable include tetanus, *Staphylococcus aureus*, Group A streptococcus and wound botulism. The prevalence of tetanus among IDUs in the UK is low, with only two of the 175 reported cases of tetanus identified in England and Wales between 1984 and 2000 known to have occurred in IDUs. This is in contrast to the USA, where IDUs accounted for 17% of cases between 1995 and 2000 (CDC 2003). However, in 2003 there was an outbreak of tetanus among UK IDUs, with most of those infected reporting 'skin popping' (the subcutaneous injection of heroin). Many were un-immunised or partially immunised and the distribution of the cases suggests that the outbreak may have been due to heroin contamination, rather than injection practices. This outbreak has led to an updating of vaccination guidance for IDUs to ensure tetanus immunisation status is actively checked (HPA 2007a).

Wound botulism occurs when wounds, such as injecting sites, are infected with *Clostridium botulinum*. Wound botulism among UK IDUs is rare, and prior to 2000 no cases had been

reported among IDUs although by the end of 2006, 134 cases had been reported, with at least seven fatalities. In contrast *staphylococcus aureus* is a common pathogen among IDUs, and causes infections which can vary in severity from minor skin and soft tissue infections to life-threatening invasive disease such as bacteraemia and endocarditis. Between April 2003 and March 2007, 60 cases of sepsis due to MRSA were identified among IDUs in England and Wales, 50% of whom presented with injection site abscesses or skin infection. Group A streptococci can also cause skin sepsis and bacteraemia, and injecting drug use is a key risk factor with 20% of reports of Group A streptococcus in the UK being related to injecting drug use. However, the numbers of infected IDUs are diminishing and reported cases of Group A streptococcus have decreased in recent years (HPA 2007a).

#### 1.1.5 Injecting risk behaviours

Almost a quarter (23%) of UAPMP respondents reported sharing needles and syringes in the previous four weeks. Sharing filters, mixing containers and water was more common, and almost half of UAPMP respondents (45%) reported that they had shared these types of paraphernalia within the previous four weeks. Different transmission rates for HIV and HCV have been identified. In a longitudinal study (1983-1994) of HIV positive IDUs and their HIV negative heterosexual partners in Scotland, Wyld et al., (1997) found that among 31 injecting drug using couples, 52% seroconverted for HIV and 80% seroconverted for HCV, whereas among 30 non-injecting couples, 40% seroconverted for HIV and there were no seroconversions for HCV.

In 2006, 90% of current and ex-IDUs participating in UAPMP reported that they had ever accessed an NSP, however among recent initiates (those who reported first injecting within the previous three years), the rate was lower at 85% (HPA 2007a). Studies in the UK have observed higher rates of HCV infection in younger injectors and those in the early years of their injecting career (Hickman et al 2007). Studies conducted internationally have also found that recently initiated IDU have higher HIV and HCV seroincidence than IDU with longer duration of use (Garfein et al., 1998; Nicolosi et al., 1992; van Ameijden et al., 1992). A Canadian study (Miller et al., 2007), which explored longitudinal drug use and sexual risk patterns among IDUs, identified that factors associated with younger age included borrowing syringes, and frequent injection of heroin, cocaine, and speedballs. In addition, young IDUs were found to be less likely to access drug treatment or methadone maintenance therapy. These studies highlight the need for services to intervene early in drug users' careers and the need for interventions tailored to young people.

#### 1.1.6 Policy responses

Since the late 1990s the focus of policy around drug use has broadened from a public health perspective to also include the minimisation of wider social harm, including crime and antisocial behaviour. The 1998 government ten year drugs strategy, *Tackling drugs to build a*  *better Britain*, identified the need for further action to 'improve the health of drug misusers and drive forward action to reduce the risk of death'. The 2008 updated drugs strategy, *Drugs: Protecting families and communities*, continues in the same vein, stating an intention to:

'Continu[e] to promote harm minimisation measures including needle exchange and drug-assisted treatments that encourage drug users to enter treatment, in order to reduce the risk of overdose for drug users and the risk of infection for the wider community' (2008: 29).

Following a rise in drug-related deaths in 2005, the government launched an action plan to reduce drug-related harm, which was aimed at directly reducing the number of drug-related deaths and BBV with wider goals of preventing drug misuse and encouraging stabilisation in treatment and support for abstinence (DH 2007). In addition, there has been growing recognition of the need to reduce HCV transmission in IDU populations. Since the publication of *Getting ahead of the curve* (DH 2002), hepatitis C has been identified as needing 'intensified action' to improve its prevention, diagnosis and treatment. IDUs have been identified as a particular target due to the high rates of transmission as a result of injection equipment and paraphernalia sharing. Initiatives include developing clinical networks for the assessment and treatment of patients with HCV and the provision of services for particular groups of patients, including those who may experience social exclusion, such as prisoners and IDUs. Increased monitoring will enhance the targeted delivery of treatment in the future.

Harm reduction recognises the importance of reducing the risks associated with drug misuse by providing means of reducing sharing of injecting equipment, providing support in stopping injecting, providing opioid substitution therapies (OSTs) for heroin users and supporting the transition to abstinence from illegal drugs. Most harm reduction interventions specifically aim to prevent the transmission of BBV infections and other drug related harms, including overdose and drug-related deaths. These include: needle and syringe programmes (NSPs) offering injecting equipment and paraphernalia; advice and support on safer injecting; reducing injection frequency and reducing initiation of others into injecting; advice and information on preventing the transmission of BBVs and other IDU-related infections; advice, information, counselling and testing for hepatitis and HIV; the provision of hepatitis A and hepatitis B vaccinations; advice and support on preventing risk of overdose and drug-related death; risk assessment and referral to other treatment services (Abdulrahim et al., 2006).

## 1.1.7 The National Treatment Agency's 2005 survey of needle exchanges in England.

In 2007 the NTA reported on the findings of a survey of NSPs in England and also other efforts to reduced drug-related harm, in particular the transmission of blood borne viruses (NTA, 2007). The overall aims of the study were to investigate the extent and nature of NSPs and other measures to reduce harms related to drugs; to assess data reporting systems; and

explore the commissioning, planning and delivery of NSPs and harm reduction services. To achieve these aims a number of task were undertaken including identifying services that provided needle exchange and hard reduction programmes; the gathering of data on needle exchange activity; investigating aspects of the commissioning, planning and management of NSPs and harm reduction services; and examining services delivered.

The study was a mixed method approach adopting both qualitative and quantitative research methods. The quantitative aspect consisted of questionnaires sent to Drug (and Alcohol) Action Team (D(A)AT) partnerships and joint commissioners, specialist NSPs and pharmacy based exchange coordinators.

It was evident from the findings that commissioners only had limited information on NSPs in their area, restricting their ability to assess service provision in their area. Data on service activity was described as poor and monitoring and information systems were reportedly diverse.

A key finding was the wide variability in England with regards to the provision of NSP and harm reduction interventions. It was reported that there was no rationale for this diversity and no uniformity in what services were offered. Consequently, a substantial number of individuals were being denied the range of interventions in line with Models of Care Guidance (NTA, 2006). The findings suggested that a substantial number of D(A)AT residents did not have easy access to NSP facilities, and facilities were more limited in rural areas compared to urban areas. Furthermore, access was often limited to the working week and few were open in the evening.

With regard to types of services it was found that specialist NSPs formed 20% of all NSP facilities and pharmacies comprised the remaining 80%. Information obtained suggested that a significantly greater number of visits were made to pharmacy NSPs than to specialist NSPs and they also had more service users. This was not necessarily determined by prevalence or population density.

The number of needles distributed by pharmacies and specialist services was similar; however specialist services dispended a larger number of needles and syringes per contact. Overall the number of needles and syringes available to injectors was limited, indicating that the numbers supplied were not sufficient. Both pharmacies and specialist services offered a range of injecting equipment, although specialist services were more likely to distribute paraphernalia and a wider range of items. There was however no uniformity in what injectors received, with substantial regional differences.

There were significant variations between services and between D(A)ATs with regards to BBV prevention interventions and differences in the provision of hepatitis B immunisation and hepatitis C testing. Consequently large numbers of injectors did not have access to such interventions. Also many injectors did not have access to harm reduction support. In addition, although the majority of services carried out an assessment, approximately 40% did not address hepatitis B immunisation or testing for BBVs, and one third did not discuss injecting hygiene and safer injecting techniques. Finally, overdose prevention training was only undertaken in half of the services and only a quarter assessed new service users risk of overdosing.

Data on return rates suggested that a higher rate of returns were received by services than pharmacies. However, this finding must be treated with caution due to the low response rate. In addition, equipment taken from pharmacies was often reportedly returned to specialist services.

## **1.2 Objectives**

The National Institute for Health and Clinical Excellence (NICE) was asked by the Department of Health to develop guidance on needle and syringe programmes: providing injecting equipment to people who inject drugs.

(see http://www.nice.org.uk/guidance/index.jsp?action=byID&o=11829).

The guidance complements and supports other NICE guidance on drug and substance misuse and provides recommendations for good practice aimed at encouraging the optimal provision of needle and syringe programmes (NSPs) among injecting drug users. NSPs were defined as those organisations that supply injecting equipment used to prepare and take illicit drugs. Most NSPs are provided by pharmacies or specialist drug services. The target population included those who injected opioids, stimulants, and other illicit substances. It also included those who inject anabolic-androgenic (AAS) steroids and other performance and image enhancing drugs (PIEDs).

The Centre for Public Health (CPH; <u>www.cph.org.uk</u>), Liverpool John Moores University (LJMU) was commissioned to systematically review the evidence of effectiveness and cost effectiveness of NSP interventions (Jones et al., 2008). Twenty four primary study reports and ten systematic reviews and meta analyses met the inclusion criteria of the evidence review, and 13 economics evaluations were reviewed in the cost effectiveness report. One effectiveness study examined issues related to coverage, 14 studies examined different types of NSPs, seven studies examined additional harm reduction services offered by NSPs, and two studies examined NSPs delivered alongside opiate substitution therapy (OST). Collaborating colleagues at Leeds Metropolitan University conducted a systematic qualitative review in order to provide a situated narrative perspective on the review questions (Cattan et

al., 2008). The review identified 40 studies for inclusion, 38 of which used interviews and 17 of which used interview, ethnographic or observation methods. Working in collaboration with CPH, colleagues at the London School of Hygiene and Tropical Medicine, Imperial College, and Bristol University undertook a *de novo* economic evaluation (Vickerman et al., 2008), based on a dynamic model of HCV and HIV transmission. The impact on effectiveness and cost-effectiveness were assessed in two settings with contrasting HCV prevalence.

The findings of the effectiveness review and economic appraisal were presented to the Public Health Interventions Advisory Committee (PHIAC) in July 2008. PHIAC considered this evidence and comments from stakeholders to determine:

- Whether there was sufficient evidence (in terms of quantity, quality and applicability) to form a judgement.
- Whether, on balance, the evidence demonstrated that the intervention was effective or ineffective, or whether it was equivocal.
- Where there was an effect, the typical size of effect.

PHIAC developed five draft recommendations (Box 1) based on the following criteria, and derived from evidence statements generated by the literature reviews:

- Strength (quality and quantity) of evidence of effectiveness and its applicability to the populations/settings referred to in the scope.
- Effect size and potential impact on population health and/or reducing inequalities in health.
- Cost effectiveness (for the NHS and other public sector organisations).
- Balance of risks and benefits.
- Ease of implementation and the anticipated extent of change in practice that would be required.

Recommendation 1: evidence statements Q3.2a, Q3.3d, Q3.6a, Q3.6b
Recommendation 2: evidence statements E5.1a, E5.1b, E5.1c, E6.2b, E6.2c, E7.1a, E7.1b, E7.1c, E7.1d, Q3.2a, Q3.3a, Q3.3b, Q3.3c, Q3.3d, Q3.4a; IDE
Recommendation 3: evidence statements Q3.3a, Q3.4c; IDE
Recommendation 4: evidence statements E6.3b, E6.3c, E6.4b, Q3.3b, Q3.3d, Q3.4a, Q3.5a
Recommendation 5: evidence statements E6.3b, E6.3c, E6.4b, Q3.3b, Q3.4b

Where E, Effectiveness Review evidence; Q, Qualitative Review evidence; IDE, Inference Derived from the Evidence.

The five draft recommendations were included in draft guidance that was issued by NICE for consultation and fieldwork in September 2008.

This document is the report arising from the fieldwork testing of the draft recommendations and describes a key stage in the process of developing the *final guidance*. The objective of the fieldwork phase was to integrate the best scientific evidence on NSPs, with knowledge derived from practice, planning, and policy. This involved appraising the draft recommendations for practice that had been derived from the public evidence for the likelihood of success in routine practice within the UK, as opposed to evaluative conditions (i.e. as part of research studies), mostly outside of UK settings.

The overall aims of the fieldwork meetings were to gain an understanding of the views of professionals on the relevance, usefulness and feasibility of the draft intervention guidance to their current practice; and to understand what factors could either help or hinder the effective implementation and delivery of the draft recommendations as part of current practice.

To achieve these aims, a series of fieldwork meetings were convened in Bristol, Liverpool, Sheffield and London, in September 2008. Two semi-structured interviews were also conducted in order to obtain supplementary information and opinions on specific topics from experts. Experts and practitioners from a variety of organisations and services involved in NSPs, health, drug services, pharmacies, criminal justice, and a broad range of support work were invited to the fieldwork meetings so that the draft recommendations could be appraised from the point of view of different types of professional and voluntary experiences, including differences in locality of delivery of NSPs. NSP service user representatives were also invited to attend (see Appendix 1 for the list of attendees).

The fieldwork was conducted by CPH with the additional assistance of two independent facilitators, Andrew Bennett (Liverpool, UK), and Dr Lucy Pickering (Oxford Brookes University), both of whom were chosen because of their expertise on the topic and in this type of fieldwork methodology. Through a series of structured discussions attendees were asked to assess the likelihood of the relevance, usefulness and feasibility of the draft recommendations, based on a number of factors, including their experiences and understandings of current policy and the environment, clients, and communities with whom they worked.

This report summarises the key pointers arising from the fieldwork meetings including the data and concepts as they emerged. This includes discussion of any possible implications for primary care trusts (PCTs), strategic health authorities, regional directors of public health, local authorities, the voluntary and community sectors, the Department of Health (DH)

research and development function and policy leads in the DH and other relevant government departments.

Box 1 (following pages) Draft recommendations considered at the field meetings

## Recommendation 1: consultation with the community

# Who should take action?

- Local strategic partnerships, local drug partnerships (including drug and alcohol action teams [DAATs]), drug joint commissioning managers and primary care trust (PCT) commissioners.
- Public health practitioners with a remit for substance misuse.

