Needle and syringe programme fieldwork

Full Report

Addaction Research & Development
in association with
Tiny Spark Projects

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Executive Summary

Addaction was commissioned by the National Institute of Health and Care Excellence (NICE) to examine the relevance, use, acceptability and ease of implementation of the revised NICE guidance for Needle and Syringe Programmes (NSPs) (PH18), in particular the ten areas of recommendations within the draft guidance.

NICE circulated the draft guidance to stakeholders across England as part of their usual stakeholder consultation process. To complement this, Addaction conducted focused research fieldwork to consult the views and experience of commissioners, professionals and managers with public health and blood-borne infection prevention as part of their remit working within the NHS, local authorities and the wider public, private, voluntary and community sectors. Recruitment was aimed at professionals responsible for commissioning and delivering services that supply injecting equipment, paraphernalia, and advice/treatment associated with harm reduction.

Methodology

Addaction applied in-depth qualitative data collection across targeted areas of England using a sampling matrix to obtain a representative sample of the population. The matrix included key informant groups within the cohort described above, as well as a covering variety of geographical and socio-economic factors that could influence implementation and delivery of NSP provision, particularly those in direct relation to Performance and Imaging Enhancing Drug (PIED) users and younger Injecting Drug Users (IDUs).

The qualitative research component was conducted by Tiny Spark Projects (TSP), commissioned by Addaction as research partners to deliver this fieldwork for NICE. The researchers used a mixed method approach to gather information from recruited participants depending on the individual and setting/environment of the service. This data collection consisted of six focus groups of between six and seven individuals, as well as eleven individual semi-structured one-to-one interviews conducted over the telephone. This mixed method approach ensured that the fieldwork benefitted from both focus group and interview techniques, with a range of views collected in both group and one-to-one settings.

Fieldwork and data analysis

Fieldwork was undertaken using focus groups and one-to-one interviews with professionals involved in the delivery or commissioning of Needle and Syringe programmes (NSP), or those with a remit of harm reduction work. Semi-structured interview schedules were devised based on the aims of the fieldwork.

Discussions in relation to the recommendations covered areas such as current practice, local issues, strengths and weaknesses of the recommendations, ease of implementation and areas of ambiguity.

All data were analysed using a thematic analysis approach. A coding matrix was developed in order to help to analyse the data firstly, by the geographical location of the focus groups and interviews, and secondly, by the recommendation. Analysis found common themes with regards to each recommendation, as well as some

cross-cutting themes between the recommendations. A summary of the key issues for each recommendation is reported below.

Findings and summary of key issues for the recommendations

Summary of key issues for Recommendation 1

A summary of issues relating to the implementation of community consultation and involvement, as highlighted by participants, is provided below:

- As services were currently operating with limited resources this may impact on the implementation of the recommendation in its entirety;
- The challenge of engaging with 'harder to reach' injecting populations, and families and carers was highlighted;
- How is 'local community' being defined within the recommendation?;
- The challenge of consulting with communities and the issue of 'NIMBYism';
- Strengthening the example within the recommendation to include public health messages, with a larger emphasis on promoting benefits such as reducing BBVs;
- Consulting with some other key partners and stakeholders is regarded as key;
- Gaining strategic 'buy-in' from stakeholders is essential, as is addressing the knowledge gaps of some of the wider strategic bodies with a remit of public health and health and well-being.

Summary of key issues for Recommendation 2

A summary of issues relating to the implementation of collating and analysing data, as highlighted by participants, is provided below:

- Data issues remain a concern specifically the inconsistency and validity of data collected;
- Pharmacies may find the implementation of this recommendation challenging;
- A national approach to data collection and reporting would be beneficial in order to reduce inconsistency and establish benchmarks;
- Receiving meaningful, local data from bodies such as PHE was inconsistent across areas.

Summary of key issues for Recommendation 3

A summary of issues relating to the implementation of meeting local need, as highlighted by participants, is provided below:

- The recommendation focused too much on the 'geography' of the area as opposed to 'demographics of the service user group';
- More comprehensive, local data is required to inform the local assessments of need;
- Local Joint Strategic Needs Assessments would not incorporate NSPs;
- There were concerns relating to the promotion of coloured syringe identification schemes as anecdotally participants suggested this scheme did not necessarily prevent accidental sharing.

Summary of key issues for Recommendation 4

A summary of issues relating to the implementation of monitoring services, as highlighted by participants, is provided below:

- A number of issues relating to data were discussed including the impact of these on the effective monitoring of services, including inconsistencies in data collection, levels of data collected by pharmacies and the need for a standardised approach.

Summary of key issues for Recommendation 5

A summary of issues relating to the implementation of developing a policy for young people aged under 16, as highlighted by participants, is provided below:

- There were concerns that the involvement of Safeguarding Boards may impact on current practice;
- The focus of the recommendation on under 16's is counter to other guidance and structures relating to young people;
- The competency levels of staff in adult services and pharmacies when working with and assessing young people may need to be developed;
- There were concerns around the appropriateness of pharmacy provision of this age group;
- Many participants felt that the involvement of parents or carers would be a challenge and may deter engagement with young people.

Summary of key issues for Recommendation 6

A summary of issues relating to the implementation of providing a mix of services, as highlighted by participants, is provided below:

- A number of challenges were perceived for this recommendation. For example, financial constraints, spreading services 'too thin' and the need to educate influential bodies such as Health and Wellbeing Boards;
- The use of the example of vending machines in the recommendation prompted concerns as they were linked to the lack of interaction between a service user and harm reduction worker. Examples of how these could work in practice was suggested.

Summary of key issues for Recommendation 7

A summary of issues relating to the implementation of providing equipment and advice, as highlighted by participants, is provided below:

- There were a number of circumstances where limits on equipment may be appropriate.

Summary of key issues for Recommendation 8

A summary of issues relating to the implementation of community pharmacy-based needle and syringe programmes, as highlighted by participants, is provided below:

- The expertise and knowledge of some pharmacists were considered to be limited, and training was not always well attended/provided;
- There was a lack of awareness by some providers/commissioners in relation to the extent and depth of contact pharmacy staff have with some service user groups;
- Engagement of pharmacy staff in local meetings and events is reportedly weak;
- It was felt there should be greater emphasis on better joined up working and robust pathways between pharmacies and specialist NSP/drug treatment services;
- There should be greater clarity regarding responsibilities for ensuring that Hepatitis B vaccinations are made available to pharmacy staff.

Summary of key issues for Recommendation 9

A summary of issues relating to the implementation of specialist needle and syringe programmes: level 3 services, as highlighted by participants, is provided below:

- A number of currently provided level 3 interventions were not included in the recommendation;
- It was felt there should be greater joined up working and robust pathways between the provision of NSP and drug treatment/recovery services;
- Hepatitis B vaccinations for all staff could be made available.

Summary of key issues for Recommendation 10

A summary of issues relating to the implementation of providing needle and syringe programmes for people who inject performance and image-enhancing drugs, as highlighted by participants, is provided below:

- This provision is often delivered within existing services/resources;
- Working and engaging with this group required a significant level of knowledge and expertise.

A number of cross-cutting themes emerged, which can be summarised as follows:

- Links with recovery;
- Issues relating to Blood Bourne Viruses;
- Division in the opinions on pharmacy provision;
- Emerging cohorts of service users.

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1. Introduction

National Institute for Health and Care Excellence (NICE) is in the process of revising their published public health guidance on 'Needle and syringe programmes: providing injecting equipment to people who inject drugs' (PH18). The guidance is also being updated to include advice on two specialist areas; providing NSP to users of performance and image enhancing drugs (PIED), providing Needle and Syringe Programmes (NSP) to under 16's.

The updated guidance will cover NSPs which supply needles, syringes and the other injecting equipment used to prepare and take illicit drugs (for example, filters, mixing containers, sterile water). These may be provided by specialist drug treatment services, pharmacies, mobile/outreach facilities, accident and emergency departments, police custody suites, hostels, GP surgeries, voluntary agencies and gyms. The guidance will also focus on harm reduction interventions provided by NSPs. These may include the provision of information and advice (including face-to-face advice) on safer injecting practices (including the prevention of injection-site infections, blood-borne viral infections and overdoses) and safe disposal of used equipment.

2. Research aims and objectives

The overall aim of this NICE fieldwork was to examine the relevance, use, acceptability and ease of implementation of the NICE guidance for Needle and Syringe Programmes (NSPs) (intended to replace the existing guidance, PH18, in early 2014), in particular the ten areas of recommendations within the draft guidance.

NICE circulated the draft guidance to stakeholders across England as part of their usual stakeholder consultation process. To complement this, Addaction was commissioned to conduct focused research fieldwork to consult the views and experience of commissioners, professionals and managers with public health and blood-borne infection prevention as part of their remit working within the NHS, local authorities and the wider public, private, voluntary and community sectors. Recruitment was aimed at professionals responsible for commissioning and delivering services that supply injecting equipment, paraphernalia, and advice/treatment associated with harm reduction.

The specific aims of the fieldwork outlined by NICE were to address the following questions and areas of exploration in relation to the draft guidance.

i) What are the views of NHS and local authority commissioners, managers, health and social care practitioners, and specialist NSP staff on the relevance and usefulness of the NICE recommendations to their current and future practice?

ii) What factors could either help or hinder the effective implementation and delivery of the NICE recommendations, as part of current or future practice?

iii) What are the potential consequences of the NICE recommendations for improving health and tackling health inequalities?

iv) What is the potential impact of the NICE recommendations on current policy, service provision or practice?

v) Which of the NICE recommendations are both feasible and likely to make a difference to practice?

vi) What should be the relative priority of each of the NICE recommendations?

3. Methodology

3.1 Sampling

Addaction applied a purposive sampling technique, in the form of a non-probability sample of in-depth qualitative data across targeted areas of England. Addaction utilised a sampling matrix in order to obtain a sample representative of the population – those organisations and individuals implementing, and affected by, the recommendations within the revised PH18 guidance. In the preparation of the final sampling matrix (which can be found in appendix A), any inadequacies were addressed and corrected in consultation with the NICE project team to ensure that the strategy was inherently non-discriminative to avoid targeting or omitting specific subpopulations, which could have created bias within the outcomes of the fieldwork.

The matrix included key informant groups within the cohort described above. In addition, a variety of geographical, socio-economic factors that could influence implementation and delivery of NSP provision were also included, particularly those in direct relation to Performance and Imaging Enhancing Drug (PIED) users and younger Injecting Drug Users (IDUs). Furthermore, responding to a request from the NICE project management team, Addaction attempted to consult with individuals and organisations from mental health services (particularly those handling dual diagnosis), homelessness services, and safeguarding boards. All participants in the fieldwork were identified as experts in their professional area and/or experienced senior positions, representing a diverse mixture of roles/experiences within the health and social care sector.

In order to focus the recruitment drive, Addaction's geographical area of 'North and West' region was targeted for the fieldwork exercise. This is a large geographical area covering a number of counties from the West Midlands up through to the North West of England. This area was selected as the region consists of a range of services which include young people's (YP) service provision, as well as a number of well-established harm reduction services and NSPs. It is also under the direction and management of Addaction's leading senior management harm reduction specialist. This region was selected on the basis of services operating in a variety of urban and rural locations as well as being culturally diverse, both internally and externally of Addaction, ensuring the sample would reflect the balance of service provision across the UK. In addition to this extensive region, the London Borough of Brent was also added to the sampling strategy to increase the representativeness of the sample, particularly to reflect unique, inner-city populations such as London.

3.2 Recruitment

The recruitment strategy used all of the identified Addaction services' external networks and partnerships with key informant stakeholders involved in the delivery and commissioning of NSPs.

To initiate the recruitment drive, regional stakeholder and expert virtual groups were convened, drawing on Addaction's established partnership and excellent links in the region and substance misuse field. An initial, extensive list of individuals and agencies to be contacted was then generated for each area in collaboration with these groups. Subsequent snowball sampling was then employed (i.e. asking each interviewee to highlight other key informants/groups), ensuring further and extensive coverage within the sample population.