- Consult with people in the local community (including those who inject drugs) to help assess the need for and to plan needle and syringe programmes (NSPs).
- Provide local people with information about the purpose of the programme. Acknowledge and respond to any reservations they may have about such a service: for example, specify how any resulting drug-related litter will be dealt with.

## **Recommendation 2: accessibility and distribution**

## Who should take action?

- NSP providers (specialist drug services and retail pharmacies).
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.
- Public health practitioners with a remit for substance misuse.

- Commission a range of services to ensure needles and syringes are widely available and meet local need within the area covered by the local strategic partnership. This should include:
  - outlets that distribute needle and syringe packs (for example, pharmacies)
  - specialist NSPs that offer or refer people to, additional harm reduction services (for example, treatment for Hepatitis C) and other specialist services
  - needle and syringe disposal, in line with 'Tackling drug related litter' (Department for Environment, Food and Rural Affairs 2005).
- Use local data on disease prevalence (for example, hepatitis C), populations (for example, the number of sex workers, crack injectors and homeless people in an area) and geography (for example, whether it is an urban or rural location) to ensure there is a balance of services, based on local need. Services should include a mix of:
  - pharmacy-based distributors and specialist NSPs within the PCT/local strategic partnership area, and
  - generic and targeted services (the latter should meet the needs of particular groups, such as people who are homeless).
- Ensure specialist drug services that offer opiate substitution therapy also distribute needles and syringes.
- Coordinate the provision of needle and syringe programmes to ensure a service is available for a significant period of time during any 24-hour period. As an example, PCTs could ensure that needle and syringe services form part of the 'necessary enhanced services' offered by '100–hour' pharmacies.
- Ensure people who use NSPs are provided with sharps bins and advice on how to dispose of needles and syringes safely.
- Ensure plans are in place to deal with any drug-related litter that may result from extending

the opening times and locations of NSPs.

- Audit and monitor services to ensure they meet the needs of people who inject drugs.
- Consider providing and evaluating schemes to distribute needles and syringes:
  - via vending machines, mobile vans and non-pharmacy outlets (for example in sports venues for PIED users).
  - to people who have left prison and who are injecting drugs.

# Recommendation 3: accessibility and distribution

# Who should take action?

• Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Do not restrict the number of syringes/packs an injecting drug user can receive at any one time (within reason).
- Ensure syringes and needles are available in a range of sizes in locations sited across the area covered by the local strategic partnership. (They should only be provided in venues where safer injecting advice and information is available). In addition, other legally permitted injecting equipment associated with illicit drugs should be made available. (This includes, for example, filters, mixing containers and sterile water.)
- Ensure syringe identification schemes (involving, for example, the use of coloured syringes) are available. Encourage people who inject drugs to use easily identifiable syringes to prevent their injecting equipment inadvertently getting mixed up with someone else's.

## **Recommendation 4: pharmacy-based NSPs**

## Who should take action?

- Retail pharmacies that run an NSP.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Commissioners should ensure a range of pharmacy-based NSP services is available including:
  - distribution of needle and syringe packs
  - distribution plus harm minimisation advice and information
  - distribution plus harm minimisation advice and referral to specialist services.
- Pharmacies and commissioners should ensure staff who dispense needles, syringes or packs receive appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion, to respect the privacy of people who inject drugs and to treat them in a non-stigmatising way. Staff in pharmacies that provide more than just needle and syringe packs should be trained to provide health promotion advice, in particular, on how to minimise the harm caused by injecting.
- Pharmacy staff should be able to provide information about agencies offering further support to people who inject drugs (this includes details about local DAAT services).

# Recommendation 5: agency-based NSPs

# Who should take action?

- NSPs based within a specialist drug service.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

- Ensure a selection of individual needles, syringes and other injecting equipment is available (in addition to pre-prepared needle and syringe packs).
- Ensure NSPs based within a specialist drug service offer comprehensive harm reduction services, including advice on safer injecting practices, assessment and treatment of injection-site infections and help to stop injecting drugs.
- Ensure NSPs based within a specialist drug service provide access to:
  - hepatitis B vaccinations and boosters
  - testing for hepatitis B, hepatitis C and HIV
  - opiate substitution therapy
  - primary care services (including dental care and general health promotion advice)
  - secondary care services (for example, for Hepatitis C and HIV treatment)
  - welfare services, for example housing and legal advice.
- Commissioners should ensure people who inject drugs receive integrated care for all their health needs.

## 2. Methods

## 2.1 Field Meetings

Four fieldwork meetings were held in Bristol, Liverpool, London and Sheffield in September 2008. Delegates were invited from the regions in which these cities were located. These areas were chosen as each comprised urban, suburban, and rural areas with a wide socioeconomic profile. Furthermore, estimates suggest that the prevalence of injecting drug use varies between region and the historical development, and current provision of NSPs was different (Hay et al., 2007)

The aim of these meetings was to elicit views on the likelihood of implementing the draft recommendations in local practice. In order to gain a detailed understanding of the political and social context in which daily practice and delivery of service took place, experts from a variety of organisations and agencies were invited. A matrix of relevant professional roles was constructed and convenience sampling was undertaken across the health, criminal justice and social services; and independent, voluntary and community sectors (Table 1).

Considering the focus of the draft recommendations, emphasis was placed on drug treatment, pharmacy and harm reduction specialists. Letters of invitation were sent to professionals in suitable roles, drawn from CPH's contact list, and liaison with appropriate organisations such as Primary Care Trusts, (PCT) Drug and Alcohol Action Teams (D(A)AT), and the National Needle Exchange Forum<sup>1</sup>. Several societies were also contacted (e.g. UK Harm Reduction Alliance). Cross reference was made with registered NICE stakeholders to ensure adequate representation of relevant organisations. Letters were followed up by invitation emails and telephone calls where appropriate.

Sector/organisation	Example roles
National Treatment Agency	Policy & Monitoring
Research	Independent, charity, health service & University Researchers
Supplies sector	Providers of NSP supplies and harm reduction materials
Pharmacies	Retail pharmacists, coordinators of pharmacy based NSPs
Drugs	DAAT manager, drugs worker, service user representatives
Criminal Justice	Police drug specialists
Health	Nurse specialists, commissioners, policy leads, hepatologist, prescribing support
Social welfare	Service representatives (housing, employment)

<sup>&</sup>lt;sup>1</sup> <u>http://www.nnef.org.uk/</u>

The fieldwork proceeded in accordance with the NICE/CPHE Methods Manual (2006a; Chapter 7). Each meeting lasted one working day. The first part of the meeting consisted of a presentation introducing the aims and objectives of the day, and information about the development of the draft recommendations. Delegates were given the opportunity to raise general questions and clarifications about the draft guidance in this period. For discussion periods, attendees were subdivided into three or four groups, each working with a facilitator. Centre for Public Health researchers attended each meeting to provide technical advice on relating the evidence review. NICE representatives matters to (technical team/implementation) were also in attendance to respond to queries on the guidance production process. The latter two groups were independent observers and did not contribute to the discussions unless requested for matters of clarification. To assist frank discussion, anonymity of the attendees was reinforced<sup>2</sup>. A standard discussion guide was produced for each recommendation (see Appendix 5).

The specific prompt for discussion of each draft recommendation was:

Given that the evidence suggests that a particular kind of intervention/activity has worked in the following circumstances, and that this should form the basis of a recommendation, what would need to be done to make it work in your local situation? A follow up prompt was If this would not work, why not – and what would?

Delegates were asked to identify the possible barriers or facilitators, to successfully implementing a suggested intervention/activity, solutions to these barriers, and implications of the intervention in terms of increasing equalities in health and social inclusion.

Overall, discussion focussed on three areas:

**1. Relevance of the draft recommendations**: What is the current practice of professionals working in the area? Are the recommendations appropriate for these professional groups? Is there evidence, from practice or other sources, that has not been considered in developing these recommendations?

**2. Usefulness**: How might these recommendations build on or change current practice and / or service provision? What are the implications of this? Are they accessible and clear? Are they appropriate to different client groups? Are they likely to be sustainable?

**3. Feasibility**: What are the barriers to / opportunities for implementation? What further resources, training or support might be needed to implement them? To which other

<sup>&</sup>lt;sup>2</sup> No identifying information is included in representative quotes but after agreement participants are acknowledged in Appendix 1

professional groups might they apply? How might the range of professional groups involved be reached?

To achieve this, the facilitators ensured that all delegates had the opportunity to contribute views on topics such as organisational, professional and other barriers to change; needs for workforce development; current organisational and management arrangements; patterns of funding and resourcing; existing statutory frameworks; key barriers to organisational change; key challenges of front line staff in everyday delivery; potential unintended consequences of the draft recommendation(s); and examples of local experiences and good practice.

## 2.2 Data Analysis – fieldwork meetings

For each meeting, group proceedings were digitally recorded and the data transcribed by a stenographer in the week following the meeting. Centre for Public Health researchers also noted emerging themes in groups to aid discussion between meetings. Qualitative data were coded from the transcripts using thematic categorisation within and between groups. The computer software system NVivo (v8, QSR International) was used to assist all qualitative analysis. As many attendees were employed in specialised professional roles it was agreed with attendees that in order to preserve anonymity representative quotes would not be attributed to role or location of the meeting.

A *directed approach* to analysis was undertaken (Hsieh and Shannon, 2005). This approach was chosen as the key concepts of the work (relevance; usefulness; feasibility) had already been identified. Operational definitions for each category were determined according to the NICE methods manual. Sub categories were also highlighted and relevant themes that could not be categorised under the coding were given a new code. Although work of this nature is subject to subjective interpretation by the researcher, the use of independent coding reduced sources of bias (Burla et al., 2008). Each recommendation was considered separately although general themes across recommendations also emerged. The set of general themes is discussed in section 4. Representative quotations, attributed to professional role, are given for each theme summary.

In brief, one researcher firstly read the transcripts and coded the general themes within the responses. Validity was enhanced by the expertise and knowledge of the research team in this field, and therefore items unrelated to the topic of investigation were excluded. Examples of thematic subcoding categories are given in Table 2, and detailed in Appendix 4.

Response	Thematic coding
Needle exchanges have a role in lobbying and informing, because they are often one of the few services in touch with people who are not in treatment or structured care	Usefulness of recommendation
We should set the bar high on what is provided, there isn't too much cost. Advice and information should also be included	Content of recommendation
There isn't much guidance on what are acceptable return rates, if we are providing bins and not getting them back in then where are they?	Barriers to implementation

Table 2 Examples of thematic coding used in thematic analysis of fieldwork transcripts

The key themes generated by this analysis and topics discussed at the meetings showed good concordance. A second, independent researcher repeated the above processes, checking and challenging the first coder's steps/outputs with the aim of enhancing the validity of the categorisation process and minimising any of the initial researcher's biases. Given the time frame for the study it was not possible to undertake a validity check on the emerging categories with each of the study's respondents. However, the report was circulated among the attendees of the meetings for feedback and comments to check for accuracy and to ensure that anonymity in quotes was upheld. Finally, each set of categories were then re-read by the initial researcher in relation to all of the responses received in order to confirm that the categories reflected the thematic content of the responses. After consensus was reached among the researchers regarding the results of this qualitative analysis (see Appendix 6 for example), the first draft of this fieldwork report was produced.

# 2.3 Semi structured interviews

Two individual semi-structured interviews were conducted in addition to the four fieldwork meetings. Twenty five individuals expressed an interest in taking part in interviews, but only two could allocate time during the fieldwork period. An interview schedule was developed in order to capture the opinions of professionals not in attendance at the fieldwork meetings but who wished to contribute to the consultation (Appendix 6).

The interview schedule was designed to ensure the data generated was directly comparable to that emerging from the fieldwork meetings. Data were analysed in the same way as the group transcripts, and the interview schedule was designed to explore specific elements of the content of the guidance, in a similar way to the group discussion. Hence, these results are presented alongside field meeting data.

## 2.4 Limitations of the methodology

The fieldwork methodology suffered from a number of limitations which, although not considered substantial, may have affected the results obtained and conclusions achieved. Some of the more pertinent limitations are mentioned here.

The major limitation of the work was related to sampling of delegates. Whilst the public health arguments supporting the provision of NSPs are strong, there is some objection on both scientific and moral grounds that NSPs discourage cessation of injecting and the range of additional services on offer (e.g. citric acid, safer injecting advice) may dissuade clients from becoming drug free. Whilst this does not seem to be a consensual view, it is valid, and held by several organisations and individuals. We weren't able to identify delegates who explicitly held these views and although discussions with delegates provoked great debate and a wide range of views were expressed, it remains that this type of view on some or all of the services NSPs offer was not fully expressed in the fieldmeetings.

We anticipated that in keeping with our previous fieldwork conducted for NICE (Sumnall et al., 2007) we would conduct at least 20 semi-structured interviews with individual professionals. Twenty five individuals who expressed interest in contributing to the fieldwork, but were unable to attend fieldmeetings were invited to take part. Unfortunately, only two individuals were available for interview during the NICE consultation period. Data from these two individuals were analysed independently and data was integrated into the overall results. Although the small number of interviews was disappointing, this data was originally intended to be supplementary and the fieldmeetings were considered to produce sufficiently rich data to compensate for the lack of interview participants.

Characteristics of injecting drug use (e.g. prevalence, health burden, social costs) are often locally determined, and these influence local needs. Although we cannot entirely preclude the possibility that the views expressed at the events were exclusive to localities, the regions chosen to host the meetings were selected on the basis of drug use prevalence, geographic and socioeconomic representativeness. This increased the representativeness of the areas. Furthermore, the analysis showed that there was concurrence between meetings on descriptions of typical local experiences.

The aims of the fieldwork phase were largely determined by the need to consult with professionals on the content, practice implications, and potential impact of the draft recommendations. Although the researchers analysed data independently of these aims, and identified themes accordingly, the final report was drafted to be of maximum utility to PHIAC, hence some areas of discussion, which were of interest to professionals, but not relevant to the overall aims of the fieldwork report, were omitted.

Finally, the qualitative methodology used to analyse data was straightforward. Directed thematic categorisation was chosen because it generated data in a relatively rapid manner, and it enabled comparison and contrasting of data from the group discussions and individual interviews. However, this approach meant that it was not possible to validate emerging themes with fieldwork participants/interviewees or retest themes within the wider research team.

## 3 Results

Results from interviews and field meetings are presented by recommendation, and each section is addressed sequentially. Where appropriate, results are presented under sub-themes in the context of the relevance, usefulness, and feasibility of the recommendation, but to ensure a clear narrative these themes are not presented as exclusive sections.

## **General Comments**

During the introductory speeches and presentations, meeting delegates were given the opportunity to make general comments on the guidance or to ask questions on topics which they believed the draft guidance did not adequately consider.

- Although acknowledging various barriers and facilitators, delegates welcomed NICE guidance on this topic which they believed would improve the quality of services for IDUs.
- Clarification was needed on how the NTA would respond to NICE guidance and what its obligations to deliver it were.
- Opinions were mixed on the title of the guidance. Some delegates welcomed reference to *Needle and Syringe Programmes* rather than *Needle Exchange*, as it recognised the philosophies behind the service, and that there was no expectation that clients would have to return used equipment. Conversely, other delegates preferred the term *Needle Exchange* as although not a service requirement, it made it easier to persuade service users to return their used or unwanted equipment. Supporters of this term also believed that it helped address public concerns about drug-related litter. Other delegates believed that both terms limited the description of typical NSP activities to solely providing needles and syringes, when they actually provided a variety of services.
- Delegates noted the lack of recommendations concerning prison based NSPs. They
  required clarification on 'NHS equivalent' services for prisoners, as there was the
  expectation that NHS services provided to the general population of IDUs would also
  be provided to prisoners with respect to quality and range.

## 3.1 Recommendation 1

## Consultation with the community

## Who should take action?

- Local strategic partnerships, local drug partnerships (including drug and alcohol action teams [DAATs]), drug joint commissioning managers and primary care trust (PCT) commissioners.
- Public health practitioners with a remit for substance misuse.

## What action should they take?

- Consult with people in the local community (including those who inject drugs) to help assess the need for and to plan needle and syringe programmes (NSPs).
- Provide local people with information about the purpose of the programme. Acknowledge and respond to any reservations they may have about such a service: for example, specify how any resulting drug-related litter will be dealt with.
  - The importance of *requirements for public consultation was recognised* by delegates; indeed, this was often a pre-requisite for new funding or sustained funding for expansion of services. The benefit of providing a service that was sensitive to local needs and concerns was clear, especially if local populations had been involved from an early stage. This also provided a *rare opportunity for the views and needs of Injecting Drug Users (IDUs) to be heard in the community*. However, in practice there had been mixed experience with these processes, and there was little standardisation in approach. Consultations had been dominated by vocal neighbourhood groups, and examples were provided whereby proposed schemes had to be abandoned because of local opposition:

"...lack of consultation is the reasons why it [i.e. establishment of service] didn't' work for one NSP that I know of. There is a stigma. For the next NSP that was established 120 people were consulted and it was well received. When consultation didn't take place it was not well received."

"In [...] we have had experience of trying to establish a needle exchange in one part of the borough, and had a lot of local objection. Ultimately, the residents' views mean that we could not go ahead, even though there was local need."

"I've stood up in meetings where we've had councillors say 'I don't know why you're calling these people service users, they are scum'. And you think right, that's interesting, the press are here but you're happy to say it. And so where you've got that sort of feeling already, that's where we've had to go out for consultation."

Where proposed schemes had continued despite strong local objections, projects had to spend time and resources reassuring local residents and organisations that certain fears were unfounded. The most common concerns from the public stemmed from the beliefs that NSPs promoted/sustained injecting drug use, and more general fears such as an increase in crime and drug related litter. A response to this was to redefine the consultation towards a public information initiative. This approach would often be implemented retrospectively, meaning that a new service would be introduced and then the public engagement would begin:

"...the history is that harm reduction services would never have been adopted throughout the country basically if the approach hadn't been softly, softly [...] whereby you just didn't tell people what you were doing, you went ahead and did it."

"NICE has included this recommendation to consult with people. Is that because there is evidence to say that, if you do not consult but just develop a programme in certain communities or geographical areas, you create bad feelings or programmes have to be withdrawn, or is this just a politically correct statement?"

"I think in essence, the idea of consulting with the community is absolutely right...but there has to be a caveat in that if there is a need for a service, consultation should be around how that service is provided, not will that service be provided or not."

 This '*information rather than consultation*' approach was believed to be justified because of the perception held by delegates that NSPs were effective and cost effective (for example, according to the NICE evidence reviews associated with this guidance) and therefore the public health arguments were greater than public concern:

"For all these health promotional programmes, if we have evidence of effectiveness, do we need widespread consultation with the public?"

 Describing the advantages and benefits of NSPs was seen as a way of alleviating local fears. By focusing on public health objectives or the potential cost savings arising, providers could persuade the community about the need for, and philosophy underlying NSPs. For example, by reducing sharing of injecting equipment and associated risk behaviours, NSPs could reduce the incidence of blood borne viruses and other harms in the local community. Extended pharmacy opening hours would benefit all populations, and so too would the presence of specialist nurses. In order to present this argument it was important that IDUs were seen as integral to, and part of, the local community. In many instances NSP clients would be the sons, daughter, brothers, and sisters of local community members. Projects were cited whereby community pharmacy counter staff were trained and assigned to explain the purpose of NSP to customers that visited the site of a new (pharmacy-based) programme. On other occasions members of the public in opposition to a new project would be invited to join steering groups in order to become involved in the long-term development of the service; however, delegates reported that such invitations were rarely accepted.

"When you talk to the community and they know your purpose it is ok. What they read in the papers is not right. They need to be informed correctly. They take it on board when they have the right information. People have misconceptions."

"I try to introduce myself to the community. I go to the church fete. People know who I am...I try to reduce people's fears when I talk to them...there is opposition and fears but It can be overcome."

- Other responses to the challenges raised by public consultation were proposed. One idea raised was to carefully consider the terminology used. Needle and syringe programmes, was thought to lack the suggestion of the personal responsibility of IDUs to return equipment (and thus reduce needle litter) that was carried with needle exchange. However, this terminology did not represent services' perspective that needle return was not expected. Harm reduction service or safer injecting service was also preferred as this presented NSPs as one of several health responses to drug use.
- Some public concerns were still considered legitimate though, and drug services (or DAATs) would have to take responsibility for responding to these. Delegates believed that NICE guidance should specify both the community and professional roles targetted in the consultation. This latter group would be an addition to the guidance but was pertinent for responding to drug related litter which would most often be co-coordinated by the local council, rather than drug services. As there is variation in the process of commissioning NSPs between PCTs and Local Authorities, a standard guide for consultation was not deemed useful as different procedures were in place. Police had often given informal consent to local projects, particularly with regards to the provision of injecting equipment other than needles and barrels

which are restricted under section 9a of the Misuse of Drugs Act<sup>3</sup>, but it was considered important for the legitimacy of the NSP in the local community that this should be formalised.

"Its about having the right people on board, before the wrong people start objecting, in terms of having the commissioners, the council, or in [...] for example, where we have the elected Mayor. If he is not on board nothing will be put through. After bringing the right people on board first, you can then go to the wider community, because you have champions, the statistics, and the evidence base. Then, unless you have a very good reason to object, you can say we are going ahead."

- The need for, and content of consultation was also determined by geography. One example was given of a small geographical area in a major city centre with very high density of IDUs where the decision for the siting of a new pharmacy based NSP was made on the basis of a suitable premise being available rather than the results of public consultation. Another notable example concerned rurality. Delegates believed that NSPs were more likely to produce opposition in rural areas where a fixed site would be more noticeable or where there was a lack of choice of pharmacy sites.
- Consulting with local IDUs was, in contrast to public consultation, considered vital to the success of NSPs. The needs of this group would necessitate establishment of the service (assessed through good quality needs assessment research), but its characteristics would be determined by client opinions and preferences. The process of consultation was expected to be difficult, especially where a NSP was being introduced into an area for the first time and where a research based approach would be needed, but consultation was thought to be particularly useful to determine characteristics of the service such as syringe pack sizes, location of sharps bins, and service opening hours (although this was frequently set by staff employment contracts and available funding). With a diverse range of cultures served by the NSPs, consultation would also allow consideration of differences in injecting practice. For example, one delegate discussed the high population of IDUs from Eastern Europe in his area and noted that their injecting technique was often different to indigenous injectors. Part of the consultation should also be used to establish user responsibilities with regards to use of the service. Although it was the right of IDUs to have access to NSPs, delegates thought that the community perception of the service was also partly the responsibility of clients and

<sup>&</sup>lt;sup>3</sup> This section of the Act controls supply of articles to be used for the preparation or consumption of illicit drugs, such as foil used for the purposes of smoking heroin or to construct crack pipes. Citric acid and sterile water for injection were made exempt from this section in 2003. However, water has to be provided in accordance with the Medicines Act, and so is only available in 2ml glass ampoules.

their behaviour (it should be noted that discarded drug related litter was thought by some delegates to be the fault of IDUs not in contact with NSPs, or from other neighbourhoods, although this was not a view shared by all). Local press was frequently mentioned as misreporting stories related to drugs and drug users, but service users had to be pragmatic and realise that until there was a wider shift in societal perceptions, their behaviour would always be closely examined

"Litter gives NSPs a bad name. But in the city centre IDUs may be homeless and there is no disposal. The press and public also have a negative view. We have a traffic light system of drug-related litter which takes into consideration the public health risk, displacement, the use of the area. We let the users know the repercussions of litter; like police enforcement. This will have a knock on effect. "

"The thing is, users hate it themselves and they want bins, but getting the council to agree is difficult."

"For consultation we have walked to sites of drug related litter with the [community] group, met with current injecting drug users, and involved them to get feedback on the practicalities of bin placement. This includes talking about where people are scoring and using."

"...we need multiagency working to get the community behind it and express that the number of needles on the street can be declined. That's how we also get the community behind it."

- Several barriers to user group consultation were identified. The most prominent
  was that many, if not the majority, of IDUs were not in contact with NSPs. A mixture
  of approaches was required in order to effectively consult with clients. Some
  delegates preferred that service staff (including pharmacy counter staff) received
  formal training in how to consult, others that an informal, outreach based approach
  using the skills of NSP workers or peers should be used. Examples were given of
  local projects such as the Interaction service run by Rochdale DAAT (and volunteers)
  which had reported success in reaching Asian drug users, a typically hard to reach
  group.
- Pharmacies were considered to be different to agency based NSPs as NSPs were an additional health service within the pharmacy mix and so was believed to receive less community opposition. Many (non-IDU) pharmacy users were believed to be often unaware that the NSP service was even provided. Delegates doubted the usefulness of raising the profile of IDU services in such circumstances. Of course NSP clients needed to be aware of the facility, through the use of window

NSP signs (green/red arrow logo) and information provided through local drug and health services and workers, but this did not have to be made. Of concern, was the view of service user representatives that opposition to NSPs sometimes came from pharmacy staff who would be responsible for delivering the service. Whilst the public health value of needle and syringe provision was acknowledged by these staff, delegates thought that moral objections might preclude provision of items such as paraphernalia and other injecting equipment. It was therefore essential that pharmacy staff were included in any public consultation or information exercise.

• Performance and image enhancing drug users were thought to be more likely to use pharmacy and outreach based services that other IDUs, but services for them had been, and should be, influenced though direct consultation.

"We have had an interest in PIEDs for some time, and have a robust scheme in [...] for that group of service users. Since then we have opened the drop in. It was based in gyms and through outreach, but now we have more and more people coming into the centre and accessing not only syringe exchange, but other services that we offer. If you go to those service user groups [i.e. for opiate using IDUs], those client groups are very rarely on them, they are not there."

### 3.2 Recommendation 2 Accessibility and distribution

### Who should take action?

- NSP providers (specialist drug services and retail pharmacies).
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.
- Public health practitioners with a remit for substance misuse.

### What action should they take?

- Commission a range of services to ensure needles and syringes are widely available and meet local need within the area covered by the local strategic partnership. This should include:
  - outlets that distribute needle and syringe packs (for example, pharmacies)
  - specialist NSPs that offer or refer people to, additional harm reduction services (for example, treatment for Hepatitis C) and other specialist services
  - needle and syringe disposal, in line with 'Tackling drug related litter' (Department for Environment, Food and Rural Affairs 2005).
- Use local data on disease prevalence (for example, hepatitis C), populations (for example, the number of sex workers, crack injectors and homeless people in an area) and geography (for example, whether it is an urban or rural location) to ensure there is a balance of services, based on local need. Services should include a mix of:
  - pharmacy-based distributors and specialist NSPs within the PCT/local strategic partnership area, and
  - generic and targeted services (the latter should meet the needs of particular groups, such as people who are homeless).
- Ensure specialist drug services that offer opiate substitution therapy also distribute needles and syringes.
- Coordinate the provision of needle and syringe programmes to ensure a service is available for a significant period of time during any 24-hour period. As an example, PCTs could ensure that needle and syringe services form part of the 'necessary enhanced services' offered by '100–hour' pharmacies.
- Ensure people who use NSPs are provided with sharps bins and advice on how to dispose of needles and syringes safely.

- Ensure plans are in place to deal with any drug-related litter that may result from extending the opening times and locations of NSPs.
- Audit and monitor services to ensure they meet the needs of people who inject drugs.
- Consider providing and evaluating schemes to distribute needles and syringes:
  - via vending machines, mobile vans and non-pharmacy outlets (for example in sports venues for PIED users).
  - to people who have left prison and who are injecting drugs.
  - There was general consensus that there was already a good range of services available that provided needles and syringes to local populations. The examples of the types of service that should be offered that were included in point 1 of the recommendation were well represented locally. Where some current services were believed to fail was in attracting and retaining different populations of IDU (particularly those who were homeless, or injectors of drugs such as PIEDs); working closely with a range of health and drug providers; or providing services that were 'widely available' and met 'local need' (as per the wording of the recommendation). This latter point was largely believed to be a result of a lack of understanding of levels of local coverage. Delegates did not believe that NICE's decision to leave 'coverage' undefined in the draft guidance text was helpful:

"What needs to happen is that the committee drafting this needs to define a public health definition of coverage in terms of reducing infection spread and other points that needle exchanges are supposed to do. Ideally they need to include a target of what coverage to achieve in each local area, the most important being what proportion of injections occurring in that area should be done with the person having a fresh needle and syringe available to them."

 Local NSPs had targets set by commissioners for the number of equipment returns (for example 70%), but delegates stated that they had not been given equivalent targets for coverage, which they believed was of greater importance. This was believed to not only be a result of the introduction of easily measurable performance-based targets, but the difficulties in estimating local coverage, which depended on accurate estimation of the number of local IDUs (including non-NSP attendees) and a thorough understanding of injection patterns and behaviours.

"I would not know how to start estimating the percentage of injections covered by sterile needles and syringes. You have a mixture of people coming in who are injecting once a week, or once a fortnight when they receive their money, and people who inject eight times in one day for example...From a harm reduction point of view, our main outcome is knowing that everyone who wants to access the service is going away with a sterile needle"

 In practice this meant that many services provided as much injecting equipment as requested, without the expectation of returns. This had led some NSPs to miss their 'returns' targets.