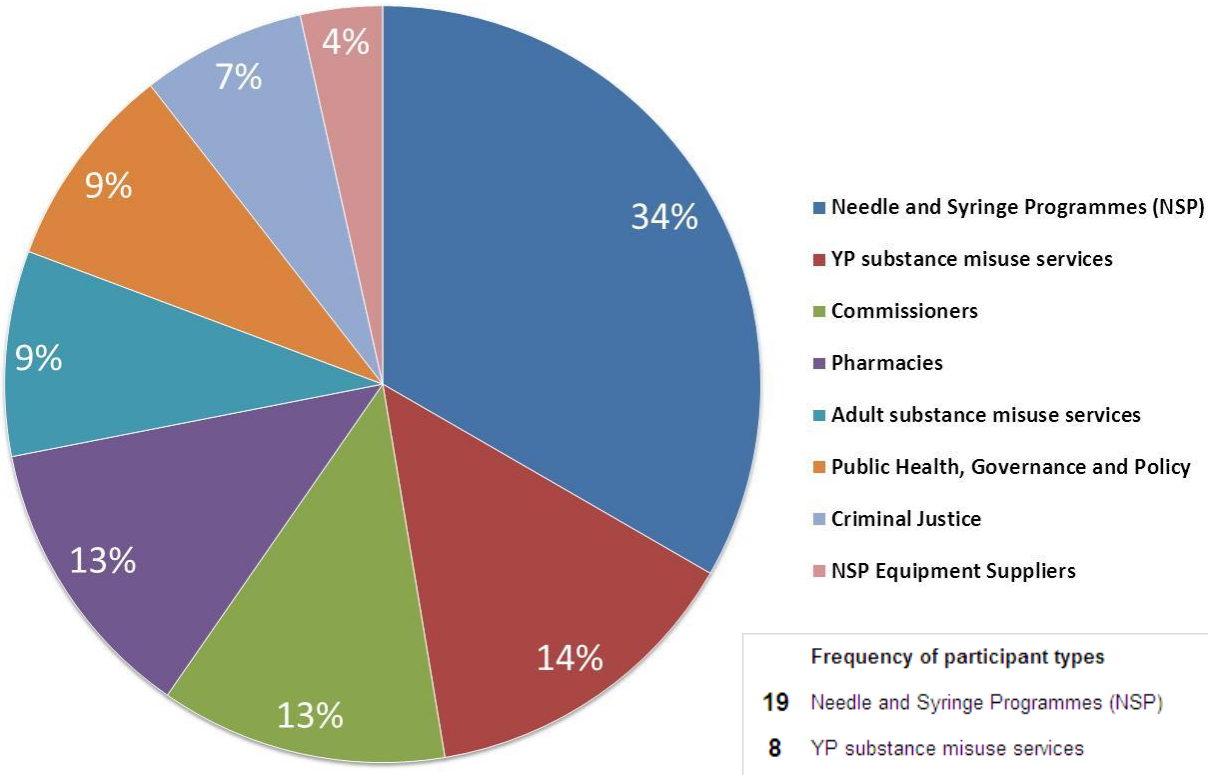
Following a successful recruitment drive, 7 focus groups and 11 interviews were arranged in 6 different areas of England, in a range of settings and populations (further discussion on the data collection methods can be found in Section 3.3 below). Data collection was conducted between 25th September 2013 and 11th October 2013 and the geographical areas are listed below (with the focus group location in brackets):

1 Lancashire (Preston),
2 London (Brent),
3 West Midlands (Walsall),
4 Liverpool (Liverpool),
5 Halton, Cheshire and Liverpool (Liverpool YP),
6 Barnsley and West Yorkshire (Barnsley),
7 Coventry and Warwickshire (Coventry).

To ensure the target sample size (n=57), all of the focus groups and interviews were purposely over-recruited to mitigate attrition in the data collection phase.

Breakdown of participant profession types

There was an extensive range of professional types and organisations represented amongst the participants recruited, with a good representation from the key areas identified within the sampling frame. Please see the diagram and table below for a breakdown and frequency of types of participants contributing to the fieldwork.



	Frequency of participant types
19	Needle and Syringe Programmes (NSP)
8	YP substance misuse services
7	Commissioners
7	Pharmacies
5	Adult substance misuse services
5	Public Health, Governance and Policy
4	Criminal Justice
2	NSP Equipment Suppliers
57	Total

As mentioned, NICE requested that homelessness, mental health and safeguarding were included in the sample and significant effort was made in attempting to recruit from these profession areas. Unfortunately, due to a number of cancellations and no-shows from all the homelessness and mental services recruited, these services were not represented in the data collection. Nevertheless, although not directly employed by homelessness and mental health services, many of the research participants consulted were experienced in these specialist disciplines and provided insight into these areas throughout the fieldwork exercise. Furthermore, professionals with responsibilities for safeguarding and public health governance and policy were successfully represented (9% of the participants -please see above).

Furthermore, there was representation from a number of Addaction services (42% of participants), and although this could present some bias within the fieldwork, it was felt that because of the geographical spread, contextualisation and localism in participant experience and practice, as well as the range of staff and service delivery represented, this did not pose a problem for the research in the data analysis stage. In addition, there was a significant range of other NSP and substance misuse service providers represented throughout the data collection.

3.3 Data collection method and approach

The qualitative research component was conducted by Tiny Spark Projects (TSP), commissioned by Addaction as research partners to deliver this fieldwork for NICE. TSP is an innovative research and 'Recovery' consultancy, with significant experience of delivering qualitative research projects of this nature, specialising in understanding the needs of service users, practitioners and professionals within the health and social care sector.

The researchers used a mixed method approach to gather information from recruited participants depending on the individual and setting/environment of the service. This data collection consisted of focus groups of between 6 and 7 individuals from a range of organisations and professional backgrounds, as well as 11 individual semi-structured one-to-one interviews conducted over the telephone. This mixed method approach ensured that the fieldwork benefitted from both focus group and interview techniques, with a range of views collected in both group and one-to-one settings. Having both data collection methods available also ensured that those participants expressing difficultly in attending an extended focus group could be offered an telephone interview.

In order to maximise the opportunity with participants from both the focus groups and interview sessions, copies of the draft guidance and recommendation summary were sent to the research participants prior to the data collection stage. This action assisted participants in the preparation of their assessment of the content, practice and impact of the recommendations, as set out in the 'Methods for the development of NICE public health guidance – 3rd edition'[1] and ensured they were familiar with the documentation, in order to fully test the draft recommendations in line with the objectives of fieldwork.

[1] Specifically, please see Appendix M, page 5 within the NICE document referenced

4. Fieldwork summary and data analysis

4.1 Fieldwork sessions

Focus groups and one-to-one interviews were conducted to elicit participant's views on the relevance, use, acceptability, areas of ambiguity and ease of implementing the recommendations in local practice. This process also assisted in identifying the priority order of the recommendations.

Each focus group ran for approximately four hours and telephone interviews lasted between 45 to 60 minutes. As stated, all participants received a copy of the draft guidance prior to the focus group/interview. Furthermore, copies of the draft recommendations were displayed as a visual aid during the focus groups, and interviewees were asked to have a copy of the recommendations to refer to during the interview.

All participants received an update on the aims of fieldwork, including confidentiality, and a formal consent process was undertaken, prior to each focus group/interview. Participants were informed about how data would be used in the report, and were assured that they would not be identified by name or area, and that their professional role would only be attributed to them.

Two members of the Tiny Spark Projects' team were present at the focus groups, one to facilitate and one to scribe notes of the discussions. Within the focus groups, participants were given time to read the recommendation, which was then followed up with a series of semi-structured questions (see Appendix B) in order to start discussion and elicit opinions. It was the role of the facilitator to ensure all group members received an opportunity to express their opinion/experience as groups consisted of a mix of professionals in a range of roles (see breakdown of participant profession type above). Telephone interviews were conducted by one member of the research team.

In addition a NICE representative (technical team) attended two focus group sessions in Liverpool, as an observer.

Throughout discussions, participants expressed the extent to which they supported the recommendations, and the potential barriers that may exist in the implementation of the recommendations. Participants referred to local issues and practice which provided the context for their response to the recommendations. Summaries of this background information have been used within the findings section to qualify statements.

4.2 Data analysis

Consideration was given to the use of recording equipment in the focus group sessions, however as the research team had the specific role of a scribe, it was decided that this was unnecessary. All sessions and interviews were written up electronically and data were analysed thematically. A coding matrix was developed for data analysis, and as the key aims of the project had already been identified (to assess the content, practice and impact), these were used as the basis of the matrix, forming the thematic codes and sub thematic codes.

Sub themes were highlighted within the thematic codes so that findings could be appropriately categorised. Data were analysed in a number of ways using the same matrix:

- Firstly, by geography, in accordance with the locations of the seven focus groups, in order to explore whether specific local issues were pertinent to that area, and;
- Secondly, by recommendation, where all localities were grouped together and themes specific to that recommendation were explored.

Both types of analysis considered the data, in turn, and were coded separately. In addition, the context in which the recommendations were being discussed was key to ensuring the data were appropriately categorised. For example, with a general theme of 'pharmacy provision' where participants were discussing current practices this was included under the 'relevance' code of the recommendation, and where participants discussed potential strengths or limitations of pharmacy provision, this data fell within the 'feasibility/implementation' code.

Members of the research team repeated this exercise to ensure discrepancies in the coding were minimised. Where discrepancies occurred, the transcripts were revisited and discussed in order to apply the most applicable code. It is acknowledged that coding exercises of this nature can be limited by the subjective interpretation of the data by researchers.

It is important to note that there were no significant themes by geography, and that all themes reported on were specific to the recommendation. The findings section takes each recommendation in turn and presents the data relating to that recommendation. In addition, there were a number of cross-cutting themes between the recommendations, which are explored at the end of the findings section.

Examples of the thematic codes were:

- **Relevance of the recommendation** - current practice, missing elements of the recommendation, appropriateness to a range of target populations and services.

- **Feasibility/ ease of implementation** – barriers and support for the recommendation, additional policy and guidance, local issues, capacity and resources, training requirements.

- **Usefulness/ areas of ambiguity** – content of the recommendation, interpretation, wording issues, inaccuracies, health inequalities.

Where available, quotes from participants have been incorporated within some parts of the findings section to strengthen/evidence specific points raised by participants.

5. Findings

Recommendation 1 Community consultation and involvement

Who should take action?

- Health and wellbeing boards.
- Commissioners of:
  - drug services
  - infectious disease services
  - pharmacy services
  - primary care services.
- Public health practitioners whose remit includes needle and syringe programmes (NSPs) and infectious disease prevention.

What action should they take?

- To help assess the need for, and to plan, a needle and syringe programme, consult:
  - different groups of people who inject drugs (including both those who use a needle and syringe programme and those who don't)
  - families and carers of people who inject
  - front-line workers in needle and syringe programmes and related services.
- Consult local communities about how best to implement new or reconfigured needle and syringe programmes. Promote the benefits of the service. For example, explain how it will help reduce drug-related litter by providing safe disposal facilities such as drop boxes and sharps bins.

For further recommendations on community engagement, see Community engagement to improve health (NICE public health guidance 9).

Findings

Participants' feedback on NICE Recommendation 1:

Current practice

There was a consensus relating to the importance of consultation, and participants reported that consulting with the groups listed in the recommendation was generally current practice. Participants reported, however, that there were challenges when consulting with some of the groups listed, these are discussed below. A number of participants also reflected that sometimes specific consultations were not conducted for Needle and Syringe Programmes (NSPs) – but rather, they were conducted across a system of services including NSPs. More precisely, regular 'reviews' of NSP provision/services were currently undertaken with service users and staff members.

'This recommendation seems sensible and involving those groups does happen across the whole treatment system, not just for harm reduction or Needle and Syringe Programmes. It hasn't happened for the needle and syringe provision yet but we are looking to re-commission services so we would look to do some community

consultation, whether it would be specifically on the needle and syringe service, I'm not sure' – Commissioner.

'We're always asking service users what they think of the service and what we could do better, we review it on a regular basis' - Provider

It was recognised by a number of participants that current consultation processes could be improved in some areas, however there were a number of key points raised relating to the recommendation and the implications for implementation, areas to be strengthened and areas of ambiguity.

Implications for implementation

Limited resources

Participants supported the view that different levels of consultation were needed for different groups. The need for 'proportionality' was discussed in relation to limited resources – specifically reduced finances and capacity – to undertake wide-ranging consultation. Participants suggested that the recommendation does not make clear how consultations should be commissioned for different groups.