"The remit of this group is to look at optimal provision...what is optimal here is that this is a public health intervention, so it has to be on a large scale; you have to flood an area...The baseline is to ensure the equipment is available, and then beyond that to ensure it is used by making it available at the right times, in the right places, and by motivating people to use it. There is no use doing all of that unless the equipment itself is available."

- A wide variety of locations were mentioned that could provide low level NSP services, such as making needle packs available. It was suggested that an essential component of all drugs workers' training should be injecting equipment exchange. Although controversial, it was suggested that street level drug dealers should be provided with needle packs to distribute with a drugs purchase. Some DAATs specified that any service potentially in contact with IDUs should have access to injecting equipment (e.g. police custody suites, A&E). These types of approaches had met resistance from both providers and service staff. Staff in particular felt uncomfortable about leaving packs in locations where drug service support and advice on safer injecting was unavailable, although one solution to this problem was proving harm reduction information and lists of local services alongside packs. Some police forces were noted as being resistant to this type of approach. The justification provided was that when an IDU had been arrested, injecting equipment and drugs would be confiscated. Officers would subsequently not allow injecting equipment into the custody suite, and so despite the presence of on-site arrest referral workers, arrestees would often leave the police station without clean injecting equipment.
- The majority of delegates used epidemiological data in planning, commissioning and delivering work but believed that the collection and dissemination of *local data* in particular would need to be improved if recommendation 2 was to be achieved. The Health Protection Agency's (HPA) Unlinked Anonymous Survey of HIV and Hepatitis in IDUs aims to measure the changing prevalence of HIV and other BBVs in current and former IDUs who are in contact with specialist drug agencies (e.g. NSPs and treatment centres). Whilst data like these provides disease prevalence information, it

is not sensitive enough to allow local geographical analysis below PCT level or analysis by specific populations (e.g. PIED users, IDU sex workers). In its current reporting format, data are only provided to the general reader by region (e.g. North West), and so DAATs would need to act as mediators to ensure local services are kept notified and respond to pertinent trends<sup>4</sup>.

Drug service and NSP workers also valued anecdotal information from drug using clients. This provided a 'street' perspective on epidemiological data and insights into the nature of the local drug market. For example, emerging and changing trends in drug administration routes, local increases in prevalence of particular drugs that were not captured in statutory data collection, or drug batches (particularly heroin) that were believed to be of greater purity than those usually available. Interventions and advice provided could be adapted accordingly:

"AAS [anabolic-androgenic steroids] users are not in the data though so more work needs to be done in this area."

- It was believed that there was *less of a problem accessing and using data that estimated the size of drug using populations*, and a number of sources were available (e.g. police, Home Office, PCT data, intelligence systems such as the Inter Agency Database in Merseyside)
- Delegates requested that NICE issued stronger guidance on auditing and monitoring of services so that it was conducted in a systematic and consistent manner. Clear objectives of this work needed to be stated. DAATs and PCTs would require this information for commissioning of services, performance management, and policy targets, but NSPs need to be assured that the process would also derive benefits for the organisation and its clients. Examples of ongoing informal data collection schemes conducted with NSP clients were presented, and although provided good information on preference and need, were rarely conducted in a systematic or research based way. It was believed that monitoring would be easier in pharmacies because of the more limited range of services provided. In pharmacies a 'tick box' approach (e.g. client satisfaction survey) might be used, but this would not suffice for agency based NSPs which provided a greater wealth of services and were often allied to drug treatment. It was believed by some delegates that not all NSPs viewed data collection for auditing or monitoring as important, and there were general concerns over data quality, confidentiality and the burden of extra work that development of monitoring would require.

<sup>&</sup>lt;sup>4</sup> Commissioning templates are available through the HPA for PCTs, e.g. <u>http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\_C/1195733744529</u>

"We have always collected it [i.e. auditing and monitoring data]. We feedback to the DAAT to make a case, and we find that mostly the DAAT are open to suggestions."

"Lots of it is collected as paperwork but we need trends. We need the correct tools if we are required to collect data."

"I get funds according to activity. More detailed data exists...Service users can give limited information but if you get them to return they can give you more."

One proposed model was based on auditing introduced at community GP surgeries:

"Rather like GPs have to have patient surveys every six months, which are scrutinized by the PCT, there needs to be some quality assurance with the service [i.e. NSP] across the board, so that it is not done on a whim but nationally."

Another model combined the process of exchange with client feedback:

"The two or three questions we asked were in conjunction with users. Each pharmacy was given 20 or 30 of these little cards. The idea was that, after you handed out the needle exchange pack, you were given one of these little cards and tried to encourage them to complete it and deposit it in a little box in the pharmacy, in an anonymous manner."

 One of the perceived advantages of pharmacy based NSPs was that clients do not have to engage with staff if they do not wish to; they are able to access injecting equipment and then leave. The requirements of monitoring may disrupt this type of service use, and so pharmacy staff would require careful training to ensure that whilst the importance of monitoring was explained to service users, it did not interfere with the convenient and quasi-anonymous nature of the rapid exchange.

"We have been trying to combine it [i.e. improved pharmacy NSP monitoring] with the quality and assurance tick box for pharmacies. On the back is a barriers to treatment tick box. We did not know whether or not we would get any responses. We didn't receive a huge number of responses, but we did receive some"

 In April 2008 the NTA introduced the Needle Exchange Monitoring System (NEXMS), which is designed to collect data on the number and type of NSP in each DAAT, the number of needles and syringes distributed and returned, and provide estimates on the number of clients, and the proportion of those in contact with structured drug treatment. If implemented as planned this system would improve monitoring of local need and performance of NSPs, which for the latter element delegates believed was less than optimal, particularly at pharmacies. *Some service workers and managers had negative perceptions of the value and utility of drug treatment monitoring systems such as NDTMS<sup>5</sup> and this view was extended to NEXMS.* Apart from a general unease, specific criticisms about NEXMS were not forthcoming in the field meetings, but individual interviewees elaborated. The system was believed to have been rushed into operation after the disappointing findings of the NTA Needle Exchange 2005 Survey, and without adequate piloting, user consultation and training. Data quality was believed to be low despite the extra time investment needed by NSPs to enter data.

Discussion of the co-provision of opiate substitution therapy with NSPs focused on the implications of this approach for treatment compliance and client confidentiality. User group representatives, supported by pharmacy co-ordinators, reported that in their experience service users often had difficulty in obtaining injecting equipment and OST (typically methadone) in the same pharmacy, as not all businesses offered the combination. Service users preferred separate provision as they were worried that their key drugs worker would find out they were still injecting, in contradiction of agreed treatment plans and goals. One result of this was the fear that OST prescriptions might be withdrawn. However, both NSP providers and drugs workers reported that they prioritised harm reduction and so would not act to withdraw methadone prescriptions if evidence of continued injecting arose. It was acknowledged though that this was a view that was not consistently held across the field, particularly if practitioners (both drugs workers and NSP staff) prioritised drug free status or abstention rather than controlled use.

"DIP [Drug Interventions Project] is next door to us. People panic as there is the chance that someone will see them coming through the door [of the NSP]. I tell them to say they are coming in for condoms. They fear that prescribing services will find out. People are scared of being taken off their [methadone] script."

The recommendation of ensuring significant access to services during a 24 hour period produced useful debate. 100-hour pharmacies were thought to provide one suitable option (perhaps with the addition of an on-site drugs worker), as they were valued by the general public, but the majority of delegates agreed that twenty four hour opening of services was not needed, or indeed economically feasible. It was believed that extended opening hours would not necessarily increase service use, but

<sup>&</sup>lt;sup>5</sup> National Drug Treatment Monitoring System (NDTMS)

referring to discussions on services needing to be sensitive to differences in IDUs lifestyles (see below), times of access would change. Furthermore, some delegates argued that the overall objective of this point (i.e. increasing access and availability of NSP provision) was more important that specifying which type of organisation (i.e. 100-hour pharmacy) should deliver it. The strength of pharmacies providing NSP services were highlighted here, in that despite often not offering additional services to IDUs, they offered the convenience of extended opening hours and being located in the most populated areas of the community. It was unrealistic to expect other pharmacies not licensed for 100 hours to extend their opening hours, though:

"It might put pharmacies off, if they are deciding whether or not to participate in the programme, when they have to open and close late. If we know that most service users want to use it during normal opening hours, as the rest of the population uses their pharmacies, which would not be an issue."

"...What is stated is one possible way of doing it, but in another area it might be secondary exchange, peer exchange. It might be A&E in another area."

"Clarifying the vision of 'widely available' is necessary, as well as the objective we should be aiming for, which is when you are thinking of injecting, you should almost be able to reach out your hand and grab a fresh syringe."

- The disposal of drug related litter was primarily thought to be the responsibility of the local council's/authority's Environmental Services departments and systems of disposal were already in place (for example specialist cleaning services in known public injection sites, and community telephone lines). Not all councils were thought to implement 'Tackling Drug Related Litter' fully, especially where litter was located on private property, or where owners were usually charged for disposal or expected to dispose of equipment themselves. Anecdotally, delegates reported that some private landowners were aggrieved that it was their responsibility, and not the council's, to design and implement responses to litter if they did not wish to pay repeat disposal charges. There was also the belief that telephone hotlines were underused as the public were not aware of them. This led to fears that members of the public would try and dispose of discarded equipment themselves, without being in possession of the necessary safety equipment. Delegates agreed that guidance on promoting strong local agreements would maximize success of this element of the recommendation.
- As discussed in Recommendation 1 above, NSPs worked closely with IDUs to ensure that personal responsibility for the safe disposal of injecting equipment was

understood. Even those IDUs who stated that they didn't want a sharps bin were provided with one, so that they could pass it onto other IDUs. These were often marked with the NSPs logo in order to track travel in the community, and if disposed of inappropriately efforts could be increased to educate clients. Delegates believed that drug-related litter should be defined, as it was not limited to needles and syringe barrels, but also included packaging, mixing equipment (e.g. stericups, spoons), and swabs. NSP clients should also be persuaded to include these items in sharps bins in order to decrease litter. Despite some examples of initial local objections, new schemes increasing the provision of public needle disposal bins were largely successful. The challenge for project managers was to ensure that they had sufficient local intelligence to ensure that public bins were located in the optimal locations for populations such as the homeless or sex workers. Example locations for the placement of bins included public toilets, parks, waste ground, and car parks, although these would need to be updated in response to changes in IDU behaviour.

"...we were trying to put sharps bins in public places. For years we went back and forth on it, with comments like 'we do not want them, because they encourage everyone'. However, we managed to put some in [...], in the public lavatories, which worked fantastically well straight away, apart from the bins being too small; they were stuffed full of syringes. People saw the impact immediately, and now the local councils are approaching us..."

"Most drugs litter is about wrapping, tins and equipment other than used sharps. Actual used sharps is quite a low proportion of drugs litter. People, when they understand that, are always very surprised by the low proportion of used syringes."

- Delegates did not agree that increased opening hours would necessarily lead to increased drug related litter. Clarification of the evidence supporting this statement was requested.
- All types of NSP needed to be sensitive to the often chaotic lifestyles of some clients. Assessment of peak utility through informal monitoring was often the first step in deciding the busiest hours of client demand. The lack of provision available on Sundays was seen as a particular problem. Some boroughs, even in big cities, had low pharmacy provision on Sundays, which meant that IDUs could have to travel several miles to access clean equipment. Even IDUs who frequently practiced safe injection may on occasion adopt unsafe practices if there was an unexpected change in drug use circumstances. In such instances, the convenience of reusing injecting equipment was acknowledged:

"In [...] we have one significant area where we know there is high drug prevalence and has no needle exchange, GP or health service provision at all. It also has low pharmacy provision, so if you lived in that area, on a Sunday, you would have to travel three or four miles, which is far in a London borough."

"...people we were talking to...they were conscientious for 10 months of the year, even up to an hour before they ran out [of clean equipment], but they weren't organized sufficiently to know that they were going to run out...They knew they had a couple of needles there and it was going to last them till the next day...but someone came round, they had some gear and they used it and they run out [of sterile equipment] but want to carry on using."

Demand was also determined by the client profile. For example, sex workers, or employed IDUs would need the exchange at different times than the unemployed. One delegate reported that the international evidence suggested that extending opening hours did not lead to an increase in drug litter.

- The *injecting behaviour of anabolic steroid users was considered to be different to other IDUs*. These users would typically plan injecting cycles several weeks in advance and would have specific regimens that would be rigorously followed. The priority with this population was to ensure that specialist safer injecting advice and opportunistic intervention was available on the infrequent occasions that they would attend NSPs.
- By ensuring that a range of resources providing needles were available in multiple locations, IDUs would have quick and easy access to equipment at whatever time it was needed:

"...via pharmacies, outreach, A&E, walk-in centres, custody suites, children's centres, large work places, vans, vending machines, I could go on."

"...we have a night bus at pub closing times that deals with minor injuries and also provides needle exchange."

However, at the present time there was perceived to be an *inequality in service provision* across geographies, and this was perceived to be worse in rural locations. Furthermore, local examples of extended services that were rarely used were given (e.g NSP open on Sundays, A&E provision), which emphasized the need for prior client consultation before starting a new piece of work, and effective advertising once it was operational. It was also acknowledged that this approach would, in part,

contradict recommendation 3 which states that needles and syringes should only be made available in venues where safer injecting advice and information is available. It was unrealistic to expect the provision of personalised advice out of hours in many locations, as the staffing costs would be prohibitive. If at a minimum the advice provided could comprise harm reduction leaflets, or information cards providing contact details for local services, then delegates believed that this problem could be overcome.

Service staff were, in principal, supportive of vending machines, particularly as an out-of-hours resource, but believed that their use required further research. Others were unsure of the existing evidence supporting their use, and whilst there was evidence suggesting a need, commissioners in particular would request to see evidence of effectiveness before introduction. Again, drugs workers were concerned that easy access via vending machines would mean that they could not provide the specialist (harm reduction) advice that some IDUs needed. A small number of examples were given where attempts had been made to introduce vending machines locally. There was often opposition from councilors and local residents towards these schemes and the security of machines had to be carefully thought out. Responses that were perceived to have worked well incorporated the use of security PIN codes or access cards available from NSPs. PINs would have the additional benefit of providing services with an indication of who had used the machine and what types of equipment they were taking. Machine placement would always have to be on the basis of local need, and delegates preferred that they were near to specialist services. Some delegates wished to limit the access to vending machines by young people (aged under 18), citing NTA guidance which specified that they should only be provided with a few days worth of equipment in order to encourage repeated visits to NSPs. An anticipated public concern was the security of machines, and the potential for unauthorized access to needles by young people, and drug-related litter.

"At the moment I know a lot of people like the idea of vending machines, but pushing that through the borough councils is quite difficult. We would like that to help with out-of-hours coverage, but, although we have a good set up, it is an area that needs to be improved and we will struggle. It will be a blanket 'no' at the moment."

• Delegates believed that the wording of the final statement in this draft recommendation was unclear, and needed to be stronger. Rather than referring to people who have left prison it should target people who are leaving prison (i.e. being released from custody), as the former statement would include all ex-prisoners regardless of the elapsed time since last custody. It was the view that all prisoners who were drug users (or even those that were 'drug free') should be provided with

needle and syringe packs on their release as part of a wider body of harm reduction resources and information materials. This was especially important for those prisoners who were released on a Friday afternoon and who would potentially have no access to drug services/NSPs until the following week. Another suggestion proposed was that advice provided to ex-prisoners should promote the smoking of opiates rather than injection if use was going to occur (as prisoners' tolerance to opiates would be reduced after a prison stay).

*"If people are leaving custody looking to use drugs, if they are definitely going to score before 10PM, can we not just give them a pack?"* 

"We have a resettlement worker who is engaged with all the prisons, and will make appointments with people when they come out. You could expect to pick up a need from that route, because they then have access to needles."

"One of the things on that note that we felt would be a good response hasn't quite happened yet, but a response towards reducing drug related deaths from people leaving prisons. That might be one of the appropriate places to provide foil rather than injecting equipment in trying to get them if they are going to use, to smoke, rather than inject."

"... just feels a bit almost quite a difficult area to introduce injecting to a group that have often moved from injecting to smoking in prison and then back into injecting when they're leaving prison, exposing them to a high risk of overdose."

"As well as overdoses, we use it [foil] when people are coming to see us after leaving prison. Often people want to take pins [needles] alongside the foil, but at least you have spoken to people about it."

### 3.3 Recommendation 3

### Accessibility and distribution

### Who should take action?

• Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

### What action should they take?

- Do not restrict the number of syringes/packs an injecting drug user can receive at any one time (within reason).
- Ensure syringes and needles are available in a range of sizes in locations sited across the area covered by the local strategic partnership. (They should only be provided in venues where safer injecting advice and information is available). In addition, other legally permitted injecting equipment associated with illicit drugs should be made available. (This includes, for example, filters, mixing containers and sterile water.)
- Ensure syringe identification schemes (involving, for example, the use of coloured syringes) are available. Encourage people who inject drugs to use easily identifiable syringes to prevent their injecting equipment inadvertently getting mixed up with someone else's.
- Delegates requested that PHIAC consider an alternative title for this recommendation to avoid confusion with recommendation 2.
- Allowing unrestricted distribution of syringes/packs and associated injecting equipment without the expectation of return (although this was encouraged) was the norm for most NSPs, in the belief that it promoted harm reduction. Indeed, no example was provided of personal experience of a service where this was not case. However, delegates believed that this recommendation was still important as it would *promote consistency across NSPs*. Examples were given (mostly of pharmacies) where it was believed that staff would only give out one syringe pack per visit, or insisted on exchange.

"You have people needing injecting equipment; they should have it. Ideally they would exchange, but the priority is to put clean equipment out there. We encourage people to bring it back and provide them with equipment to do that...people on the streets might only take two or three at a time, but will come in every day and put their used ones back in the bin"

"I hear that the pharmacy exchanges will give a pack per person per visit. We have even heard of people being refused packs because they had not brought any returns" However, NSPs would still encourage workers to discuss injection issues with clients and raise queries if large numbers of packs might be taken away. Furthermore, delegates emphasised that injecting equipment and paraphernalia should not be distributed without accompanying advice, and so there would be a large training demand, particularly for pharmacy assistants. Although restrictions were not applied, workers encouraged clients to make repeated visits so that further advice could be given, and if appropriate, interventions offered. This was considered important if it was suspected that secondary exchange of needles was occurring:

"If they ask for five or six packs at one time, try to have a conversation with the service user to say, 'Look, if you are collecting on another person's behalf, it is better for that person to come in..."

"You would want the pharmacist or whoever is supplying that [i.e. paraphernalia] to have some understanding of how it was being used. You do not want them to be distributing stuff, when they do not know how it would be used, in case they are asked questions by the service user."

The 'within reason' clause was acceptable to some delegates as it accommodated the discretion of those providing the service. However, to ensure consistency, others thought that the amount should be clearly defined as some workers had received very large requests for equipment in the past which reduced their ability to address health needs (as this would result in fewer service visits by the client). It was suggested that the wording should also reflect equipment limitations based on assessments of individual need, although this would only be appropriate for trained workers, which would exclude most pharmacy counter staff.

"It's not a condition at all [one for one exchange] but its purely to try and encourage people to come in and see us so that they've got specialists there or people who are able to help with the consequences of injecting."

One client group that was thought to benefit from some restriction of supplies was young people. Although agency based NSP workers would never give out too little equipment to force a return visit to the service, they were sometimes hesitant about providing unlimited amounts as it would mean that there would be large gaps before they encountered the young person again.

"...if you look at young people under 18 and the NTA guidelines, actually you can't give out more than three days worth, or you're not supposed to give out three days worth. So I think if we're going to put something like this in the guidance, we need to clarify exactly who that relates to and how, and whether it's across the board or whether it's different for young people, and how that's actually going to work."

- As outlined in the discussion of Recommendation 1, because of legal restrictions, some NSPs had experienced difficulties when providing sterile water that was not in 2ml glass ampoules. One manager reported that his organisation was threatened with prosecution by the Medicines and Healthcare Products Regulatory Agency for not complying with this requirement.
- Some delegates were concerned that the wording of the recommendation specified that only legally permitted injecting equipment associated with illegal drugs should be made available. Whilst it was appreciated that NICE should not condone breaches of the Misuse of Drugs Act, NSPs thought that provision of foil was an important part of their work. Whilst not strictly classed as 'injecting equipment', workers issued foil to encourage users to take a break from injecting or encourage a permanent change in administration route. By drawing attention to the legal status of some types of paraphernalia, delegates were concerned that the tacit approval that some had received from the police for use of foil would be removed.
- The term 'packs' was also thought to be too specific, or should at the very least be defined in the document. Delegates agreed that it was *important to offer a choice of syringes and needles* as individual need and preference would depend on the history of injection, route of injection, and drug injected. For the second variable, for example, it was noted that intragroin injectors would require longer needles. Offering a choice of equipment was seen as a good way of attracting users who were not already in contact with services.

"We do not give out packs; we only provide what the person specifies rather than a pack of goodies."

"Providing a range will attract users that may not already use the service such as young people, steroid users, and users of Melanotan<sup>6</sup>...we had six girls come to our service last week who were injecting Melanotan."

'Pick and Mix' approaches were highly regarded for use in both pharmacies and agency based NSPs. These types of schemes allow clients to specify on a standardised form the size and number of syringes/needles required. This was believed to reduced wastage (and subsequently drug-related litter), ensured that the equipment was tailored to the individual's administration needs, and allowed time for conveying brief advice whilst the order was being filled. It was appreciated though that some organisations, particularly

<sup>&</sup>lt;sup>6</sup> Injectable hormone shown to induce skin tanning in some studies

pharmacy based NSPs, did not have the stock room space to hold a wide variety of equipment sizes, or the staff time to fulfill individualised requests in the busy commercial environment. However, time spent fulfilling any client requests provided a good opportunity to give brief advice.

"The ideal would be pick and mix, but there might be time constraints to making that up in pharmacists."

"We used to do packs, and still do them through pharmacies. The main reasons we changed to pick and mix is to slow people down when they come in. if you spend 25 seconds putting stuff together you can say 'How are you?"

- Delegates briefly discussed whether 'information and advice', as included in point 2 of the recommendation, were the same. Only trained specialists could offer advice about safer injecting, but any NSP staff member could provide information (e.g. leaflets). As noted in the discussion of recommendation 2, there seemed to be a contradiction in the recommendations, as this point stated that equipment should only be available in locations where advice and information was available, whereas the previous focussed on increased availability, regardless of support offered. Delegates wanted this point to be clarified in the final guidance. Finally, delegates also wanted this recommendation to reflect that clients should be instructed about the risk of also sharing paraphernalia, and not just needles/syringes. Distributing information leaflets alone was considered insufficient as many IDUs would have problems with literacy and comprehension of written instructions. As the majority of NSP provision lay in pharmacies, where specialist advice might not be available, it was considered appropriate that these venues provided a range of resources, including posters, DVDs and audio instructions.
- The sub section about syringe identification schemes prompted a variety of responses. Although delegates were in favour of identification strategies in general, particularly for those injectors living in shared accommodation or in a relationship, and reported that a lot of clients viewed the use of coloured syringes favourably, there were still other concerns. Importantly, distribution of this type of equipment needed to be accompanied by advice on other safer injecting practices in order to counteract false assurances that simply the provision of syringe identification would be sufficient to reduce the risks of sharing. Other delegates were more circumspect. It was believed that although identification schemes worked well with less 'chaotic' or more 'organised' IDUs, equipment that might be perceived to promote reuse (by 'chaotic' injectors) should avoided. Although reuse does occur it is important that clients were taught how to reuse more safely (i.e. cleaning and sterilising own equipment), and identification systems might be useful in this context. Other problems were cited with this type of equipment. Some IDUs were reported to

believe coloured syringes were of poorer quality and NSP managers thought they were more expensive than regular equipment<sup>7</sup>. Drugs workers were concerned that intoxication led some injectors to forget what colour their equipment was, and there was the risk that supporters of particular football teams would select syringes in their team's colour. Some delegates thought that unless carefully worded this recommendation would also promote the business of particular equipment suppliers. Overall, delegates believed that the content of this section of the recommendation should be broader and that *PHIAC should consider providing examples of a range of schemes and equipment that aimed to reduce sharing, and not just limit the example provided to coloured syringes*.

"When you're faced [intoxicated] and the lighting's not very good, how well can you tell if that's pink or orange."

"...or if two people bring orange into the room."

### 3.4 Recommendation 4 Pharmacy-based NSPs

### Who should take action?

- Retail pharmacies that run an NSP.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

### What action should they take?

- Commissioners should ensure a range of pharmacy-based NSP services is available including:
  - distribution of needle and syringe packs
  - distribution plus harm minimisation advice and information
  - distribution plus harm minimisation advice and referral to specialist services.
- Pharmacies and commissioners should ensure staff who dispense needles, syringes or packs receive appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion, to respect the privacy of people who inject drugs and to treat them in a non-stigmatising way. Staff in pharmacies that provide more than just needle and syringe packs should be trained to provide health promotion advice, in particular, on how to minimise the harm caused by injecting.
- Pharmacy staff should be able to provide information about agencies offering further support to people who inject drugs (this includes details about local DAAT services).

<sup>&</sup>lt;sup>7</sup> It should be noted that colour identification syringes are provided at the same price as

- With regards to content and wording of the recommendation, delegates wanted *reference to packs removed at higher tiers* (to encourage tailored equipment provision as discussed in recommendation 3) and the inclusion of harm reduction materials and paraphernalia.
- Delegates supported the proposed tiered structure of pharmacy provision, and provided local practice examples, although many questioned how this structure was derived. Commissioners for rural areas in particular valued the services that pharmacies offered as they would not otherwise be able to provide adequate coverage for their IDU population.

"You've got to be realistic...some pharmacists will give out a fantastic treatment. They will go to every training course that's going; they'll have lots of people using their service because they are well liked within the drug using population. Then you'll have others who are not so keen but because they're in the right location, you have to use them."

"I think some of the relationships between the service users and pharmacists is really positive and they have a much closer relationship. They often know each other much better because they're seeing each other far more frequently...especially if they go on supervised methadone as well."

"[...] recently started that type of thing only we've only got two tiers at the moment, but we are aspiring to the third tier. So we have the packs only, the pick and mix with the information and advice, and then the third level would be the additional tag-on of more specialist advice and Hep B Vaccinations and that sort of thing. Now obviously that's got financial implications, that third bit, because they'd want to get paid more for that...We're still negotiating on finance but its something we're aspiring to."

Delegates believed that even those pharmacy staff that would work at the lowest proposed tier (distributing needles and syringes) would still require specific training (and associated resources) on the principals of NSP and harm reduction. Clients would also often pose informal questions they were unable to answer, such as correct needle sizes for particularly sized barrels. This uncertainty extended to their knowledge of the range of specialist services available locally. In addition, it was believed that there was a high turnover of pharmacy counter assistant staff<sup>8</sup>, and so

regular equipment by some suppliers.

<sup>&</sup>lt;sup>8</sup> Although as Schafheutle et al (2008) discuss, pharmacy support staff report a median of 1-5 years experience in their current post, and > 10 years in total [Schafheutle EI, Samuels T, Hassell K (2008) Support staff in community pharmacy: who are they and what do they want? International Journal of Pharmacy Practice16: 57-63]

training should be on offer throughout the year, or local champions appointed to disseminate best practice.

"It is the responsibility of us as commissioners of the service [i.e. pharmacy NSP] to ensure we are giving them all the relevant information and signposting."

"You need to have the opportunity when the service user turns up wanting to seek some advice to be treated through the pharmacy. The staff need to be trained to be able to deal with that added value service. I feel very strongly about that."

"...we're not actually saying that all pharmacy staff should have to make any kind of judgement about the quality of [external drug] services what's an appropriate service, but simply that they should have the information about what services there are."

"It's an ethical responsibility for the pharmacists to be giving out good advice with what they're selling or giving away."

Other delegates argued that *if pharmacies were only going to offer exchange then this was a service that could be done by vending machines instead.* Pharmacy staff often requested good quality training but this was not always provided, especially if they worked for a chain which developed their own training programmes. Pharmacy counter staff and dispensers should also be made aware of basic safer injecting practice, through standardised and quality assured training. Harm reduction training could be included in pharmacists' Continuing Professional Development provided by PCTs and the national Centre for Postgraduate Pharmacy Education (CPPE); local pharmaceutical committees and Harmonisation of Accreditation Groups (HAG) were proposed as one means of co-ordinating this in partnership with DAATs, and providing the necessary quality standards. It was important that the quality of counter assistant and technical staff training was also assured by similar bodies.

*"If the only level of service they are going to give is at the same level as a vending machine that is rather disappointing. There has to be an opportunity for interaction with a service user."* 

"In my mind, the minimum should be distribution and referral onwards. As a bare minimum, it should be transaction and signposting."

"We've only ever done evening stuff but it's still difficult to get the counter staff along. Because the pharmacists have to attend a certain number of training events...But then actually getting 'real' people there, because it's fine getting the pharmacist there, they tick the box and that goes towards their accreditation. But actually getting the other staff there is quite difficult."