This recommendation is straight forward. Some of the points within it will lead to interesting conversations like how to engage with service users not engaging in NSP. The recommendation is right, but it will be difficult to implement some parts of however that shouldn't stop us. Its about how consultations are commissioned – for example we could commission a service user group to consult with different groups of injectors – NSP Manager

It would be difficult to implement due to engagement issues with service users, families and the local community, and commissioning issues – who commissions all of this? – Public Health Practitioner

The cost of conducting a full community consultation would be costly. This city is very large with many diverse communities so it would be really expensive for an already cut back budget. In principle it is sound, but in reality you might not be able to implement it in its entirety - Commissioner

Consultations with key groups

Service users and staff members

Service users considered to be 'hard to reach' and/or not accessing NSPs were discussed as being challenging to consult with, along with those who buy their equipment from the internet. According to participants, the growing cohorts of people injecting performance and image enhancing drugs including Melanotan and Botox are challenging groups to engage and consult with as they do not associate NSPs with their own use of 'drugs'.

These harder to reach injecting populations were seen to be key groups to consult in order to improve engagement with them and identify new trends, however, there was recognition that this would be a time-consuming process.

Families and carers

Providing opportunities to consult with this group was considered important, however, previous experiences had proved this to be challenging to implement in

practice. One participant felt that organisations such as specialist family and carer groups were best placed to conduct such consultations.

'Consulting with family/carer's would also be challenging as we wouldn't necessarily want to consult with family members of those using the needle exchange service' - Commissioner.

'Families and carer's of people who inject – this would be difficult to implement in practice as we already promote and offer consultations but they rarely take them up, especially the families of those who are injecting and accessing NSP' - Provider.

Community members

When contemplating the introduction of new/reconfigured services to a new area, participants stated that consulting with this new community (local residents and retailers in town centres were referenced in particular) was important. Participants supported the view that new communities required a deeper level of consultation in order to ensure they understood the importance of these services, supported the introduction of them and knew who to contact if they needed to.

'Its important when commissioning a service that local residents are consulted, and providers should do this. It's important for both the community and the service to get to know each other's faces' - Commissioner.

The difficulty will be clarifying the wider community – different types of consultation's are needed for different populations – Public Health Worker.

There were participants who felt consultations with the local community provided an opportunity for local people to 'work with you rather than against you', however, other participants felt that once local communities were consulted with and were made aware of NSP provision, this had the potential to create community resistance.

'The wider community wouldn't be aware of this provision, currently. There would be some difficulty in implementing this as you would have to be careful to get across the right message and explain it properly. I think the wider community would be reluctant to have it on their doorstep' – Pharmacist.

<u>The issue of NIMBY (Not In My Back Yard)</u>

Participants recognised that getting the support of local communities was not always easy, as there could be 'fear and mistrust' about the issues and the perceived message to the public was one that accepted and 'encouraged' drug use. As discussed above, consultation exercises may increase public anxiety about the placements of NSPs i.e. 'not on my doorstep'.

<u>Strategic and political issues</u>

Current strategic and political influences within the substance field and wider public health domain were discussed in relation to both supporting and hindering implementation of recommendation 1:

- A number of participants stated that applying the influence of Public Health England (PHE) would support them to promote and educate the wider community about the benefits of NSPs. For these participants, they supported the inclusion of **'public health practitioners'** within the section **'who should take action'**, however, some felt there was a larger role for Public Health England in this recommendation. It was stated that the focus should include an approach that improved the public's understanding and awareness of the service within a public health context.

- Whilst participants welcomed and/or agreed with the involvement of Health and Wellbeing Boards under **'who should take action'**, with some emphasising the importance of their involvement, it was also felt that currently these groups had a 'lack of knowledge' with regards to the work of NSPs. For these participants, there was a need to educate such partners with regards to the purpose and benefits of NSPs, prior to Health and Wellbeing Boards making decisions or taking action by way of consulting with the community.

The message

Participants felt strongly about ensuring the 'right message' was conveyed to local communities with regards to the importance and benefits of these services. Many participants felt by limiting the example to drug-related litter it did not promote the broader health benefits of such services to local communities, and that a public health message would be more powerful. It was reported that the benefits of services which aim to reduce the transmission of Blood Borne Viruses (BBVs) was one that participants felt communities would be supportive of. In addition, a number of participants questioned the evidence that the presence of NSPs reduced drug-related litter.

'I really think there's a clear responsibility to improve the public's understanding and awareness of these services within a public health context and how we aim to improve public health issues. This doesn't come across in the recommendations, at all' - Commissioner.

Drop boxes

The example of drop boxes and reducing drug-related litter prompted significant debate across the focus groups, with many participants having had previous negative experiences of attempting to introduce drop boxes in public arenas such as car parks, gyms and toilets. A small number of participants described it as 'a nightmare' resulting in costing them 'a lot of time and effort' with little outcome, whilst others perceived resistance as an issue:

'With regards to the recommendations about drug-related litter and drop-boxes – I'm not sure all areas have these and it might cause problems for local politicians in terms of implementing it as they might be seen to be supporting drug use' – Public Health Worker

There were a small number of positive comments relating to the benefits of promoting a reduction of drug-related litter to communities and how communities have the potential to inform the most appropriate settings for drop boxes, with some participants reporting a good partnership with local retailers in town centres with regards to this issue.

Gaps within the recommendation

Participants highlighted a number of key partner agencies and stakeholders as missing from the recommendation:

'Who should take action'

- Police and Crime Commissioners, also possibly Chief Constables as they now have potential influence when consulting with the community and assuring members about community safety matters;
- Other primary care service providers, specifically sexual health services;
- Public Health England;

Other groups to consult with:

- Pharmacists and pharmacy counter staff – this point was raised by pharmacists who stated they had a great deal of contact with service users and often limited contact with commissioners. It was felt that this group was underrepresented in consultations on provision.
- A number of participants requested the inclusion of Men Who Have Sex with Men (MSM) under the point relating to **'at risk groups'**. It was reported that in some high risk areas across the country (for example London and Manchester), there is an 'alarming trend' in the increased transmission of HIV and Hepatitis C within this group relating to injecting. In addition, there has been trends of MSM injecting drugs such as Crystal Methamphetamine and Mephedrone, and therefore a need for specific information and services to help to cater for these injecting service users. It was reported sexual health clinics may be more appropriate;
- Established, representative service user groups.

Areas of ambiguity

Participants highlighted two main points that were ambiguous and requested further clarification:

- There was a significant amount of discussion relating to definition of 'local communities' as participants interpreted this to mean different things i.e. 'local residents', 'whole communities' or 'specific communities'. Participants felt that clarification was needed surrounding this issue and asked for a definition of 'local communities' as stated in the recommendation.
- With regards to the reference relating to drop boxes in the example provided – participants questioned whether there was an existing opinion on were these should be placed i.e. within public places or within services?

Recommendation 2 Collating and analysing data

Who should take action?

- Health and wellbeing boards.

- Commissioners of:
  - drug services
  - infectious disease services
  - pharmacy services
  - primary care services.

- Public health practitioners whose remit includes needle and syringe programmes (NSPs) and infectious disease prevention.

What action should they take?

- Collate and analyse local data from Public Health England and other sources to estimate the:
  - Prevalence and incidence of infections related to injecting drug use (for example, hepatitis C and acute septicaemia) and other problems caused by injecting drug use (for example, number of people overdosing).
  - Numbers, demographics, types of drugs used and other characteristics of people who inject, for example:
    - ◊ rates of poly-drug use
    - ◊ number of young people (aged under 16) who are injecting
    - ◊ number of performance and image-enhancing drugs users
    - ◊ people who inject occasionally, for example, when they go to night clubs
    - ◊ other at-risk groups, such as sex workers or homeless people.
  - Number and percentage of injections covered by sterile needles and syringes in each of the groups identified above. (That is, the number and percentage of occasions when sterile equipment was available to use.)
  - Number and percentage of people who had more sterile needles and syringes than they needed (more than 100% coverage).
  - Number and percentage of people who inject drugs and who are in regular contact with a needle and syringe programme. (The definition of regular will vary depending on the needle and syringe programme user and the types of drugs they use.)

- Map other services that are commonly used by people who inject drugs, for example, opioid substitution therapy services, homeless services and custody centres.

Findings

Participants' feedback on NICE Recommendation 2:

Current data collection and issues of inconsistency

Participants reported that services currently collected a 'significant amount of data' and that the majority of the data specified by the recommendation is in line with current data collection. However, it was also reported that there are currently inconsistencies in relation to what is collected, and how, at local, national, and even organisational, levels (the types of data reported to be the most challenging to collate according to a significant number of participants have been summarised under 'wording/ambiguity' below). Some participants agreed that the NICE recommendation may help standardise data collection however it was clear that there was little agreement between participants on what was regarded as the most appropriate data for collection.

Analysed data

Participants reported that internal collation and analysis of service data occurs, but once data is reported to commissioners and other local partnerships, it is rare that the analysed data is reported back to services or, when it is, it is usually out of date. This was particularly the case with fieldwork participants from pharmacies. There was an agreement from the majority of participants that they should receive analysed data to help inform the planning, delivery and commissioning of services. This would also help to benchmark the services against a national standard.

A national approach

There was a strong emphasis on the inconsistent use of the national reporting tool, NEXMS, which participants reported had 'died a death' due to NSPs being considered 'low threshold' services and the lack of a requirement for service users to provide services with significant levels of information. These issues, including no mandatory requirement to implement NEXMS, have resulted in areas collating, reporting and analysing data in different ways. Many participants felt there was a gap in terms of a standardised approach and national system for data collection for NSPs. Participants agreed that developing a national process and system would be helpful in order to obtain 'a more realistic view' of how these services 'meet local need'. It was also clear from responses that the approach needed to clearly set out what should be collated and for what purpose to ensure they do not deter service users from accessing NSPs.

'What should be clearer is how it is going to be used on a wider, national basis. I think a standardised data set that is implemented and used nationally is the only way we can effectively monitor services. We need to be clearer about what is the issue and what are we collecting for. We are low threshold, easily accessible services and we will put people off if we ask loads of questions' – NSP Manager

Pharmacy data

It was felt that some pharmacies may find it challenging to implement this recommendation as collecting information from service users was often difficult i.e. because of a lack of confidential spaces or the 'quick transaction' service in some pharmacies. It was felt that where pharmacies had an appropriate environment and a

good, trusting relationship with service users, data collection tended to be a lot more detailed. A number of commissioners also highlighted that it was challenging to collect data from pharmacies.

Validity of the data

The validity of data was questioned as services 'entrust' service users to give accurate and honest data. Data relating to numbers in treatment was given as an example where service users may tick the box perceived as the 'right box' just to be 'left alone'.

Data sources

There were inconsistencies between whether services received data from PHE or other sources, as the recommendation seemed to suggest. In addition, where areas received this data, the meaningfulness of this data to NSPs was questioned with a number of participants reporting it was 'out-of-date' and not always relevant to NSPs.

'We've had estimates about prevalence from the NTA 2010/11 but it was irrelevant to our local figures; national and Local Authority figures bore no resemblance and didn't reflect our local service figures, for example, with heroin and crack injecting or use decreasing – this was not the case for us' – NSP Manager.

It was felt that it would be useful for services and commissioners to know what data was being held by PHE and how local data is fed into national data. There was a consensus amongst participants who welcomed 'real-time' data from PHE and feedback on service data in order to identify trends and respond appropriately to need.

'The data you get is an analysis of what we were doing 6 months ago so its not very meaningful' – Provider.

'I don't know what data is held by PHE, data would be welcomed by PHE, especially prevalence and incidence of Hep C, and it would be good to have guidance on what PHE is collating and how this is reported to partnerships' – Public Health Worker.

A smaller number of participants reported there was a 'slight issue' with PHE's lack of understanding of NSPs, in particular the confidentiality element and there being no requirement for service users to provide information. There was a concern that having such a requirement, or trying to collect a lot of data, could deter service users from accessing services, which in turn, could lead to a broader Public Health issue, for example, people sharing equipment.

Wording/areas of ambiguity

A number of issues were highlighted in relation to the wording or areas of ambiguity within recommendation 2:

- One participant suggested changing the wording in the first line **'and other sources to estimate'** to 'and other sources to ***determine***'.
- A further participant felt that there needed to be an emphasis on the 'reliability' of the evidence being collated and analysed. The participant therefore suggested that the wording should include 'from a range of ***reliable*** sources'.
- Many participants felt that the sentence **'collate and analyse local data from Public Health England and other sources to estimate the…' could**

be clarified: as many of the participants did not receive information from PHE or consistent 'other sources'. It was felt the lack of a standardised approach to what data was received was a concern for this area of work.

- It was also felt there were some issues of ambiguity, as the phrases drug users and drug injectors were used interchangeably.
- In the example provided in the list, 'people who inject occasionally'... – 'when they go to night clubs', participants felt confusion and suggested that the recommendation led the reader to feel that they had to collect data from this cohort, which participants felt would be challenging to collect.
- Within the point, **'Prevalence and incidence of infections…'** to explicitly distinguish between 'viral' and 'bacterial' infections.
- Participants reported that it was not clear as to who collects, or is expected to collect, the data on young people – adult services or young people services?
- Many participants reported the follow two points as being unclear:
    - 'Number and percentage of injections covered by sterile needles and syringes in each of the groups identified above. (That is, the number and percentage of occasions when sterile equipment was available to use.)
    - Number and percentage of people who had more sterile needles and syringes than they needed (more than 100% coverage)'.

In relation to the latter two sub-points, providers questioned the usefulness of collecting this information for NSPs, and were unsure as to how the information would be obtained:

'I wouldn't understand how to monitor 'number and percentage of… It doesn't make it clear how the information should be collected and why, it needs to be more clear and meaningful' – Provider.

'There is ambiguity around those points as I wouldn't know what this would tell us or how we would get this data' – Provider.

Recommendation 3 Meeting local need

Who should take action?

- Health and wellbeing boards.

- Commissioners of:
  - drug services
  - infectious disease services
  - pharmacy services
  - primary care services.

What action should they take?

- Ensure the results of consultation and data analysis (see recommendations 1 and 2) form part of the local joint strategic needs assessment.

- Commission a range of generic and targeted needle and syringe programmes to meet local need, based on these results. For example, ensure services are offered at a range of times and in a number of different locations. Take the geography of the area covered into account (for example, whether it is an urban or rural area). Targeted services should focus on the specific groups identified.

- Ensure services aim to:
  - Be accessible.
  - Increase the proportion of people who have more than 100% coverage (that is, the number who have more than 1 sterile needle and syringe available for every injection).
  - Increase the proportion of each group of people who inject drugs who are in contact with a needle and syringe programme.
  - Ensure syringes and needles are available in a range of sizes and at a range of locations throughout the area.
  - Encourage identification schemes (involving, for example, the use of coloured syringes).
  - Consider supplying low dead-space injecting equipment (if this can be obtained at equivalent prices).
  - Offer advice and information on services that aim to: reduce the harm associated with injecting drug use; encourage people to stop using drugs or to switch to a safer approach if one is available (for example, opioid substitution therapy); and address their other health needs. Where possible, offer referrals to those services.

- If applicable, commission outreach or detached services for areas where there are high levels of drug use or populations that do not use existing needle and syringe programmes.

- Develop plans for needle and syringe disposal, in line with Tackling drug-related litter (Department for Environment, Food and Rural Affairs 2005). Include the provision and disposal of sharps boxes for the safe disposal of needles. Consider providing public sharps bins (drop boxes) in areas where drug-related litter is common. Work with members of the local community, people who inject drugs and the local police service to agree the location for drop boxes.

- Commission integrated care pathways for people who inject drugs so that they can move seamlessly between the full range of services, including treatment

services.

Findings

Participants' feedback on NICE Recommendation 3:

Strengthening current practice

Across the focus groups there was support for this recommendation and what it aimed to achieve. However, there were a number of issues highlighted with regards to where the focus should be for this recommendation. There were a number of points which participants felt would strengthen the recommendation and further improve current practice.

With regards to current practice, participants felt that majority of the recommendation was already implemented, with a large proportion of participants stating that their local area had good or sufficient coverage in terms of geography and opening times.

A number of participants felt that the recommendation, and current commissioning practices, focussed on the 'geography' of services as opposed to the 'demographics' of the service user group. Including demographics would enable services to be more accessible and responsive to the needs of the different cohorts of service users.

'There needs to be reference made to the demographics of different client groups that are non-geographical. Where it says, 'for example' 'MSM' could be included
– Provider

Local data, and the issues with data as discussed in recommendation 2, also needed to be more comprehensive in order to improve practice and implement this recommendation effectively.

Drop boxes and drug-related litter

In relation to the commissioning of drop boxes, it was highlighted that this was often a 'politically sensitive' issue, and one that may be difficult to implement in practice due to the challenges surrounding 'selling' the concept to the wider community, politicians and even to local partnerships. The guidance on tackling drug-related litter was viewed to be very important in order to gain stakeholder buy-in however a number of participants, including commissioners, proposed a need for 'refreshed' guidance as many participants felt that the 2005 guidance was out-of-date as it did not make 'responsibilities clear' and did not support them to influence their colleagues in the area of drug-related litter.

Equipment issues

In relation to low dead space injecting equipment, it was stated that a culture change was needed as there was potential resistance from service users to switch to this equipment. There was a need to ensure the right messages were conveyed by services about a decrease in wastage and improved health benefits. Within a number of groups, there was a limited understanding relating to low dead space equipment.

A number of participants also had concerns with the point relating to **'encouraging identification schemes (involving, for example, the use of coloured syringes)'**

as the anecdotal evidence-base gathered by services from service users suggested that coloured syringes did not prevent the accidental sharing of equipment. In addition, participants reported that the use of this type of equipment should not be encouraged nationally as it fails to convey the right message of a 'clean kit for each hit'.

Pharmacy provision

There was significant discussion in relation to the role of pharmacies and the provision that pharmacies offer. Participants' views and experiences of pharmacy provision were divided.

There was support for pharmacy provision where pharmacies see the NSP service as an important part of their service to the local community, and were committed to this aspect of their work. Where this was the case, a number of suggestions relating to optimising this provision were made:

- They have a lot of contact with service users, and therefore they are a key signposting and onward referral agency;
- They can gain 'the trust' of service users, and therefore can hold consultations in order to gain specific information relating to the individual;
- Pharmacists should be represented on local NSP forums and meetings;
- Pharmacies could also be utilised in other ways, for example, testing and vaccinating service users.

There were also some concerns in relation to pharmacy provision with one participant stating they should be complementary to specialist NSP's rather than alternative services:

- Pharmacies had a breadth of different clients and do many different jobs which impacts on their time to engage with individuals. One pharmacy had developed a specific stand for the client group in the chemist, with information on signposting, techniques, viruses, wounds – but recognised that not all staff in chemists were au fait with this level of information.
- Training pharmacists was also an issue and participants felt that this should be mandatory for pharmacists and counter staff.

Inaccuracies within the recommendation

Participants highlighted inaccuracies within the point - **'ensure the results of consultation and data analysis (see recommendations 1 and 2) form part of the local Joint Strategic Needs Assessment'**:

- The level of detail being recommended would not usually be included within the Joint Strategic Needs Assessment (JSNA). Locally, the JSNA was regarded as a 'high level' document and would not include this level of service.
- When thinking about young people, local area needs assessments would not cover NSP so this was viewed to be irrelevant.

Wording/areas of ambiguity

A number of participants highlighted issues with wording or possible areas of ambiguity within recommendation:

- Participants questioned why the equivalent prices were mentioned in relation to 'low dead space injecting equipment';

- There was an implication that drop boxes were the 'expectation' and participants suggested that this should be explored locally.

Strengthening the recommendation

A number of issues were raised throughout discussions which prompted participants to think about how the recommendation could be strengthened:

- It was suggested that a specific point relating to ensuring services for specific groups are commissioned (based on local need) needed further emphasising in addition to how this provision should be set up in practice (based on best practice), for example, young people not mixing with adult injectors**;**
- Including a point about meeting the needs of hidden or hard to reach groups for example young Asian males 'using steroids', men who have sex with men (MSM);
- Including provision within custody suites. This was supported by many of the participants as it was felt that if NICE included custody suites then there would be 'less resistance' from commissioners;
- In relation to the point - **'Commission integrated care pathways for people who inject drugs so that they can move seamlessly between the full range of services, including treatment services'** it was suggested that *'and sexual health services'* should be included;
- The recommendation could be more aspirational in terms of what services deliver, participants stated that:
    - *'There needs a point adding to say services should 'strive to reach hard to reach communities'* - Provider
    - *'The section under "ensure services offer advice and information on services that aim to:" this is quite standard and should be more aspirational. We should have leaflets about local services in addition to safer injecting practices'* - Provider
    - *'The point about outreach and detached services – these are good ideas however I think we want more of a focus on people being attached to services where there is more aspiration and recovery'* - Provider
- Under **'who should take action'**, it was felt that the following should be included:
    - commissioners of sexual health services / GUM clinics;
    - Local Pharmaceutical Committee should be included.
- Under the point **'Offer advice and information on services that aim to: reduce the harm associated with injecting drug use; encourage people to stop using drugs or to switch to a safer approach if one is available (for example, opioid substitution therapy); and address their other health needs. Where possible, offer referrals to those services',** a number of items should be added:
    - That written information on local services should be available and given out in addition to the information as above;
    - That reference to Blood Bourne Viruses (BBVs) is made explicit within the point;
    - There was a suggested change in the wording of **'where possible, offer referrals to those services'** to 'where possible, *make and encourage* referrals to those services' as this would add a more assertive wording;
    - It was suggested that the word *'current'* is inserted in **'Offer advice and information on…'**

Recommendation 4 Monitoring services

Who should take action?

- Commissioners and providers of needle and syringe programmes (NSPs).
- Public health practitioners whose remit includes needle and syringe programmes and infectious diseases.

What action should they take?

- Providers of needle and syringe programmes should collect data on service usage:
  - All services should monitor the number and types of packs or equipment they distribute.
  - Specialist services should collect more detailed data on: the amount and type of equipment distributed, the demographic details of the person who is injecting, along with details of their injecting practices and the drugs they are injecting (see recommendation 2).
- Commissioners of needle and syringe programmes and public health practitioners should ensure a local mechanism is in place to aggregate and analyse the data collected on an annual basis. The aim is to build up a picture of injecting in the local area. This data should be used as part of the collecting and analysing data process (see recommendation 2).
- Ensure local service use data are available, in anonymised form for relevant national bodies and research units.

Findings

Participants' feedback on NICE Recommendation 4:

Current practice

The recommendation to monitor services was fully supported by participants, with agreement that monitoring should take place regularly i.e. quarterly. A number of areas have involved service users in the monitoring of services and others have applied a 'mystery shopper' approach. It was felt using an example such as this could be included in the recommendation.

Data issues

A number of issues, which impact on the effective monitoring of services, were highlighted; many of these are also discussed in recommendation 2:

- A lack of knowledge relating to where local data goes following services collecting it and inconsistent approaches of services receiving local data from bodies such as Public Health England and feedback to services in relation to benchmarking/service performance;
- Inconsistencies in data collection on a national, local and organisational level;
- Levels of data collected by pharmacies;
- The need for a national reporting tool and a standardised approach;

- Reliance on service users to provide honest and accurate data, prior to trusting relationships being forged, has the potential to impact on the validity of the data collected;
- Collecting data on specific groups/hidden groups i.e. young people, PIED injectors, MSM, homeless.

'The issue with this recommendation and with recommendation 2 is <u>how</u> this should happen. Not all areas have electronic databases and it's hard to report. There are inconsistencies across the field in collecting data and therefore this impacts on how services are monitored. There is nothing nationally in place to help you monitor services… and compare performance across areas. This will give local commissioners more leverage in changing environments' – Public Health Practitioner

'Yes its absolutely important. It is useful for us to know about how your service is doing against others. It would be useful to have national and regional trends so that we know what's on the increase to be able to meet local needs' – Provider

Gaps within the recommendation

- It was reported that monitoring services should also include gathering information from partner agencies, external to drugs services, which service users may access for the provision of injecting equipment, advice and information. This could include (but is not limited to) gyms frequented by those injecting performance and image enhancing substances and sexual health services for MSM service users;
- In addition, closer working between adult and young people's services was important in order to monitor injecting behaviours;
- Current practice also included the collection of date of birth and postcode which was reported should be included within the recommendation.

Wording/ areas of ambiguity

- In relation to the point - **'Commissioners of needle and syringe programmes and public health practitioners should ensure a local mechanism is in place to aggregate and analyse the data collected on an annual basis'** – it was felt that it would be more appropriate to say *'collected on a basis that fits in with your commissioning structure'* as commissioners reported they would be doing this on a more regular basis.
- With regards to the final point – **'ensure local services use data are available, in anonymised form for relevant national bodies and research units' –** participants felt as if this was too vague and that there should be some clarity around 'why should it be made available and what is going to be done with the data?', and 'whether this is for local information or to inform national practice?
- Under the point for **'Specialist services should…'** – '*where possible'* should be added to make it more achievable for services.