 It was believed that although many pharmacists would *like to offer a more* specialised service, commercial pressures and client confidentiality sensitivities meant they were often unable to. In addition, as commercial organisations pharmacies could only be expected to deliver the services they had been contracted to.

"...there is the added pressure of being in a shop setting, where Mrs Jones is waiting for her antibiotics next to them [i.e. NSP clients]. It feels like they are almost compromising that process' anonymity. They would rather do a quick transaction and say 'There are leaflets about our service available. Have you spoken to these guys? Did you know they existed?'. It seems that is where they are more comfortable, not giving advice but just: transaction, onward referral or signposting."

 Delegates believed that whilst it was important to note that most pharmacy staff had good attitudes towards NSP clients, and despite the risk of offending staff, induction training should include advice on respect and confidentiality as stated in the recommendation. Service evaluations should incorporate an assessment of pharmacy staff attitudes to NSP clients and opinions of illegal drug use, as this might influence service utility and outcomes.

### 3.5 Recommendation 5 Agency-based NSPs

### Who should take action?

- NSPs based within a specialist drug service.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

### What action should they take?

- Ensure a selection of individual needles, syringes and other injecting equipment is available (in addition to pre-prepared needle and syringe packs).
- Ensure NSPs based within a specialist drug service offer comprehensive harm reduction services, including advice on safer injecting practices, assessment and treatment of injection-site infections and help to stop injecting drugs.
- Ensure NSPs based within a specialist drug service provide access to:
  - hepatitis B vaccinations and boosters
  - testing for hepatitis B, hepatitis C and HIV
  - opiate substitution therapy
  - primary care services (including dental care and general health promotion advice)
  - secondary care services (for example, for Hepatitis C and HIV treatment)
  - welfare services, for example housing and legal advice.
- Commissioners should ensure people who inject drugs receive integrated care for all their health needs.
  - **Delegates discussed the first point of this recommendation** (Ensure a selection of individual needles, syringes and other injecting equipment is available (in addition to pre-prepared needle and syringe packs)) **in section 3.3**.
  - Delegates suggested a change in wording for action point 2. Although recognised as standalone organisations, to emphasise the importance of NSPs in the spectrum of services offered by drug treatment, the wording should be changed to "Ensure NSPs, as part of specialist drug services..."
  - Delegates suggested a change in wording for action point 2. The support required to persuade IDUs to stop injecting was considered specialised and difficult to achieve. Although foil was not specifically mentioned in the recommendations, there was an understanding that many NSPs distributed this as a means to reduce the number of injections, although there was no

expectation that injecting would cease altogether. Delegates therefore preferred "alternatives to injecting" compared to "help to stop injecting drugs"

It was unclear to delegates what the final point of this recommendation meant (Commissioners should ensure people who inject drugs receive integrated care for all their health needs). When asked to define 'integrated care', there were few suggestions. It was interpreted to mean 'holistic care', meaning that drug services would either provide or refer to specialist health provision. Commissioners were unsure whether they had to ensure all services were available and attached to NSPs, or only that good referral systems were in place. With regards to IDUs, this not only included the provision of services outlined in action points 2 and 3 of the recommendation, but also particular items and interventions related to wound care (which would require a specialised nurse to be on-site), sexual health (e.g. distribution of free condoms), smoking cessation, alcohol harm reduction, mental health, nutrition and diet, social welfare, GP access, and early years development support for the children of IDUs. Dental care was identified as a particular priority, reflecting wider general population difficulties in accessing NHS dentists. Whereas many of these services were already in place, delegates agreed that a co-ordinated approach was not always achieved and so NICE guidance would be helpful in this respect. Finally delegates sought guidance on how commissioning could be performance managed so that the 'ensure' part of integrated service provision was met.

"Integrated care is when you can get all your treatments and conditions treated from one specialist service...so that you go to one health provider who looks after your housing, social, physical, and mental health needs and do not have to be sent to other places. Drug treatment does not provide everything but gives you access to it all, so you are not sent away to get different things sorted at different places."

"Drug users should have the same access to services. They may be reluctant to access them. We need to work harder to make sure they have the same as everybody else. Integrated health care is a funny way of putting it. It needs to say healthcare appropriate to their needs. Not all have care plans."

"I think they ought to be listed [i.e. specific items and interventions] so that people following this can get the ideas themselves. You read this recommendation and it's quite general, but it does not make you think what is missing. You only see what is there." "One NSP has a dentist for one session a week. It's been happening for years because the dentist wants to do it."

"I'm glad it's got the treatment of injection site infections because that brings in the wound care thing, which we were saying before is huge."

- One delegate raised the important point that some IDUs, particularly *steroid injectors, may not wish to receive integrated health care* via a NSP or drug service, as this population does not identify with the illicit drug using population.
- IDUs may feel *disempowered* if all their health needs are met by a single drug service as integration with mainstream providers was important if stigma was to be reduced.

### 4. Conclusions & Recommendations

A summary of major topics emerging from discussion of each particular recommendation is outlined below:

### **Recommendation 1**

- Consultations have the potential to support the development of services that are sensitive to local concerns.
- Consultation provides a rare opportunity for the views and needs of IDUs to be communicated.
- Objections from local residents have the potential to delay or cancel implementation of NSPs.
- Information provision and education is preferred to direct public consultation.
- Consultation with IDUs and other service users were critical for successful service implementation and development. This is acknowledged as being difficult to achieve especially with sub populations such as anabolic-androgenic steroid users.
- Consultation with IDUs should be bi-directional, and establish service userresponsibilities with regards to public concerns such as drug related litter, and unacceptable social behaviour (e.g. public injecting).

### **Recommendation 2**

- Although existing NSPs provide the range of services specified in the recommendation, there is currently less than optimal co-ordination of activities with a range of other health and dug providers.
- *Coverage* needs to be clearly defined in the recommendation to help support establishment of local targets.
- The majority of NSPs already provide unlimited access to injecting equipment

- Epidemiological data was useful for planning and commissioning of services, but this needed to be combined with anecdotal data and intelligence from service users and drugs workers to properly inform service provision.
- NSPs require guidance on standardised ways to monitor and audit services that is beneficial to both commissioners and providers. NSPs view existing statutory monitoring systems negatively as they do not perceive a derived benefit from participation.
- Combining or co-locating NSP within OST was welcomed, although there were some concerns with treatment compliance and client confidentiality
- One hundred hour pharmacies were just one way of ensuring significant access to services during a 24 hour period. Twenty four hour opening of NSPs was not required. The overall objective was more important than specific mechanisms, which would have to be planned locally.
- Although client responsibility was important, NSPs would look to establish string partnerships with local Environmental Services to more effectively respond to drugrelated litter. Careful consultation and consideration of the location of public 'sharps bins' would help to reduce litter.
- More work is needed to attract and retain AAS users in services. The use of other performance and image enhancing drugs was perceived to be on the increase. Providers need to be able to deliver opportunistic interventions and NSP attendance by these populations could be infrequent.
- There was overall support for vending machines, but the lack of research supporting their introduction was noted. Findings from pilot schemes suggested strong local opposition and the need for a sophisticated and secure access mechanism.
- Priority should be placed on the needs of illicit drug users leaving prison. Discharged prisoners should be provided with harm reduction packs (including information and syringe packs), and contact details for local services.

### **Recommendation 3**

- Guidance specifying unrestricted distribution of syringes/packs would promote consistency across different types of NSP.
- NSP practitioners should be encouraged to engage with clients (according to their personal training and skills) during all transactions, and encourage frequent visits.
- Limiting equipment may be appropriate where young people are concerned in order to encourage revisit.
- Legal restrictions means that NSPs are only legal able to provide sterile water in 2ml glass ampoules. Other types of packaging and delivery are in breach of MHPRA conditions.
- Investigation of the uses and the effectiveness of foil as an alternative to injecting should be included in NICE research recommendations. Despite currently being

proscribed by the Misuse of Drugs Act, there was informal distribution of foil, often with the tacit approval of police. If found to be effective, the legal status of foil should be reviewed.

- Clients should be offered a choice of syringes and needles. Non-specific syringe packs should be avoided where possible.
- Syringe identification schemes were viewed positively but should be used in parallel with more detailed risk reduction advice and information.

### **Recommendation 4**

- The proposed tiered structure of pharmacy NSP provision was supported.
- Pharmacy based NSPs were valued as they enabled commissioners to provide adequate coverage for IDUs. However, there was the perception held by some agency based NSP staff, that many pharmacy staff did not have the required skills to deliver NSPs. It was noted that this was an issue of current training provision rather than the inherent skills of pharmacy staff. Staff working at all of the proposed tiers of pharmacy NSP provision require standardised and accredited/quality assured training.
- Most pharmacy staff already have good attitudes and working practices towards IDUs. However, advice on confidentiality and client respect should still be included in basic staff training.

### **Recommendation 5**

- NSPs should be part of the core spectrum of drug treatment services, and not considered as standalone care providers.
- Persuading clients to cease injecting was difficult. Promoting alternatives to injecting was more achievable.
- Many of the services classed under *integrated care* are currently available to IDUs. Good referral systems should be developed and where possible NSP clients treatment in mainstream services to avoid stigmatisation.
- Dental care is a priority for NSP clients.

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**Appendix 1** Field meeting delegates. Please note that some participants did not wish to be identified here.

Name	Organisation
Alex Fleming	NTA
Ali Young	Islington PCT
Alison Freemantle	Lloyds Pharmacy
Allison Downing	Project 6
Andrew Gordon	Hackney Drug & Alcohol Action Team
Andrew Maguire	Harbour Drug & Alcohol Services
Andrew Preston	Exchange Supplies
Andy Power	Southwark PCT
Anna Hall	Camden PCT/DAAT
Anne Boid	Turning Point Sheffield
Ashley Robinson	The Cambridge Centre, Scarborough
Barrie McCallion	Stockport Drug & Alcohol Team (Pennine Care NHS Foundation Trust)
Brian Carrington	Cornwall and Isles of Scilly DAAT
Carry Burton	North Wales NHS Trust
Claire Barber	Boots UK
Claire Robbins	Soho Rapid Access Clinic
Clare Bircham	Rugby House, Edmonton
Clare Liptrott	Tameside & Glossop PCT
Colin Tyrie	Manchester PCT
David Gordon	Hampshire Partnership NHS Trust
David Robinson	Camden and Islington Substance Misuse Services
Donna McDonald	Basement Drop-in For the Homeless, Liverpool
Dr Eliot Ross Albert	National Users' Network
Dr Gill Lewendon	Plymouth Teaching PCT
Dr Jenny Scott	University of Bath
Elizabeth Foote	Lighthouse Project, Liverpool
Emma Marwood	City of London DAT
Frank Henderson	Surrey Harm Reduction outreach Service
Gary Beeny	Lifeline Manchester
Gary Cooks	County Durham DAAT
Gemma Fairburn	Turning Point, Castleford
Gilly Ingram	Harm Reduction Co-ordinator, Bournemouth
Helen Trudgeon	Hepatology Dept, Derriford Hospital, Plymouth
Hillary Smith	Sefton Service User Forum
lan Deasha	Manchester DAST
Ian Venables	KCA UK (East Kent)
Jan Underwood	EDP Drug and Alcohol Services, Exeter
Jill Kershaw	Rochdale Community Drug Team
Joanne Howard	Bolton Drug Service
Jody Clark	Drugs and Homeless Initiative, Bristol
John Bolloten	Bradford council
John Maliphant	Bristol Drugs Project
Jon Griffiths	North Somerset DAT
Lisa Mallen	Counted4
Lisa Pashley	Pennine Care NHS Trust
Lou Wilkins	The Health Shop, Nottingham

Marcus Roberts	DrugScope
Margaret Lee	BARCA-Leeds
Mark Harris	NTA NW
Mark Harrison	County Durham DAAT
Mark Knight	Salford DAAT
Maxine Worden	Drug & Alcohol Action Team, Kirklees PCT
Mike Ashton	Drug and Alcohol Findings
Mike Bradley	Devon & Cornwall Police
Mike Liffen	Oldham Alcohol & Drug Service
Mike Wilcock	Prescribing Support Unit, Royal Cornwall Hospital
Nigel Critchley	Salford Drug & Alcohol Service
Patrick Crowley	Turning Point Sheffield
Paul Caddick	Sefton Service User Forum
Paul Laing	Hull City Safe
Peter Duggan	Merseyside pharmacy co-ordinator
Rachael Sadegh	Tower Hamlets Drug and Alcohol Action Team
Rachel Irving	Suffolk Community Healthcare
Rich Luck	The Cambridge Centre, Scarborough
Richard Holt	Freshfield Services, Cornwall
Ross Coomber	University of Plymouth
Roy Jones	Turning Point Hungerford Drug Project
Saidat Khan	Ealing PCT
Sally Woffenden	Barnsley MBC
Sam Smith	Poole Addictions Community Team
Sarah Evans	Community Voice, Merseyside
Sharon Peppard	Hounslow DAAT
Steve Eastwood	Halton DAAT
Steven Whiston	Bury Substance Misuse Services
Sue Bradley	Basement Drop-in For the Homeless, Liverpool
Sue Neely	Liverpool DAAT
Sue Taylor	Devon Local Pharmaceutical Committee
Susie Dadlani	Surrey PCT
Suzanne Gilman	Rochdale DAAT
Tara Woodhouse	Cheshire & Wirral NHS Foundation Trust
Teresa Young	Blackpool PCT
Terry Shields	South London and Maudsley NHS Trust
Virginia Compton	Torbay Primary Care Drug Service

**Appendix 2** Presentation given to field meeting delegates summarising the NICE guidance development process and outlining the objectives of the fieldwork meetings.

### Public Health Draft Guidance Needle and syringe programmes: providing injecting equipment to people who inject drugs

# Purpose of today

Welcome and introduction

### Aim

The aim of the workshop is to explore the relevance, usefulness and feasibility of the draft guidance and the conditions required for effective implementation and delivery of the specific recommendations

### Content

- Purpose of today's event
- How the recommendations have been developed
- Public health need and practice
- The recommendations explained
- The group work

## How the draft recommendations were derived

- Department of Health asked NICE to produce public health guidance to encourage the optimal provision of needle and syringe programmes (NSPs) among injecting drug users
- Liverpool John Moores University, Centre for Public Health conducted a comprehensive systematic review of the evidence

.... cont/.

 London School of Health and Tropical Medicine did the economic modeling

### Needle and Syringe Programmes – Fieldwork report

## 28<sup>th</sup> October 2008

# were derived cont/.

- The Public Health Interventions Advisory Committee (PHIAC) considered both documents and drafted preliminary recommendations
- Recommendations now open to consultation, including today's stakeholder meeting

NSPs supply needles, syringes and the other injecting equipment used to prepare and take illicit drugs (for example, filters, mixing containers and sterile water). The main aim is to reduce the transmission of blood-borne viruses through injecting drugs.