Recommendation 5 Developing a policy for young people aged under 16

Who should take action?

- Children's safeguarding boards.
- Commissioners and providers of needle and syringe programmes.
- Commissioners and providers of young people's services.

What action should they take?

- Work together to agree a local, area-wide policy on providing needle and syringe programmes and related services to meet the needs of different groups of young people aged under 16 who inject drugs.
- Make the governance responsibilities of drug services and safeguarding boards clear. The safeguarding board should approve the local policy.
- Ensure the policy covers the following:
  - How to achieve the right balance between protecting (safeguarding) the young person and providing them with advice on harm reduction and other services. This should take due account of: the young person's capacity to consent; the risks they face; the benefits of them using services; and the likelihood that they would inject anyway even if sterile needles and syringes were not provided.
  - How to encourage young people to ask for advice and help from staff providing the services (as well as, or instead of, providing them with needles, syringes and injecting equipment).
  - How to assess service users: their age and how mature they are; the degree or seriousness of their drug misuse; whether the harm or risk they face is continuing or increasing; and the general context in which they are using drugs.
  - The skills, knowledge and awareness that staff need to provide services.
  - Parental or carer involvement: generally this should be encouraged, although it is not always possible or appropriate.
  - Pharmacy provision: pharmacies with staff trained in assessing young people's competence to consent may be suitable venues for providing young people with needles, syringes and injecting equipment, if the young person is also encouraged to make contact with specialist services.
  - The role of needle and syringe programmes as part of a range of services for young people and including seamless transition from youth to adult services.
- Regularly review the policy.

Findings

Participants' feedback on NICE Recommendation 5:

All participants supported and welcomed the introduction of a recommendation focussed on young people, with a number of participants stating it was 'long overdue'. Participants were under the impression that discussions on such a topic as young people would generate a number of issues which would need to be carefully 'thought through'.

'What's in this recommendation is good. It will lead to some interesting discussions locally and nationally. Safeguarding and parental involvement will be the interesting topics. Debates will also be focused on the no limits on the amount of equipment that is distributed. We have to have these discussions and make sure the young person is at the centre' - Provider

Generally, participants reported that it was relevant to them, however, there were a small number of participants from adult services/commissioning that did not think this recommendation was relevant to them.

Current practice

Currently, on the whole, participants reported that they had processes and pathways in place to respond to the needs of the young person. Many participants made positive reference to the Drugscope guidance which had been used to guide current practice, and a number of participants stated that they had, or were in the process of developing, a working policy. It was common practice to ensure that young people were referred into or accessing treatment services in addition to ensuring the young person still received the equipment and the harm reduction advice they needed. Many participants felt there were very low numbers of service users in the under 16 age group, and more of a need with those aged 16, 17 and 18 years old.

Concerns and challenges for the recommendation

There were a number of concerns and challenges highlighted by participants for the recommendation.

<u>Barriers: Local Safeguarding Children's Boards (LSCB)</u>
Participants agreed that safeguarding was very important and would always be a consideration when working with this group (and with vulnerable adults). However, there was a divide in opinion with regards to how supportive the involvement of Safeguarding Boards would be in the development of a local policy for young people.

Some participants suggested that the involvement of safeguarding in the development (and implementation) of a local policy may be 'problematic' and may act as a 'barrier'. It was suggested that highlighting this issue to the LSCB may prompt a response that include suspending a service to young people until a policy is then developed. In addition, once a policy was developed, there were further concerns regarding the negative impact on current informal practices, which, in reality, worked well. In addition, it was argued that the approval of a policy by the LCSB's may be easier for under 18's rather than for under 16's.

<u>Concerns regarding the age</u>

There was significant debate around the age group defined by the recommendation and many participants agreed that the policy age should be increased, for example, to under 18's.

Levels of competency within adult and pharmacy services

In terms of assessing a young person under 16, the use of the Fraser guidelines and Gillick competencies were essential, therefore this was a competency-based issue for those delivering the service. In addition the support for young people requiring this type of service would be different to an adult i.e. intensive and wraparound support, linked to treatment services. Therefore it was suggested that there was a training requirement for adult services and pharmacy provision in areas such as the Fraser guidelines and Gillick competencies, in addition to, an understanding of the level of service appropriate for a young person, before this recommendation could be implemented.

Pharmacy provision

There was some reluctance from participants in relation to pharmacies being an appropriate outlet for the provision of NSP to young people due to a perception that they were not equipped to assess young people, advise them on harm reduction or complete a CAF. A number of other factors also made pharmacies a less attractive option for delivering services to young people, according to participants:

- The use of locum pharmacists within pharmacies;
- Many pharmacists operate at Level One only;
- Where there were low-usage pharmacies there was a reliance on pharmacist's 'good will'. In such cases, it was felt that a good quality assessment in the pharmacist was 'unlikely';
- Some pharmacies lack confidential spaces and therefore more specialist Young People's services, rather than generic pharmacy services, were deemed more appropriate environments.

Parental or carer involvement

Many participants felt that the involvement of parents or carers would be a challenge and may deter engagement with young people.

Areas of ambiguity

Involvement of safeguarding

- The recommendation was ambiguous in relation to who would lead on the policy – drugs services or safeguarding teams – and who would be ultimately accountable for ensuring the policy was adhered to?

Age

- The rationale of a policy for under 16's was unclear and participants highlighted other guidance and structures that this conflicted with, for example:
  - The Children's Act addressed under 18's;
  - Specialist young people's services are for under 18's and sometimes up to 21 years old, there a vast variations across local areas;
  - Under 18's fits within commissioning frameworks for young people's and adult services;
  - NTA guidance (Assessing young people for substance misuse, 2007) covers up to 18;
  - NDMTS.

Inconsistency within national guidance presents an issue for practice and may have the potential to leave staff 'vulnerable' in relation to what was the correct guidance to follow. This vulnerability related to particularly to those in adult services. In addition, guidance focussing on under 16's revealed a 'grey area' with regards to what services are delivered to the 16 to 18/19/21 age groups.

Assessing young people

There were concerns around the points relating to the assessment of a young person's 'maturity' and that it was ambiguous in terms of what the recommendation was asking for. Participants questioned the process if staff felt that the young person lacked maturity, would they 'not supply' the young person with the equipment they needed.

Strengthening the recommendation

Age

It was suggested that the recommendation covered under 18s and that a separate sub-recommendation could be included for under 16's and under 13's in line with Fraser guidance. There was also a sense that an under 18 recommendation could further strengthen the transition from young people to adult services.

National template

Participants stated that there needed to be a nationally driven, example policy that could be tailored locally.

A number of participants were positive about the role and involvement of safeguarding boards, highlighting that the support of this body can help to optimise delivery of services to young people. Examples of best practice in this area could be identified and shared nationally, as a template for practice.

Assessment issues

Participants felt that the area of the recommendation relating to assessing young people needed to be 'more robust' and it needs to consider questions such as 'what are we assessing them for, and why? Is there a minimum age limit?'.

Participants felt that there needed to be clearer guidance nationally around working with young people from an adult services perspective, particularly around assessing young people and how this should be done. It was suggested that the recommendation, for extra clarity, could emphasise the need to use validated tools to assess young people and give examples of these.

Peer education opportunities

Young people were viewed to be an 'uninformed' group who relied on others to educate them on drugs and injecting practices. There was an agreement that peer-to-peer training was vital in this respect and in relation to messages about BBVs, and that the recommendation could include this as a consideration.

Hidden need

Many participants discussed a 'hidden need' with regards to young injectors as they can access services such as gyms and buy equipment from the internet. In addition, pharmacies may appeal to young people as they are more anonymous. It was felt that this hidden need could be made more explicit with in the recommendation.

Recommendation 6 Providing a mix of services

Who should take action?

- Health and wellbeing boards.

- Commissioners of:
  - drug services
  - infectious disease prevention services
  - pharmacy services
  - primary care services.

What action should they take?

- Use pharmacies, specialist needle and syringe programmes and other settings, and approaches, including outreach and detached services, to provide geographical coverage and a balanced mix of the following levels of service:
  - Level 1: distribution of injecting equipment either loose or in packs, suitable for different types of injecting practice, with written information on harm reduction (for example, on safer injecting or overdose prevention).
  - Level 2: distribution of 'pick and mix' (bespoke) injecting equipment plus health promotion advice (including advice and information on how to reduce the harms caused by injecting drugs).
  - Level 3: level 2 plus provision of, or referral to, specialist services (for example, specialist clinics, vaccinations, drug treatment and secondary care).

- Coordinate services to ensure injecting equipment is available throughout the local area for a significant time during any 24-hour period. For example, encourage needle and syringe provision in pharmacies with longer opening hours. Or increase capacity through the use of out-of-hours vending machines for groups that wouldn't otherwise have access to services – or not at the time that they need them.

- Ensure services offering opioid substitution therapy also make needles and syringes available to their clients, in line with the National Treatment Agency Models of care for treatment of adult drug misusers: update (2006).

Findings

Participants' feedback on NICE Recommendation 6:

Current practice and challenges for the recommendation

The vast majority of participants supported the recommendation and reported that its content reflected current practice and agreed that sufficient geographical coverage was in place in their locality.

There was however some debate about whether geographical coverage should be the priority. It was suggested that the 'quality and breadth of service delivery' and meeting the needs of the 'demographics' were of greatest importance. Participants believed this message could be strengthened in recommendation 6.

'I don't think the message is right in this recommendation, its not about the coverage of services, its about making sure people have enough equipment to last them' – Pharmacist

A number of participants also discussed the importance of NSP's being attached to services and not 'spreading distribution too thinly':

'With this recommendation, if it is taken literally then, if we spread distribution too far then we will lose them [service users] and they will be out there and we won't be able to engage with them. Only when we're engaging with them are we getting them to seriously think about the risks of sharing' – Provider

For a number of managers and commissioners, financial restraints were also seen as a factor which would present challenge for implementation.

'I'm looking at this with recommendation 2 and targeted and generic services is great. But we need to consider that resources have been cut' – Provider

In addition, it was also felt that Health and Wellbeing Boards would currently need 'a lot of help' and 'support', as well as education in order for them to 'run with it'.

Vending machines

The use of the example in the recommendation relating to vending machines provided much debate across all focus groups and interviews. There was a clear divide between whether participants supported this element of the recommendation or not.

Where participants welcomed this type of provision, they emphasised the importance of the placement of such outlets within controlled environments, with some participants suggesting hostels and A&E being ideal settings. A number of examples were highlighted by group members as to where vending machines had been previously implemented including within police stations in South Wales and a 24 hour outlet in an A&E Department in Warwickshire. There was a suggestion that case studies could be cited in the recommendation.

Other participants raised concerns relating to the use of vending machines and it was felt that this would limit the potential for discussions/engagement with a Harm Reduction worker. It was felt that for young people it was particularly important that they had access to a worker, and that the use of the vending machines where young people were concerned could drive this cohort of service users further 'underground'. Maximising the potential for that 'teachable moment' with all service users was a key consideration for participants.

In addition, as with the example of drop boxes, there were concerns about vending machines being 'politically sensitive' and therefore local councillors and politicians may find it difficult to implement these locally.

'The same issue arises with vending machines as with drop-boxes – this might be difficult to implement politically' – Public Health Worker.

'I'm not sure about vending machines, you need to provide a service when giving out needles and syringes and there's no advice, or conversation with a harm reduction worker, with this type of provision' – Pharmacist.

Pharmacy provision

There were some interesting discussions with regards to the provision of NSP via pharmacies. See recommendation 8 for discussions relating to pharmacy provision.

Wording/areas of ambiguity

There were a number of areas within the recommendation highlighted as being ambiguous and in need of clarification:

- There was some debate regarding the final point - **'ensuring services offering opioid substitution therapy also make needles and syringes available to their clients, in line with the National Treatment Agency'**
    - A number of participants did not think this was appropriate, although links and robust pathways between these services were essential.
    - There was a sense that the recommendation needed to be more specific and that the word 'ensure' on this point could cause a 'backlash'. Participants reported concerns such as 'it sets up a dichotomy', 'can handing out kit and methadone be seen to be positive'?, 'this becomes an ethical issue' and 'it causes a dilemma about what services and workers are meant to provide'.
- One participant felt the wording in recommendation 10 was more appropriate and could be used within this recommendation – **'Are provided at times and in places that meet the needs of people who…'**
- One participant felt that the use of the word *'services'* on the point stating **'coordinate services to ensure injecting equipment is available throughout the local area for a significant time during any 24-hour period'** should be replaced by the word *'provision'* as it was felt that it is not for service providers to provide this and it seems to be directed at providers in the way its written.
- There were calls for the recommendation to be more specific, instead of using terminology such as 'significant' and 'throughout' the local area or inserting the word 'adequate' before the term 'geographical'.

Gaps within the recommendation

<u>'Who should take action?'</u>

A number of participants felt there were some key groups who should be included under this section of the recommendation:

- Crime and Disorder Partnerships (CDRPs) were key partners within a number of localities;
- Commissioners of sexual health services.

<u>Information and advice across all levels of provision</u>

Many participants felt that information and advice relating to local drug treatment services, in addition to harm reduction, was available, and highlighted within the recommendations, as key across <u>all</u> provision of NSP including pharmacy provision. A number of participants felt that this should be the standard across all levels of provision.

<u>Tailored provision</u>

With regards to young people it was felt that the recommendation did not make it clear what level of service would be suitable for this service user group. Many

participants highlighted that NSPs for young people should be delivered separately from a service being accessed by adults. Participants also suggested that young people may be accessing equipment in venues such as gyms, and agencies need to engage and 'reach out' to these venues in order to engage with this cohort.

It was also identified by participants that having tailored services for other groups who may not access drugs services, for example Performance and Image Enhancing Drug (PIED) users and MSM, should be made explicit within the recommendation.

One suggested recommendation was:

'Where possible, have separate, tailored services for each demographic of service user' – Provider

Criminal justice services

A small number of participants also highlighted that they felt criminal justice services, such as custody suites and prisons were excluded from the recommendation. It was suggested that these should be included as there was a need for safer injecting equipment and information in these settings – it was highlighted that these are 'transient passengers' and 'captive audiences'.

A number of missed practices

- A number of participants raised that there should be greater emphasis with regards to reducing the transmission of BBVs within the recommendation;
- What about providing oral testing?
- Messages on vein care?
- Delivering hard hitting messages such as 'this is how you can get the best out of your veins'
- Liver Function Tests (LFT) and cholesterol checks, particularly for steroid users

Training and guidance

Across all focus groups there was support for the inclusion of training within the recommendation, especially with regards to expanding services to young people.

With regards to guidance, a large number of participants stated they were 'surprised' to see 'Models of Care' cited within the recommendation, and perceived this to be 'out-of-date' guidance. Participants questioned why more up-to-date guidance was not referenced, for example, Strang's *Medications in recovery re-orientating drug dependence treatment*.

Recommendation 7 Providing equipment and advice

Who should take action?
Needle and syringe programme (NSP) providers.

What action should they take?

- Provide people who inject drugs with needles, syringes and other injecting equipment. The quantity provided should not be subject to a limit but, rather, should meet their needs. Where possible, make needles available in a range of sizes and colours and provide syringes in a range of sizes.
- Do not discourage people from taking equipment for other people (secondary distribution), but ask them to encourage those people to use the service themselves.
- Ensure people who use needle and syringe programmes are provided with sharps bins and advice on how to dispose of needles and syringes safely.
- Provide advice relevant to the type of drug and injecting practices, especially risky practices such as injecting in the groin or neck.
- Provide other equipment associated with injecting drugs and encourage people who inject drugs to switch to a safer method, if one is available.
- Encourage people who inject drugs to mark their syringes and other injecting equipment or to use easily identifiable equipment to prevent sharing.
- Encourage people who inject drugs to use other services that aim to: reduce the harm associated with injecting drug use; encourage them to stop using drugs or to switch to safer methods if these are available (for example, opioid substitution therapy); and address their other health needs. Advise them where they can access these services.

Findings

Participants' feedback on NICE Recommendation 7:

Support for the recommendation

Participants supported the recommendation and felt it was in line with current practice. There were a number of areas which participants highlighted as requiring further consideration to strengthen the recommendation.

Limits of equipment
In principle, all participants supported the statement **'the quantity provided should not be subject to a limit but, rather, should meet their needs**' and welcomed the sentiment that provision should be based on need.

Secondary distribution
The statement for secondary distribution received strong support across all focus groups and interviewees, and participants emphasised that within current practices

workers would be expected to encourage people to come in themselves. A number of participants stated that their services had internal policies around secondary distribution and that generally they would not place a limit on providing equipment for secondary distribution.

'I like the element in this recommendation about secondary distribution as the benefits far outweigh them sharing. We know people use together. I support the secondary distribution and individuals themselves coming into the access the provision' - Provider

Implications for implementation

Limits of equipment - caveats

There was consensus across all focus groups and interviews that no limitations were placed on equipment for adult opiate and/or crack injectors. However, in practice, limitations may be applied for specific groups, so a caveat was attached to the support for this statement for the following:

- For young people the 'no limits' on equipment was not always applied, in order to maintain contact with the young person.
- For PIED users, a number of reasons were given:
    - As a way of maintaining contact as many do not have a great deal of interaction with services and can 'disappear for years'. Some services look at providing enough equipment for a 'cycle' with the plan to see someone in between 'cycles';
    - Gym personnel would access the service for extremely large quantities of needles and syringes – 'hundreds' – and the service had to have a limit on equipment in this instance – in some services internal policies have been developed. It was reported that this practice was effective in increasing the numbers of steroid users to access services, many of who had poor knowledge of 'stacking and cycles';
    - This latter point relating to PIED users was disputed by a minority of participants who felt they should not be limited and should be treated 'the same as heroin users'. Many participants recognised there was a 'difficult ethical balance' to strike as if the service did not provide enough equipment then they could 'lose them'.
- For equipment being dispensed for secondary distribution it was reported that it is not always feasible to implement this in practice as consideration needs to be given to how much equipment is appropriate to provide.
- A number of participants discussed costs and restraints on budgets as impacting on placing limits. This was the therefore linked to the rationale for suggesting in 'Gaps within the recommendation' that commissioners are involved in taking action on this recommendation.

Provision for those out of area

A number of participants reported anecdotal evidence suggesting that service users were accessing NSPs outside of their locality and this may lead to local commissioning implications in the future.

Training and guidance

There was a suggestion that the recommendations could usefully signpost readers to current information sites and guidance that workers can access in relation to the following:

- There was a concern around the lack of training and accessible information for PIED use, particularly in relation to the vast number of types of steroids and courses, as well as the alternative methods of use.
- It was also reported that there needed to be further debate and guidance around injecting in the neck.

Giving the right messages

- As previously mentioned, an issue highlighted by a number of participants related to the use of coloured barrels ('never share' equipment). It was reported that coloured equipment was not always effective as people injecting together may have chosen to use the same colours'. There was a sense that service users needed further educational input in this regard.
- A number of participants reported that 'marking your syringe' was an 'age old' practice and that the message should be 'a clean kit for every hit'. In addition, there was discussion around the importance of giving the messages that educate users - 'your veins will last longer if you use a clean syringe'.
- Pictorial messages in packs with syringes which provide easy to understand diagrams on safe practices were suggested as a potential option for the future.
- Harm reduction and information relating to local contacts and services were considered to be essential to anyone receiving packs of needle, syringe and other injecting equipment.

Other equipment and paraphernalia

Spoons

- One participant felt that there was too much of an emphasis on needles and not on other equipment such as spoons and not sharing these. Spoons are shared as they hold heroin and people do not want to waste it. It was suggested that advice should be focussed on a 'longer hit' – 'this will get more drugs into your body' – messages to which some service users may be more receptive.

Water

- There were a number of participants who highlighted that they were able to provide water whereas others were not commissioned to provide this service, but wanted to. These discussions raised issues in terms of consistency of service.

Foil

- There were numerous discussions about the use of foil and how this differed between localities. Participants were made aware that NICE could not recommend items that were not yet legal. One participant felt that there was not the evidence base there to say providing foil would be safer and argued that services were more likely to get a different type of 'foil-using' client group then getting people to switch from injecting to foil use.

Wording/areas of ambiguity

- With regards to the point – **'Do not discourage people from taking equipment for other people (secondary distribution), but ask them to encourage those people to use the service themselves'** – this should worded more positively and start with *'People should be encouraged to'*
- Within the point **'encourage people who inject drugs to mark their syringes…'** – the term, '***accidental*** *sharing* should be inserted'.
- With regards to the last sentence within the last point, **'advise them where they can access these services'**, the recommendation could include,

*'advise , **make and encourage** access to these services'* in order to strengthen practice in this area.

- A number of participants felt that the recommendation was too focussed on opiate-based practices and felt that the examples of 'groin and neck injecting' and 'switching to safer methods' was an illustration of this.
- The point relating to **'ensure people… are provided with sharps bins'** should be changed to *'have access to sharps bins'* as the original wording leads the reader to believe that it has to be a one-on-one exchange, plus some service users discard of the bins as soon as they have received their pack.
- One participate suggested that using the word *'encourage'* in the last bullet point – **'encourage people who inject drugs to use other services that aim to'** undermined the work of harm reduction services and that more appropriate wording should state *'ensure pathways and information are available to other services'.*

Gaps within the recommendation

Within the section **'Who should take action'** a number of suggestions were made as to which other groups should be included:

- Commissioners of services involved in the provision of injecting equipment;
- Other services/providers who are engaging with injectors 'elsewhere' who do not have a remit of NSP, for example (but not limited to) sexual health services.

Recommendation 8 Community pharmacy-based needle and syringe programmes

Who should take action?

- Community pharmacies that run a needle and syringe programme (NSP), regardless of the level of service they offer (see recommendation 6).
- Coordinators and commissioners of community pharmacy-based needle and syringe programme services.

What action should they take?

- Ensure staff who distribute needles and syringes have received appropriate training for the level of service they offer. As a minimum, this should include awareness training on the need for discretion and the need to respect the privacy of people who inject drugs. It should also include training on how to treat people in a non-stigmatising way.
- Ensure staff providing level 2 or 3 services (see recommendation 6) are trained to provide advice about the full range of drugs that people may use. In particular, they should be able to advise on how to reduce the harm caused by injecting and how to prevent and manage an overdose.
- Ensure staff have received health and safety training, for example, in relation to blood-borne viruses, needlestick injuries and the safe disposal of needles and syringes and other sharp equipment.
- Ensure hepatitis B vaccination is available for staff directly involved in the needle and syringe programme.
- Encourage people who inject drugs to access other healthcare services, including drug treatment.
- Provide sharps bins and advice on how to dispose of needles and syringes safely. In addition, provide a service for safe disposal of used bins.

Findings

Participants' feedback on NICE Recommendation 8:

Current practice

The vast majority of participants supported the recommendation; much of which was current practice. Participants also made suggestions which they felt would strengthen the recommendation. A number of participants stated that this document provided a useful tool to influence the practice of pharmacies within local areas.

Challenges and concerns

For many participants, including pharmacists, there were a number of challenges and concerns which may lead to difficulties in the implementation of all points.

Expertise and knowledge

For some participants the expertise within pharmacies was considered to be low. It was felt that often only one person within a pharmacy would have the appropriate level of expertise and have been trained in this area.

There was also a lack of knowledge amongst non-pharmacy participants regarding the level of contact and expertise pharmacists had in relation to this work. In addition, it was recognised that counter staff within pharmacies are a valuable source but their knowledge is not optimised.

Harm reduction work

Some participants felt that there was more work to be done with regards to the harm reduction information included in packs offered by pharmacies, and that there should be a 'minimum requirement' on information.

'Information on services and potentially a named worker in treatment services should be given out by pharmacies' – Provider

'All pharmacies should be handing out leaflets for harm reduction advice, at the minimum, and then they should be encouraging people to access them' – Commissioner

Training

On the whole, it was considered difficult to train pharmacy staff mainly due to pharmacies being unable to release staff for training. It was felt that this was a 'big concern' (particularly for counter staff – not necessarily pharmacists), and that mandatory training should be recommended. It was stated that a pharmacist within Clinical Commissioning Groups (CCG) could take a leading role. For some participating pharmacists, training had not been available within their locality 'for some time'.

Pharmacy environments

It was suggested that it was difficult for some pharmacies to work in a way that respected the privacy and discretion of service users as they did not have confidential areas and the environment was one of 'over the counter' and 'in and out'.