Some NSPs also aim to reduce other harms associated with injecting drugs

### The NICE development process

- Draft scope Stakeholder comments Final scope and responses Final scope and responses Final scope and responses Reviews and cost-effectiveness modelling Synopsis report of the evidence (executive summaries and evidence tables) circulated to stakeholders for comment Comments and additional stakeholders viakeholders with the stakeholders

Public health need and practice

- Synopsis, full reviews, supplementary reviews and economic modelling submitted to PHIAC
   PHIAC produces draft recommendations
   Braft recommendations
   Braft recommendations
   Braft recommendations
   Braft recommendations
   Braft context of the second transfer of the second second second published on second second second second recommendations
   HIAC amends recommendations
   Final guidance published on
- 14. Final guidance published on website in February 2009

### **Target population**

People who inject drugs are the target population for all the recommendations listed below. This includes those who inject opioids (for example, heroin), stimulants (for example, cocaine) and other illicit substances. It also includes those who inject non-prescribed anabolic steroids and other performance- and image-enhancing drugs (PIEDs)

Nearly 130,000 injecting opiate and/or crack cocaine users in England. The true extent of injecting drug use is difficult to determine

45% report that they had shared filters, mixing containers and water within the previous 4 weeks

The risk of death among people who inject drugs is estimated to be over 13 times higher than for the general population

### Special groups

- Anabolic steroids and other PIED
- Young people
- Crack cocaine users
- Homeless people
- Prison populations
- Women

### ive recommendations

- 1. Consultation with the community
- 2. Accessibility and distribution (i)
- 3. Accessibility and distribution (ii)
- 4. Pharmacy based NSPs
- 5. Agency based NSPs

### Evidence

- Evidence from systematic reviews shows that NSPs are an effective way to reduce some of the risks associated with injecting drug use
- The public health guidance is to encourage the optimal provision of needle and syringe programmes (NSPs) among injecting drug users

# 1. Consultation with the community

### Who should take action?

Local strategic partnerships, DAATs, joint commissioning managers and PCT commissioners

Public health practitioners with a remit for substance misuse

### Recommendations

### What action should they take?

- Consult with people in the local community (including injectors) to help assess the need for – and to plan – NSPs
- Provide local people with information about the purpose of the programme. Acknowledge and respond to any reservations they may have about such a service: e.g. specify how any resulting drug-related litter will be dealt with

# Needle and Syringe Programmes – Fieldwork report

# 2. Accessibility and distribution

NSP providers (specialist drug services and retail pharmacies)

Local strategic partnerships, DAATs, joint commissioning managers and PCT commissioners

Public health practitioners with a remit for substance misuse

# 7. Audit and monitor services to ensure they meet the needs of people who inject drugs

- 8. Consider providing and evaluating schemes to distribute needles and syringes:
  via vending machines and non-pharmacy outlets (for example in sports venues)
  to people who have left prison and who are injecting drugs

- Commission a range of services to ensure needles and syringes are widely available and meet local
- Use local data on disease prevalence, populations and geography to ensure there is a balance of services, based on local need
   Ensure specialist drug services that offer oplate substitution therapy also distribute needles and syringes

### 3. Accessibility and distribution

Local strategic partnerships, DAATs, joint commissioning managers and PCT

commissioners

# Coordinate the provision of needle and syringe programmes to ensure a service is available for a significant period of time during any 24-hour period

- Ensure people who use NSPs are provided with sharps bins and advice on how to dispose of needles and syringes safely
- Ensure plans are in place to deal with any drug-related litter

#### What action should they take?

- Do not restrict the number of syringes/packs an injecting drug user can receive at any one time (within reason)
- Ensure syringes and needles are available in a range of sizes in locations. They should only be provided in venues where safer injecting advice and information is available. In addition, other legally permitted injecting equipment should be made available (filters, mixing containers and sterile water)

# Needle and Syringe Programmes – Fieldwork report

3. Ensure syringe identification schemes Insule synings for example, the use of coloured syringes) are available. Encourage people who inject drugs to use easily identifiable syringes to prevent their injecting equipment inadvertently getting mixed up with someone else's 3. Ensure staff who dispense needles, syringes or packs receive appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion, to respect the privacy of people who inject drugs and to treat them in a non-stigmatising way. Staff in pharmacies that provide more than just needle and syringe packs should be trained to provide health promotion advice, in particular, on how to minimise the harm caused by injecting

### 4. Pharmacy based NSPs

Retail pharmacies that run an NSP

Local strategic partnerships, DAATs, joint commissioning managers and PCT commissioners

#### 5. Agency based NSPs

NSPs based within a specialist drug service

Local strategic partnerships, DAATs, joint commissioning managers and PCT commissioners

#### What action should they take?

- 1. Ensure a range of pharmacy-based NSP services is available including:
  - distribution of needle and syringe packs; harm minimisation advice and information and referral to specialist services
- Pharmacy staff should be able to provide information about agencies offering further support to people who inject drugs

### What action should they take?

- 1. Ensure a selection of needles, syringes and other injecting equipment is available (in addition to pre-prepared needle and syringe packs)
- Ensure NSPs based within a specialist drug service offer comprehensive harm reduction services, including advice on safer injecting, assessment and treatment of injection-site infections and help to stop injecting

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# Needle and Syringe Programmes - Fieldwork report

# 28<sup>th</sup> October 2008

- 3. Ensure NSPs based within a specialist drug service provide access to:

  - hepatitis B vaccinations and boosters
     testing for hepatitis B, hepatitis C and HIV
     opiate substitution therapy
     primary care services e.g. dental care
     secondary care services e.g. Hepatitis C and HIV
     welfere services e.g. hepatitis C and HIV
  - welfare services e.g. housing
- Commissioners should ensure people who inject drugs receive integrated care for all their health needs

### Group work task

To explore the relevance, usefulness and feasibility of the draft guidance and the conditions required for effective implementation and delivery of the specific recommendations



- Encourage involvement listen to all viewpoints
- Listen allow everyone a chance for their voice to be heard
- Respect no put downs
- Confidentiality

- Centre for Public Health
- Transcriber
- And YOU ...... including Needle Exchange staff Service users Treatment staff -Commissioners Pharmacy staff other health, social care and criminal justice staff

What happens next?

# Needle and Syringe Programmes - Fieldwork report

- CPH will prepare a report summarising and discussing the findings of the four fieldwork meetings (ir
- PHIAC considers fieldwork report and stakeholder comments and delivers final recommendations (insert date)
- Publication of guidance in February 09



- We will draft the fieldwork report
- You will have the opportunity to comment on the accuracy of data, and to ensure anonymity is preserved.
- Unless requested otherwise, you will be acknowledged in the fieldwork report
- Some of you may be asked to provide more detailed comments (optional)

.... cont/....

- We will ensure that you are kept informed of the publication of guidance
  After publication, CPH are able to discuss guidance in more detail with services/stakeholder groups

Higher Order Categories	Representative themes
Relevance	Current practice; current policy; target population' guidance leads; integrity of current provision
Usefulness	Content of draft recommendation; outcomes assessed; quality assurance
Feasibility	Existing guidance; existing professional structures; Quality standards; resources; consistency of delivery; training; barriers & facilitation; capacity; engagement with target group; intervention delivery

# Appendix 3 Broad coding themes used in analysis

**Appendix 4** Example coding grid for data emerging from thematic analysis of one field meeting discussion of draft recommendation 2

Recommendati	
Area	Themes
Relevance	<b>Current practice</b> 23: We used to do packs, and still do them through pharmacies. The main reason we changed to pick and mix is to slow people down when they come in. If you spend 25 seconds putting stuff together you can say 'how are you?'
	25: We have a lot of homeless people accessing our service, if they want a variety of needles they would have to get three or four different packs. Also if you can give appropriate information to each area people are injecting in.
	27: It [packs] results in more drug related litter as they throw it away.
	41: We will stick everything in a bag for people. We still use packs in pharmacies, but it is an issue of storage and space. Different pharmacies engage on different levels. Some are proactive, and will split packs down, others will not. It is important to find a balance of coverage in terms of availability, but not the attitude of people who are not supportive.
	67: We have been doing foil for some time, and many people are moving to smoking, which is breaking down the speedballing and snowballing. People are choosing to smoke one, and inject the other. This is reducing BBVs.
	69: As well as overdoses, we use it when people are coming to see us after leaving prison. It means you have something else to talk to people about. Often people want to take pins alongside the foil, but at least you have spoken to people about it.
	112: I think a lot of people we see ask us not to tell people at the specialist drug services that we have seen them. I used to work for a service with everything under one roof, and I think that put people off collecting their pins.
	176: (Facilitator): <i>How would people go about getting works out of hours?</i> 178: They would not, they would just go and use someone else's. Is it
	practical to have somewhere open 24 hours a day? 232: From my experience if you take a sharps bin you can keep forgetting to go back with it, and eventually it goes in the bin. If there was a bin in the vicinity there is a chance you would remember and drop it in.
	313: I think there are more and more doing it now. When we started it five or six years ago we went to Leeds where they had a project. There are different ways to use them, we first tried to get to grips with the issues around rurality, we had limited success with such a small client group. What it is used for now is mostly home deliveries in urban areas It is effective in engaging people in their own space, where they feel comfortable, and has good rates of return. We found it a positive intervention, and it is one of the busiest parts of our service.

Usefulness	<ul> <li>319: We do not go to homes [in mobile vans], but we go to hostels, usually in outlying areas with no services or inner city areas. The percentage rate is far higher than the one in the exchange, people always seem to bring their bins back. Recently we started taking a nurse out on a Thursday to one of the busiest sites, and she does wound care. She has had fantastic success, a girl had had an open ulcer on her leg for five years, and the nurse had seen her for three months and improved it, perhaps connected to this was the individual has stopped using, just smokes crack occasionally.</li> <li>329: We regularly see a girl whose boyfriend injects her, so we can sit with the pair of them and have a chat. That would never happen where I work because people would not come in together.</li> <li>335: We have one gym where the owner take steroids and uses the van, he sends his clients that use over, but it is a one off.</li> <li>391: You would have to be really cautious [distributing needles/packs to people leaving prison], because you are supplying equipment to people at high risk of overdosing. We talked about the legality of foil; it is a good time to introduce people to foil when they have a low tolerance.</li> <li>Current policy</li> <li>82: We tend to work more on anecdotal evidence, and tell the commissioners afterwards what we are doing. We react rather than wait to be told.</li> </ul>
	<ul> <li>Content</li> <li>5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups, I think in Nottingham 99.97% are sharing cups because they are snowballing.</li> <li>7: [Facilitator] Should the term be 'injecting equipment'?</li> </ul>
	<b>Content</b> 5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups, I think in Nottingham 99.97% are sharing cups because they are snowballing.
Feasibility	<ul> <li>Content</li> <li>5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups, I think in Nottingham 99.97% are sharing cups because they are snowballing.</li> <li>7: [Facilitator] <i>Should the term be 'injecting equipment'</i>?</li> <li>9: Yes. I think sometimes unless it says it people think they would have to pay for it. The other thing is that we have started to give foil out, so perhaps alternatives to injection could be talked about.</li> </ul>
Feasibility	<ul> <li>Content</li> <li>5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups. I think in Nottingham 99.97% are sharing cups because they are snowballing.</li> <li>7: [Facilitator] Should the term be 'injecting equipment'?</li> <li>9: Yes. I think sometimes unless it says it people think they would have to pay for it. The other thing is that we have started to give foil out, so perhaps alternatives to injection could be talked about.</li> <li>Outcomes</li> </ul>
Feasibility	<ul> <li>Content</li> <li>5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups, I think in Nottingham 99.97% are sharing cups because they are snowballing.</li> <li>7: [Facilitator] <i>Should the term be 'injecting equipment'</i>?</li> <li>9: Yes. I think sometimes unless it says it people think they would have to pay for it. The other thing is that we have started to give foil out, so perhaps alternatives to injection could be talked about.</li> <li>Outcomes</li> <li>Standards</li> </ul>
Feasibility	Content 5: It says about needles and syringes, but not about other bits, such as cups. In Nottingham the people I have spoken to are not sharing needles and syringes, but they are with cups. This morning we had heard that 45% of people report sharing cups, I think in Nottingham 99.97% are sharing cups because they are snowballing. 7: [Facilitator] <i>Should the term be 'injecting equipment'</i> ? 9: Yes. I think sometimes unless it says it people think they would have to pay for it. The other thing is that we have started to give foil out, so perhaps alternatives to injection could be talked about. Outcomes Standards Consistency

[for a vending machine].
Engagement
Delivery
21: I have an issue sometimes with the pack, because I do not think it tailors to individual need.
29: If there are not needles available to them, they might use the inappropriate needle size.
33: A concern I have is giving out mixed packs that have femoral injecting longer needles and 1mm insulin ones. If you are giving those to someone who has good surface veins but runs out of the 1mm ones they might go into deeper veins with inappropriate needles.
39: We will give out a pack for someone who wants everything compact.
120: Some would be comfortable getting the needles, but do not force the service. It has to be the service's choice as well as the user's.
126: If they ensure that specialist drug services are going to do that then the confidentiality would be important. We have the drug intervention programme next door and share a reception, so we have a separate exchange entrance on the other side of the building. That is the sort of setup that would be required, with no cameras and a clear confidentiality policy.
172: The suitability is important, they seem to get big drums of citric, and split it up. For harm reduction it is not ideal as people are dipping their hands in it.
182: A vending machine switched on for certain hours in a central location might be useful.
200: They should only have to take sharps bins if they want them.
202: I would put advice on how and where to dispose of needles and syringes safely.
220: We should be encouraging people to put all their paraphernalia in, we are not just talking about needles. It could be two thirds full of paper and cups.
293: Vending machines are also an idea for gym changing rooms, homeless hostels. It is about increasing access generally. Particularly steroid users who do not identify as drug users, they are not going to go an agency.
295: Stocking appropriate equipment in the vending machine needs to be looked at as well. It would have to cater for femoral injectors, otherwise it would just create more risk.

# Appendix 5 Fieldwork facilitators guide

# Starting the group work sessions

- 1. Start with introductions e.g. name, organisation and position
- 2. Explain again the purpose of the group discussion
- 3. We are here to examine the practical application of the recommendations not examine the evidence.