Young People

There was a lack of consensus in relation to pharmacies working with young people. One group of participants felt that there was potential for pharmacies to play a more active role in relation to safeguarding whereas another group felt pharmacies lacked the necessary skills and expertise to deliver certain aspects of a service to young people such as conducting Common Assessment Framework (CAF) and initiating safeguarding procedures. There were also concerns around the lack of general data collected by pharmacies.

Hepatitis B vaccinations

Ensuring Hepatitis B vaccinations were available for all staff was a controversial aspect of the recommendation and was viewed as a challenge by all focus groups participants and interviewees. Many participants stated that it had 'always been an issue' for pharmacies due to the lack of clarity around who pays for it and which organisation is responsible/accountable for ensuring this is available to pharmacy staff.

Strengthening the recommendation

Pharmacy provision – divided opinions

There was a clear division in the opinions and experiences of pharmacy provision. There is therefore some opportunity for the recommendation to be explicit in what is expected of pharmacies in order to improve the consistency of provision on offer. Where it worked well, pharmacies:

- were committed to this aspect of work and the client group;
- had developed 'a rapport' with service users and knew them 'very well' which in turn meant that service users 'had that loyalty' to them. Services could be expanded where this was the case i.e. providing vaccinations – there was an opportunity to 'grab 'em and jab 'em';
- had an interest in expanding services and providing levels 2 and 3;
- could commit to the training of staff;
- had good relations with drug commissioners, providers and young people services;
- recognised that not all service users want to come into 'drug services' and that by 'providing a deeper level of service was good'.

'With appropriate training, we would have 'no problem' implementing the additional level' - Pharmacist

However for other participants increased joint working and robust pathways were needed.

Increased joint working and robust pathways

For many participants the recommendation needed to explicitly state that pharmacies should engage more with specialist programmes and therefore complement specialist NSP provision.

'Pharmacy provision, I think, needs to be there to complement services rather than be an alternative. Specialist services should deliver the majority of the NSP' – Provider.

'My concern with this one is about not losing the ability to be able to engage with service users wherever they present. Drugs workers are there to sew the seeds and when we're talking about pharmacy provision, because its not their core business, what are they doing with individuals, for example, would they be discussing their substance misuse and addressing it?' – Provider

Participant's felt that the recommendation should have an increased focus on ensuring robust pathways were in place specifically into specialist NSPs, drug treatment services, and services with the remit for infectious diseases, wound care and sexual health. A number of pharmacy representatives also felt that their knowledge of where to refer/signpost service users to could be improved.

Local Forums

A number of areas recognised that pharmacies needed to be represented on local forums, events and meetings about the provision and work of NSPs.

Men who have Sex with Men

It was felt that for the MSM client group, pharmacies along with sexual health services, were optimum places to access injecting equipment, information and advice. Therefore it was suggested that the recommendation made reference to

pharmacies being aware of the needs of a range of service user groups. The influence of the Health and Living Pharmacists agenda could be support staff to become more aware of the broader needs of the individual.

Training

In light of these concerns, a number of participants felt that the recommended minimum level of training, which was already current practice in all areas, was a 'concern' as more and more people are accessing this provision and not getting specialist advice and information.

Pharmacy-based training needed to be focussed on signposting people into treatment and effective harm reduction messages. A number of participants also suggested that it would be beneficial to audit the frequency, uptake and quality of training delivered, and that training for levels 2 and 3 needed to be accredited. One area had introduced a mystery shopper approach as a quality assurance tool.

E-learning training courses – provided by the Centre for Pharmacy Postgraduate Education at the University of Manchester – was also recommended.

Interventions

A number of interventions which pharmacies could be involved in delivering were suggested for the recommendation:

- Referrals to healthcare services for proper wound and infection care;
- Referrals to sexual health services;
- Providing consultations with service users every 6 visits, for example.

Hepatitis B vaccinations

A number of participants highlighted the challenges to implementing this recommendation despite it being part of the previous set of recommendations. Therefore the group suggested that more clarification is given around individuals' roles and responsibilities, as well as clarification about who qualifies for free vaccinations, in order to help providers and commissioners to implement this.

'Who should take action'

Under **'who should take action'**, it was suggested that CCGs and the Local Pharmaceutical Committee were included for this recommendation.

Recommendation 9 Specialist needle and syringe programmes: level 3 services

Who should take action?
Specialist needle and syringe programmes (including pharmacies offering a level 3 service).

What action should they take?

- Provide sharps bins and advice on how to dispose of needles and syringes safely. In addition, provide a service for safe disposal of used equipment.
- Ensure staff have received appropriate training for the level of service on offer.
- Ensure a selection of individual needles, syringes and other injecting equipment is available.
- Offer comprehensive harm-reduction services including advice on safer injecting practices, assessment of injection-site infections, advice on preventing overdoses and help to stop injecting drugs. If appropriate, offer a referral to opioid substitution therapy services.
- Offer (or help people to access):
  - opioid substitution therapy
  - treatment of injection-site infections
  - vaccinations and boosters (including those offering protection from hepatitis A, hepatitis B and tetanus)
  - testing for hepatitis B, hepatitis C and HIV
  - specialist (non-needle and syringe programme [NSP]) services for performance and image-enhancing drug users
  - specialist youth services (for young people aged under 16 who inject)
  - other specialist clinics and services
  - psychosocial interventions
  - primary care services (including condom provision and general sexual health services, dental care and general health promotion advice)
  - secondary care services (for example, treatment for hepatitis C and HIV)
  - welfare and advocacy services (for example, advice on housing and legal issues).

Findings

Participants' feedback on NICE Recommendation 9:

Current practice
The majority of participants agreed that the recommendation supported current practice. A number of participants commented on the increase of steroid users accessing NSPs.

Some participants specifically welcomed the inclusion of sexual health services and referring to or helping young people to access young people's services.

Areas to strengthen the recommendation

Additional interventions

Many participants suggested the inclusion of a number of items within the recommendation under **'offer (or help people to access)'**, which would help to strengthen the recommendation and further align it with current practice:

- Tetanus screening;
- The introduction of Naloxone programmes, where appropriate;
- LFTs and ECGs, particularly for PIED's; this may attract these service users into the service. Where services cannot offer these internally, there should be specific pathways for PIED's to access LFTs. Participants warned that accessing this service via GP's was not sufficient;
- Cholesterol and health checks;
- Some groups stated that the offer of Brief Intervention/Extended Brief Intervention should be included;
- Reference to Dry Blood Spot Testing should also be included, especially as this provision is more cost effective and easy to administer;
- Awareness and/or information on BBVs.
- With regards to the treatment of injection-site infections participants had concerns about the appropriateness of level 3's providing this level of expertise and felt that a pathway to clinical expertise would be most appropriate, where nurses and GP's were not available on site.

Greater joined up working

There were also a large number of participants who felt that there should greater emphasis placed on joint working between all levels of provision and other services within the drug treatment system. A number of participants felt that a missing component from the recommendations were the potential benefits of the role NSPs play in relation to people accessing treatment or recovery-based services.

'Nothing is unexpected in this recommendation. There's something about wording and something that is missing is about linking into services focused on offering people recovery. NSP is often the first step for people and we need to make other things available for people' – Provider.

'The real benefit of these services [NSP's] which isn't discussed with the guidance or recommendations is its benefits is that it provides access into more structured services' – Provider

Hepatitis B vaccinations

Many participants agreed that the recommendation lacked a specific recommendation linked to the requirement for staff working directly in NSPs to have access to Hepatitis B vaccinations, as specified for pharmacy workers in recommendation 8.

Young people

In relation to young people, participants were clear that adult and young people's services should not be accessed by young people and adults at the same time and that this should be emphasised within the recommendation.

Training

There was significant discussion relating to training staff to the required standards to deliver level 3 provision. Some participants reported that it was particularly challenging to engage pharmacy staff in training as already discussed.

In addition, many of the managers and commissioners consulted highlighted that training should be quality assured and they should be evidence that training has been attended by all relevant staff.

Wording/areas of ambiguity

There were a number of areas highlighted by participants with regards to the wording, order or ambiguity of the recommendation.

- Although the groups acknowledged that the points were not in hierarchal order, a number of groups agreed that the point **'ensure a selection of individual needles, syringes and other injecting equipment is available'** should be the first bullet point as it seemed a more logical opening statement;
- Under the same point as above, **participants stated they** would like to insert the word '*wide'* – therefore a 'wide selection of...';
- Many participants felt the point – **'Offer (or help people to access)'** should read '*offer **and*** help people to access and that the brackets should be removed;
- Instead of stating **'specialist youth services'**, participants felt that it should state *'specialist drug and alcohol young peoples services'* and highlighted the difference between *youth services* and *young people's services*;
- A number of participants also raised a specific point relating to young people and that the way the recommendation was written – highlighting under 16's – meant that it was not clear what would happen with 17 and 18 year olds;
- One group also highlighted that the section where it states **'Offer (or help people to access)'**, this was confusing and suggested separating the elements on offer from those that services help people to access;
- Ensure staff have appropriate training for the level of service **on offer** and questioned whether this was ambiguous;
- The point relating to **'provide sharps bins and advice on how to dispose of needles and syringes safely. In addition, provide a service for safe disposal of used equipment'** participants suggested 'as appropriate' should be inserted as the discussion was that not all service users want sharp boxes and they are expensive to give away every time;
- In relation to the latter point, participants felt the word '*why'* should be inserted into **'provide sharps bins and advice on how and <u>why</u>…'** in order to emphasise the responsibilities of services and why this is important.

Recommendation 10 Providing needle and syringe programmes for people who inject performance and image-enhancing drugs

Who should take action?

- Providers of needle and syringe programmes.
- Public health practitioners with a remit for needle and syringe programmes and for the prevention of infectious diseases.

What action should they take?

- Ensure needle and syringe programmes:
  - Are provided at times and in places that meet the needs of people who inject performance and image-enhancing drugs. (For example, by offering outreach or detached services in gyms or services outside normal working hours.)
  - Provide the equipment needed to support these users.
  - Are provided by appropriately trained staff (in line with recommendation 8 and recommendation 9).

- Needle and syringe programmes (including pharmacies) that are used by a high proportion of people who take performance and image-enhancing drugs should provide more specialist services for this group. This includes:
  - specialist advice about stacking (using multiple products) and cycling (the length of time you take them for)
  - specialist advice about performance and image-enhancing drugs
  - specialist advice about the side effects of these drugs
  - alternatives to using these drugs (for example, nutrition and physical training can be used an alternative to anabolic steroids)
  - information about, and referral to, sexual health services for anabolic steroid users
  - information about, and referral to, specialist performance and image-enhancing drugs clinics, if these exist locally.

Findings

Participants' feedback on NICE Recommendation 10:

Support for the recommendation and current practice

There was a consensus from all participants that this recommendation was needed and much welcomed. Participants discussed how services had experienced a significant growth in the numbers of PIED users accessing the service, in addition to a group who do not currently access drug services. The largest increase had been seen in steroid users but it was recognised that there was an emerging new client groups injecting substances such as Botox, cologne fillers and Melanotan. It was reported that drug services had been proactive and adapted to respond to an increasing demand for provision for PIED service users. There was also consensus that existing services had adapted to meet this growing need and that there had been no significant funding or new services specific for PIEDs.

Two general points within the recommendation were highlighted by participants as being particularly relevant and essential to this recommendation, such as:

- '**at times and places that meet the needs of people who inject PIED'**
- **'referrals to sexual health services'**

It was felt that these points could also be relevant and used within other recommendations.

Considerations for the recommendation

Resource implications

Although the recommendation was strongly welcomed and supported, there was concern that having this recommendation within the NICE guidelines would add to the growing pressure on services to deliver this within existing resources. Many participants discussed how the drug service was not directly commissioned to work with PIED injectors, however, due to the growing numbers of PIEDs accessing their service, were delivering a service to this group. There was a sense of frustration that this had led to the provision of a limited service – providing injecting equipment, harm reduction advice and information and, in some cases, testing and vaccinations. Participants suggested that there was potential for strengthening provision to this group, citing CBT and other interventions. Many felt that the inclusion of this recommendation supported the need to review services to include this provision. However a number of commissioners felt that there were 'massive cost implications' when commissioning this provision and felt that guidance recommending implementation without cost effectiveness data was unrealistic.

Tailored services

The vast majority of participants stated that services for PIED users must be tailored to meet their specific needs, which differed significantly from those using illicit substances such as opiates and crack cocaine. Participants suggested that a range of services could be appropriate to meet the needs of this group including current specialist NSP's, pharmacies and other services with no current remit of NSP such as sexual health services. Outreach and detached services were also supported by a number of participants. A significant number of participants who suggested that perhaps drugs services were not the most suitable place for this cohort of injectors as they did not see themselves as 'drug users'.

There was a sense that specialist NSPs needed to promote themselves within a broader context within the community and not necessarily specifically linked to the drug treatment system therefore increasing the potential of the service to all groups including PIED users.

'The aim of NSP services is to providing injecting equipment, information and advice and not concern itself with the type of drug use been done; its about services being attractive and accessible to all customer groups, and services need to adapt. If this service was in a drug treatment service, it wouldn't be attractive to PIED's so the service aims need to be more clearly defined as a service that is about reducing BBVs, providing the equipment for safer injecting and providing advice and information' – NSP Manager

There were a number of interventions/equipment which participants also highlighted as being specific to help meet the meets of PIEDs, these included:

- LFT's and ECG's;
- Cholesterol and health checks;

- Tourniquets;
- A number of participants reported that many of these service users also experienced mental health issues linked with their PIED use, for example issues related to body dysmorphia, and therefore robust pathways and access to mental health services was regarded as important;
- There should be a emphasis on promoting the reduction of BBVs;
- Locally, there was little in the way of '**information about, and referral to, specialist performance and image-enhancing drugs clinics, if these exist locally'** across all focus groups and therefore participants questioned what this referred to

Expertise and knowledge

Irrespective of the service type delivering interventions to the client group, there was agreement that working with this client group required 'quite a lot of specialism and knowledge'.

Some participants reported having limited knowledge and lacked a depth of expertise in relation to delivering advice and supporting this client group whereas other participants had extensive, specialist knowledge. As a minimum, participants discussed that whole staff teams should have knowledge of 'cycling/stacking' and that this should not be limited to one or two staff members, particularly as there was growing demand. It was suggested that having one member of staff with specialist knowledge would create a 'bottleneck' within services. However, a smaller number of participants felt that there should be specific 'PIED role' within services in order to promote service engagement with resources within the community, including gyms, and educational establishments. One participant felt it was important for practitioners to 'know their limits within their expertise' – 'we're not physical activity experts nor are we nutritionists'.

Training

Participants regarded training as essential in being able to deliver an effective and appropriate service to PIED users. Many participants felt that there was a requirement for more training in this area, particularly for pharmacy workers and in services where only a small number of staff were regarded as having expertise in this area of work.

It was recognised that there were a vast amount of PIED products which were getting 'more complex by the day' and that information in the public domain relating to the use of these was often contradictory.

The type of training for staff members was also very important as some participants felt that training was often focussed at a 'high level' service and was often not appropriate to the needs of a member of staff delivering a 'street level' service. It was felt that there was a lack of training courses appropriate for NSP staff to attend.

It was also felt that there was a need for peer-to-peer training, and training and education for gym staff, and that any future training needed to reflect this.

Due to the lack of appropriate training available, there was a sense that it may take some time to build the knowledge base and expertise referred to in the recommendation.

Working with gyms

Working with gyms was considered essential in order to work with this client group. Discussion was focussed on the implementation of this approach, as it was recognised that many gyms did not want to work with drugs services due to the perceived associated stigma. A number of participants who were already working with gyms acknowledged that it has taken considerable time to build trust and develop this partnership.

It was stated that it was important to find a way in which to sell interventions to gyms – 'what can they get out of it?' – and, at local level, explore ways in which it can be made attractive to gyms. Once again, many participants advocated a peer-to-peer approach in the context of working with gyms.

Wording/areas of ambiguity

There was some discussion relating to the point which referred to **'specialist advice – such as 'stacking'**, and whether this needed to be deleted as some participants felt that it was covered in the previous statement referring to **'specialist advice about performance and image enhancing drugs'**.

With regards to the statement **'Needle and syringe programmes (including pharmacies) that are used by a high proportion of people who take performance and image-enhancing drugs should provide more specialist services for this group'** it was suggested that the statement should read '*should provide (or refer to)' or should include the caveat 'within reason'*.

It was also felt that the example relating to 'stacking' and 'cycles' was specific to steroid use and that there were no specific example provided for image-enhancing drugs.

'Who should take action'

Participants felt that commissioners of services that PIED injectors access, for example NSPs, sexual health services, should be included to commission services that address the needs of this group within a locality.

Overall comments relating to the recommendations

Recommendation prioritisation

Participants were asked to prioritise the recommendations in relation to the impact of implementation on practice. Generally participants selected more than three recommendations highlighting the importance placed on NICE recommendations. For a significant number of participants the set of recommendations 'as a whole' were a priority.

Recommendations 5 and 10 were selected by the majority of participants, and it was suggested that the inclusion of these recommendations supported the development of these areas of work and may address the 'hidden harm' associated to the cohorts of young people and PIED service users.

Recommendations 1-4 were also key for participants as they supported the planning, commissioning and delivery of services to respond to the needs of local communities. Often participants discussed how recommendations 1-4 were 'interlinked', and described how they all needed to be implemented together. There were many concerns relating to data collection and reporting, which impacts on the implementation of recommendations 1-4 and ensuring services are meeting the needs of local communities.

Recommendations 6-9 were considered to be the 'bread and butter' of the work of NSPs, with a number of participants outlining how their work exceeded what was in the recommendation.

Cross-cutting themes

There were a number of cross-cutting themes between the recommendations which are worthy of note:

<u>Links with recovery</u>
There were a number of participants who suggested that the document should make more reference to the links between NSPs and treatment/recovery services within the context of the recovery journey. Some participants highlighted that NSPs form a continuum of services and that NSPs can play a role at the start of the recovery journey. It was argued by some that it was politically 'unwise' to not make reference to the recovery strategy and where these services sit within the recovery framework.

<u>Blood Borne Viruses (BBVs)</u>
Many participants felt there should be a larger focus on the aim of NSPs to reduce the transmission of BBVs within the recommendations. The absence of such public health messages impacted on the usefulness of the recommendation to current practice.

<u>Pharmacy provision</u>
The provision delivered by pharmacies features heavily throughout the report despite the fact that pharmacy staff represented only 13% of the overall sample. A significantly high number of participants, professionals from a range of services, highlighted the provision of pharmacy as a key issue and there was a lack of consensus across participants with regards to the appropriateness of this provision.

The main concerns were in relation to pharmacies providing services to young people, but not having adequate expertise on harm reduction, and the lack of engagement with specialist NSP and harm reduction services.

Emerging cohorts

Participants discussed that the increasing numbers of 'new' cohorts of injectors such as PIED injectors were changing the landscape of NSP services meaning services were having to adapt and become attractive to different groups. This presented new opportunities and challenges for services. There were some participants who remained unconvinced about whether these services should be delivered from within drugs services.

General comments

One participant made a general comment regarding the first point of recommendation 10 as it uses the phrase **'are provided at times and in places...'** – and felt this really captured how services should be planned, commissioned and delivered. It was felt that this sentiment was not necessarily running through the whole document and could perhaps be the phrase used throughout the document to ensure services are in the right places, and being delivered at the right times.

The terminology of 'PIED' was questioned by one participant as it was reported that other institutions are currently using the term 'IPED'.

Within the introduction of the recommendations, examples of 'legal highs' are provided including Mephedrone. It was reported that this is not a legal high, but a classified drug.

Appendices

Appendix A – Sampling matrix

Characteristics	Essential	Desirable
Geography, demography and other factors		
Services for PIED users	E	
Services for IDUs under 18	E	
Urban	E	
Rural	E	
Diversity (Minority ethnic populations/gender/sexuality)		D
Transport links/accessibility		D
Criminal justice system	E	
Economically deprived		D
Economically advantaged		D
One in each of the 3 Addaction areas of the North&West Region		D
Statutory providers	E	
Voluntary providers	E	
Substance misuse service providers		
Outreach: Gym	E	
Outreach: Mobile NSPs	E	
Outreach: Community settings	E	
Stand alone NSPs	E	
NSPs within the wider treatment system	E	
Young people's substance misuse services	E	
Adult substance misuse treatment and recovery services	E	
Family services		D
Community health providers		
General Practitioners	E	
Pharmacies	E	
Healthcare walk-in centres		D
Accident & Emergency		D
Mental Health Services		D
NSP equipment suppliers	E	
Other key informants		
Commissioners, NHS and Local Authorities	E	
Hostels (voluntary and criminal justice)		D
Homelessness services		D
Police	E	
Youth Offending Teams	E	
Youth work teams		D
Schools and education institutions		D

<u>Appendix B</u> – Draft process and interview schedule for focus groups and interviews

- Prior to focus group sessions and interviews, participants will be emailed the draft recommendations along with a link to the full guidance document (from the 24th September 2013). This will allow participants to familiarise themselves with the recommendations.

- Focus groups will run 11am-3pm with a lunch break. Interviews will run for approx. one hour.

- There will be two researchers present at the focus groups. One researcher will take the lead on facilitating the discussions for each recommendation, and the second researcher will also contribute by asking questions/making suggestions where they see appropriate. In addition, the second researcher will record observations, mainly where responses differ from each service setting to ensure we understand the needs of each setting.

- At the beginning of focus group sessions/interviews, the aims of the fieldwork will be outlined (N.B. will want to outline the new direction, updated recommendations have a greater focus on provision for under 18's / PIED's, the updated guidance supersedes other versions).

- Consent and confidentiality statements will be explained.

- Participants will wear name badges displaying the service setting they are from and whether they are a provider / commissioner.

- Prior to focus groups commencing ensure:

    - Attendees sign in;
    - You have explained the confidentiality and consent form and attendees have signed the form;
    - Collect forms;
    - Go through house-keeping – fire drills and exits, mobile phones, toilets and lunch and refreshments.

- Each draft recommendation will be displayed on Powerpoint or flip chart and taken in turn (greater focus may be placed on specific recommendations when speaking to specific groups). A series of questions will follow:

<u>Focus group / interview questions</u>

1) Ambiguity. Is there any areas of ambiguity within the recommendation? Which specific element is ambiguous? Could there be any confusion with regards to how the recommendation is understood and applied in practice?

2) Thinking about your service setting:
    a) Is the recommendation relevant? How relevant is it? I.e. is the recommendation likely to help the service accomplish its goal with regards to the provision of needle and syringe programmes and/or harm reduction work?

        Prompt: Current and future service delivery / commissioning.

b) Is the recommendation practically feasible in its current form? If yes/no – why? What is it about the recommendation that does/does not make it practically feasible/useful?

Prompt: Provider and commissioner perspectives

c) how easily could the recommendation be implemented in practice? What factors would help to effectively implement the recommendation? What factors would hinder effective implementation?

Prompt: Provider and commissioner perspectives

d) Do you have any other suggestions on how this recommendation can be effectively implemented in your service setting?

3) In your opinion, would the recommendation lead to improved health outcomes for clients? Yes/ no – How and in what ways?

4) What would be the impact of implementing this recommendation on current service delivery / commissioning? i.e. will it make a difference to current practice? What type of difference?

5) Is there anything missing from the recommendation?

6) Would extra support / guidance be needed to help to implement them?

7) In your opinion, is there any specific training gaps for staff that need to be addressed to implement the recommendation?

Round-up questions

8) Reflecting on your answers which recommendations do you suggest:
   - are there any inconsistencies/discrepancies between the recommendations?
   - what would be the relative priority of each of the recommendations? And why?

Basic outline of scribe template

Focus Group:

Recommendation #

Question	Prompt for scribe	Comments
Ambiguity	*Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Relevance	Current and future service delivery / commissioning *Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Feasibility	*Record responses given by different*	

	service types *Record perspectives from providers and commissioners, where different?*	
Implementation issues	*Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Improved health outcomes? *How and in what ways?*	How are interviewees defining 'health outcomes'? *Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	

Missing elements?	*Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Impact	*Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Extra support	*Record responses given by different service types* *Record perspectives from providers and commissioners, where different?*	
Training gaps	*Record responses given by different service types*	

Training gaps (cont.)	*Record perspectives from providers and commissioners, where different?*	

Round-up at the end

Reflecting on your answers which recommendations do you suggest:

- are there any inconsistencies/discrepancies between the recommendations?
- what would be the relative priority of each of the recommendations? And why?