The aim of the workshop is to explore the relevance, usefulness and feasibility of the draft guidance and the conditions required for effective implementation and delivery of the specific recommendations

- 4. Participation important preferably from all.
- 5. We'd like to hear from as many people as possible. So, occasionally we may ask an individual to finish their point so we can get around the group. Limited time is available. Must complete the task. So, we may have to curtail and move the discussion on.
- 6. Encourage the participants' to be specific seek examples to illustrate points
- 7. Ground rules ...
  - Encourage involvement listen to all viewpoints
  - Listen allow everyone a chance for their voice to be heard
  - Respect no put downs
  - Confidentiality
- 8. Notes will be taken and the transcriber may spend time in the group. It may be important to attribute what you say to the type of organisation you work for. However, anonymity will be preserved in the draft report. You'll have the chance to read it before it is published.
- 9. Unless you tell us otherwise your participation in today's event will be acknowledged in the draft report.

Your cooperation with these matters will be appreciated

# Recommendation 1 – consultation with the community

What action should be taken?

- 1. Consult with people in the local community (including those who inject drugs) to help assess the need for and to plan needle and syringe programmes (NSPs).
- 2. Provide local people with information about the purpose of the programme. Acknowledge and respond to any reservations they may have about such a service: for example, specify how any resulting drug-related litter would be dealt with.

# Who should take action?

- Local strategic partnerships, local drug partnerships (including drug and alcohol action teams [DAATs]), drug joint commissioning managers and primary care trust (PCT) commissioners.
- Public health practitioners with a remit for substance misuse.

# Key issues

- Likely that NSP are already operating in many areas
- NSP and other drug services tend to meet with opposition from local people
- Balance between openness and opposition
- Distinguish between agency and pharmacy based NSPs is the opposition different

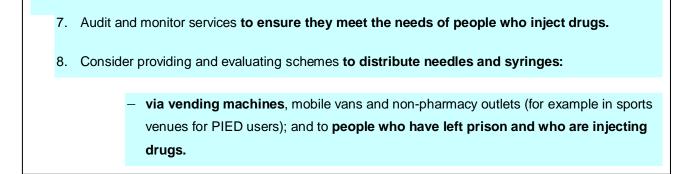
- i. Does this happen already happening already? Does it happen in a systematic & standardised way?
- i. What conditions are required to ensure that NSPs are able to operate?
- i. How should commissioners and planners consult and communicate with local people? Be specific ...
- /. How should local drug injectors be consulted? How do you consult with supposedly 'hidden populations' such as steroid users; crack users or the homeless?
- . How do you balance the views from injectors with the views of other local people?

# Recommendation 2 – accessibility and distribution

# What action should be taken?

- Commission a range of services to ensure needles and syringes are widely available and meet local need within the area covered by the local strategic partnership. This should include:
  - a. outlets that distribute needle and syringe packs (for example, pharmacies)
  - b. specialist NSPs that offer or refer people to, **additional harm reduction services** (for example, treatment for Hepatitis C) and other specialist services
  - c. needle and syringe disposal, in line with 'Tackling drug related litter' (Department for Environment, Food and Rural Affairs 2005).
- 2. Use local data on disease prevalence (for example, hepatitis C), populations (for example, the number of sex workers, crack injectors and homeless people in an area) and geography (for example, whether it is an urban or rural location) to ensure there is a balance of services, based on local need. Services should include a mix of:
  - a. pharmacy-based distributors and specialist NSPs within the PCT/local strategic partnership area, and
  - b. generic and targeted services (the latter should meet the needs of particular groups, such as people who are homeless).
- 3. Ensure specialist drug services that offer opiate substitution therapy also distribute needles and syringes.
- 4. Coordinate the provision of needle and syringe programmes to ensure a service is available for a significant period of time during any 24-hour period. As an example, PCTs could ensure that needle and syringe services form part of the 'necessary enhanced services' offered by '100-hour' pharmacies.
- 5. Ensure people who use NSPs are provided with sharps bins and advice on how to dispose of needles and syringes safely.
- 6. Ensure plans are in place to deal with any drug-related litter that may result from extending the opening times and locations of NSPs.

Continued/..



# **Issues to discuss**

- Which of the above things are happening already? Which are not? Is it positive to move forward with the things that are not happening? What obstacles exist? What conditions need to be in place to overcome the obstacles?
- Of the things that are happening at present, do they happen in **an effective and standardised way?** Are all 'special groups' (homeless, crack users etc) catered for?
- What 'additional harm reduction services' should be provided see point 1b.
- Unless discussed already, **consider point 3. What are the obstacles to this happening**? How can they be overcome?

# Key issues

- This is one big recommendation!
- It is possible that point 3 may provoke more debate

# **Recommendation 3 - accessibility and distribution**

# What action should be taken?

- 1. Do not restrict the number of syringes/packs an injecting drug user can receive at any one time (within reason).
- 2. Ensure syringes and needles are available in a range of sizes in locations sited across the area covered by the local strategic partnership. (They should only be provided in venues where safer injecting advice and information is available). In addition, other legally permitted injecting equipment associated with illicit drugs should be made available. (This includes, for example, filters, mixing containers and sterile water.)
- 3. Ensure syringe identification schemes (involving, for example, the use of coloured syringes) are available. Encourage people who inject drugs to use easily identifiable syringes to prevent their equipment inadvertently getting mixed up with someone else's

# Who should take action?

 Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

# **Key issues**

The recommendation not to restrict the number of syringes and needles – are some areas still providing equipment on a one-in, one-out basis?

- Are these things happening already? If so, is it happening in a standardised way at a national and local level?
- Are these recommendations a positive move forward? What conditions are needed to make it work well? What about cost?
- What does, 'they should only be provided in venues where safer injecting advice and information is available mean? See point 3

# Recommendation 4 - pharmacy based NSPs What action should be taken?

- 1. Commissioners should ensure a range of pharmacy-based NSP services is available including:
  - a. distribution of needle and syringe packs
  - b. distribution plus harm minimisation advice and information
  - c. distribution plus harm minimisation advice and referral to specialist services.
- 2. Pharmacies and commissioners should ensure staff who dispense needles, syringes or packs receive appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion, to respect the privacy of people who inject drugs and to treat them in a non-stigmatizing way. Staff in pharmacies that provide more than just needle and syringe packs should be trained to provide health promotion advice, in particular, on how to minimise the harm caused by injecting.
- 3. Pharmacy staff should be able to provide information about agencies offering further support to people who inject drugs (this includes details about local DAAT services).

# Who should take action?

- Retail pharmacies that run an NSP.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

# Key issue

• The nature and extent pharmacy based NSPs vary across the country

- Are these things happening already? If so, is it happening in a standardised way at a national and local level? Are the 3 types of service level in existence already? Does geography make a difference rural, suburbia, inner city estates etc
- Are these recommendations a positive move forward?
- Staff training is cited as a prerequisite of service provision are there other conditions that need to change? E.g. building design and privacy; care pathways?

Recommendation 5 – agency-based NSPs What action should be taken?

- 1. Ensure a selection of individual needles, syringes and other injecting equipment is available (in addition to pre-prepared needle and syringe packs).
- 2. Ensure NSPs based within a specialist drug service offer comprehensive harm reduction services, including advice on safer injecting practices, assessment and treatment of injection-site infections and help to stop injecting drugs.
- 3. Ensure NSPs based within a specialist drug service provide access to:
  - · hepatitis B vaccinations and boosters
  - testing for hepatitis B, hepatitis C and HIV
  - opiate substitution therapy
  - primary care services (including dental care and general health promotion advice)
  - secondary care services (for example, for Hepatitis C and HIV treatment)
  - welfare services, for example housing and legal advice.
  - 4. Commissioners should ensure people who inject drugs receive integrated care for all their health needs.

# Who should take action?

- NSPs based within a specialist drug service.
- Local strategic partnerships, local drug partnerships (including DAATs), drug joint commissioning managers and PCT commissioners.

# **Key issues**

- The definition of a 'specialist drug service' in point 2 may be important
- Some NSP have limited contact with their clients point 4 may be a challenge in some circumstances. • "I can't stop, I've got a taxi waiting."

- i. Does this happen already happening already? Does it happen in a systematic & standardised way?
- i. What conditions are required to ensure that NSPs are able to operate in this way?
- i. Consider point 2 - encourage participants to give examples of 'comprehensive harm reduction services'. Does this happen already? How far do you go with providing safer injecting advice? Should advice about groin injecting be provided?
- What happens if injectors don't want to be integrated into care? The "I can't stop, I've got a taxi ĸ. waiting' people

# Appendix 6 Individual interview schedule

# NICE Needle and Syringe Programme Draft Guidance: Telephone interview guide

# Notes to researcher

- It is not necessary to keep to the script strictly but all topics must be covered
- Interviews will not last longer than one hour
- · Make notes on particularly important/relevant points to assist the analysis process

# Preamble

- Confirm role/job title of participant.....
- Confirm participant has not/is not going to participate in NICE fieldwork meetings
- Explain that...
  - o the interview will be recorded to ensure accuracy
  - o all responses are strictly confidential
  - all responses are anonymous (no individuals will be identified) For example it will only be stated that a NSP practitioner said that...
  - Some questions may not be relevant to their specific role, although you will ask respondent for professional opinion
  - The participant may decline to answer any question
- Offer the participant an opportunity to ask questions
- Ensure participant is happy to proceed with the interview
- Check participant has draft guidance to refer to
- Ask whether participant has read draft guidance. If not interview can still go ahead as will then read out recommendations. Don't read out recommendations in full

# **Recommendation 1: CONSULTATION WITH THE COMMUNITY**

- 1. In your experience, does consultation always happen when a new NSP or service is being planned?
- 2. Do the consultations involve all those who should be included? If not who is excluded?
- 3. Is a clear plan for the consultations outlined beforehand? Who is responsible for constructing this?
- 4. In what form should the consultations take place? (prompt where should they be held? Should they be face-to-face or through other means?)
- 5. In your experience what happens if the consultation yields unexpected results (e.g. negative public feedback)? In your experience has this led to delay or cancellation of a service?
- 6. Are you aware of any instance where the public consultation has been manipulated by either service providers OR the general public/interest groups?
- 7. How should local drug injectors and potential NSP users be consulted? (prompt hidden populations such as steroid users, crack users or the homeless)
- 8. Within your experience, how is the public health need for NSP balanced against the concerns of the local population?
- 9. What local conditions are required to ensure that NSPs are able to operate? (Prompt location, what do local people need to know?)
- 10. Are there differences in acceptability of pharmacy based and specialised NSPs?

# **OVERALL:**

- 1. Do you feel recommendation one is relevant? If not why not?
- 2. Do you feel recommendation one is feasible? If not why not?
- 3. <u>Do you feel recommendation one is useful? If not why not?</u>

# Recommendation 2: ACCESSIBILITY AND DISTRIBUTION 1

- 1. What 'additional' harm reduction services should be provided (point 1b)?
- 2. What are the obstacles to providing NSP in conjunction with Opiate Substitution Therapy (e.g. worker-client relationship, confidentiality)?
- 3. How should auditing and monitoring of NSPs take place (prompt new NEEDEX scheme)?
- 4. What role do service users currently take in auditing and monitoring?
- 5. How should needs assessment and feedback be incorporated into practice?
- 6. Point four refers to services being available for a 'significant' period of time during any 24 hours. How would you define 'significant'?
- 7. What organisations are best placed to provide out of hours NSP?

- 8. Point two refers to local data regarding disease prevalence, population and geography. How do NSPs **access** such data?
- 9. Do you feel it is feasible for NSPs to use such local data? If not why not?
- 10. How is drug related litter currently dealt with?
- 11. Who is responsible for dealing with drug related litter? (prompt Is it left to the council or specific NSP schemes?)
- 12. What role do service users have to play in reducing drug related litter?
- 13. How do you reduce local fears about NSPs such as discarded needles?

# Overall:

- 14. Do you feel recommendation two is relevant? If not why not?
- 15. Do you feel recommendation two is feasible? If not why not?
- 16. Do you feel recommendation two is useful? If not why not?

# Recommendation 3: ACCESSIBILITY AND DISTRIBUTION 2

- 1. Point one recommends that no restriction is placed upon the number of packs received, within reason. Are there circumstances where restrictions might be useful (prompt need to see client on regular basis; might be sold on etc)?
- 2. What are the specific cost implications of providing unlimited syringe/packs?
- 3. What do you feel 'they should only be provided in venues where safer injecting advice and information is available' means?
- 4. Is it possible to ensure syringes/packs should only be provided where safer injecting advice and information is available **and** ensure that they should be freely available, including out of hours? Please explain.
- 5. Have you encountered problems with making legally permitted injecting equipment available (e.g. sterile water)?
- 6. Have you introduced (or know of) syringe identification schemes? (prompt so people know which syringe is theirs)
- 7. What are the positive and negative aspects of this type of syringe identification schemes?
- 8. What do you think of 'pick n mix' approaches whereby clients can indicate what barrels and needles they want (via a specially designed 'prescription pad') rather than a pack of mixed, or homogenously sized equipment?

# **Overall:**

- 17. Do you feel recommendation three is relevant? If not why not?
- 18. Do you feel recommendation three is feasible? If not why not?
- 19. Do you feel recommendation three is useful? If not why not?

# Recommendation 4: PHARMACY BASED NSPs

- 1. Staff training is cited as a prerequisite of service provision. Are there other conditions that need to change, such as building design, privacy, care pathways in order to provide an appropriate NSP service?
- 2. The recommendation (point 1) suggests a tiered approach. What kind of pharmacies would be able to deliver the full exchange, harm reduction and referral package?
- 3. Are there any unforeseen problems with such a tiered approach?
- 4. How do commissioners ensure a high quality, standardised service is delivered within tiered approaches?
- 5. Will geography make a difference to the type of NSP services that should be provided?
- 6. Are pharmacies more appealing to some drug using populations than others?

# **Overall:**

- 7. Do you feel recommendation four is relevant? If not why not?
- 8. Do you feel recommendation four is feasible? If not why not?
- 9. Do you feel recommendation four is useful? If not why not?

# **Recommendation 5: AGENCY BASED NSPs**

- 1. Does point one happen already?
- 2. Does point two happen already?
- 3. Does point three happen already?
- 4. Does point four happen already?
- 5. What do you understand 'integrated health care' to mean?
- 6. Is 'integrated health care' feasible with this client group?
- 7. What conditions are required to ensure that NSPs are able to offer integrated health care?
- 8. Can you provide any examples of 'comprehensive harm reduction services' please?
- 9. Do 'comprehensive harm reduction services' exist already?
- 10. How far do you go with providing safer injecting advice? (prompt Should advice about groin injection be given for example?)
- 11. What happens if injectors don't want to be integrated into care?

# Overall

- 10. Do you feel recommendation five is relevant? If not why not?
- 11. Do you feel recommendation five is feasible? If not why not?
- 12. Do you feel recommendation five is useful? If not why not?

# Summary

1. Do you have any other comments you would like to make about the draft recommendations in general?