Assessing and prioritizing the preferences of injecting drug users in needle and syringe exchange service development

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ABSTRACT

Background Needle exchange services are vital for the distribution of clean injecting equipment and disposal of equipment used for intravenous drug users. From the number of clean needles and syringes distributed and the estimated number of injecting drug users (IDUs), there may be insufficient use of needle exchange services. This highlighted the need to consider how services could be improved to encourage the use.

Methods A structured, short, anonymous questionnaire was distributed to IDUs through a wide range of agencies and services in North East Scotland. A form of snowball sampling was also used.

Results A total of 370 individuals responded. Respondents noted the following in their two prioritized preferred options: ‘Provision of paraphernalia’ (citric acid, water and filters; 54%), ‘weekend opening hours’ (24%) and ‘antibiotic prescribing’ (23%). Other service developments noted were: ‘friendly, approachable staff’ (16%), ‘family planning’ (10.4%), ‘dressings for wounds/sores’ (9%), ‘leaflets on safer injecting’ (7.0%), ‘advice from staff on safer injecting’ (3.0%) and ‘evening opening hours’ (0.8%). Geographical gaps in current needle exchange services were identified. There was homogeneity of responses across demographic groups.

Conclusion IDUs were willing to participate and suggested more provision of paraphernalia.

Keywords injecting drug use, blood borne virus, needle exchange, patient involvement

Background

Injecting drug use continues to be a problem in the North East of Scotland as in the rest of the UK. In the 15–54 year age group, the prevalence of illicit opiate use is 2% in Aberdeen City (one of the highest in Scotland) and 1.1% in Aberdeenshire and Moray, respectively.¹ Needle and syringe exchange services are vital for the distribution of clean injecting equipment for drug users and disposal of used equipments. Injecting drug use poses a range of harms including injecting-related injuries, overdose and blood borne viruses including hepatitis C, which is highly prevalent in the injecting drug-using population.²

The prevalence of hepatitis C in the North East of Scotland population is not accurately known, but in Glasgow a study conducted in 2004 indicated 37% of those who have been injecting for less than two years and 45% of those who started injecting after the introduction of needle exchange are hepatitis C positive.³ Thus current needle exchange services seem to have had a limited effect on hepatitis C transmission. An observational study conducted in Glasgow, examining injecting practices, found that drug users often reused the same needle and syringe, and water for ‘flushing’ syringes, during the preparation of injections and cigarette filters were used and shared.⁴

Currently, needle exchange services in North East Scotland are provided through voluntary and NHS services including 14 community pharmacies, designated NHS needle exchange services and voluntary services. Across these outlets approximately 800 000 needles are distributed to injecting drug users each year. On the basis of an estimated 2842 users (95% CI, 2458–3327) in Grampian⁴ injecting on average two times a day, this indicates approximately 2 000 000 intravenous doses/year overall. The figures for number of exchanges suggest a
shortfall of approximately 1,200,000 per annum clean needles, and that each needle is used more than two times for injecting (based on the data from NHS Grampian). This raised the following questions: are there not enough needle exchange centres? or do current services need to be improved to encourage the use? This research aimed to address these questions, with this paper focussing on the last question.

Community pharmacies provide needle exchange as one of the range of services for the general population. Non-pharmacy needle exchanges are aimed at drug users and have a more holistic, detailed service specification including assessment of drug problems, advice, inspection of injecting sites and distribution of condoms. Several NHS areas have decided to extend the range and availability of paraphernalia available from exchanges and now offer citric acid, filters or sterile water for injection. The provision of these substances may not necessarily directly reduce drug-related harm, but they might attract more users into services. An evaluation of the changes to the Lord Advocate's guidance to increase the provision of needles and syringes found that drug users did not seem to feel that more needles and syringes were necessary and many were unaware of the change.3

Patient and public involvement in NHS services design and development is now given greater importance than in the past.5 The Scottish Executive has outlined key themes for patient/user involvement outlined in Patient Focus and Public Involvement 20016 which are knowing about health service users and talking and working with users, the public and communities. Drug users are considered a marginalized and vulnerable group by INVOLVE (formerly Consumers in the NHS).

Accessing the population of injecting drug users (IDUs) is challenging. This is common to a range of hidden populations such as homeless people, prostitutes and illicit drug users.7 The health problems they experience may include higher than average levels of blood borne viruses and sexually transmitted infections. The social stigma associated with many of these health problems further alienates these groups and makes it more difficult to access them for appropriate prevention and care.8 IDUs that are in touch with services are accessible and much research has been done successfully with this group although their direct involvement in service development is not widely documented in the literature. Those IDUs who do not or rarely use services are difficult to contact and involve. The size of this group can only be estimated, yet the involvement of this group was a key aim in this project.

Aim
The overall aim of the study was to identify and quantify IDUs’ preferences for service development to increase use and, by implication, improve harm reduction.

Objectives
(1) To elicit users’ prioritized preferences in needle exchange service development to maximize service use.
(2) To elicit views from injecting drug users who do not, or rarely, use current services.
(3) To identify geographical areas considered by users in need of needle and syringe exchange services (not reported in this paper).

Methods
The study used a mixture of qualitative and quantitative methods covering service providers, service users and non-users. The study had two stages:

(1) Content setting interviews with service providers and service users to identify their views of potential developments.
(2) Questionnaire development and distribution.

Ethical approval was granted by NHS Grampian Research Ethics Committee. Initially, content setting interviews were conducted with six service providers and 11 injecting drug users (IDUs) attending needle exchange services. This purposeful sample covered a wide geographical spread across the study area and included a range of types of needle exchanges centre, i.e. voluntary services, NHS services and community pharmacies. As well as being content setting interviews, these initial interviews gathered qualitative data covering views on current services use and barriers to use which are reported elsewhere.9

From interviews, a list of potential service developments was identified for inclusion in the questionnaire. The questionnaire was designed to be very user friendly. It was structured to fit on one page only, and mostly tick boxes were used to minimize writing with an open response on suggested areas requiring further needle exchanges. Questionnaires were gummed on one side so they could be folded and easily sealed for anonymous postal return. The pre-paid reply address was printed on the reverse side. Clear instructions were given on the questionnaire and a study information leaflet was also distributed giving background information and instructions on participation.
Questionnaire piloting and distribution
The questionnaire was piloted with 13 IDUs to test readability, ease of completion and willingness to participate. Few changes were required. Following this, 44 face-to-face questionnaires were completed with a researcher in a range of pharmacies, voluntary agencies and NHS needle exchanges centres. This was undertaken because it was not known what the level of participation to the wider distribution would be, and the research team wanted to ensure they had some participation.

To gain the views of as many IDUs as possible, questionnaires were distributed as widely as possible to all services and agencies thought to come into contact with IDUs. This list of centres was produced through brainstorming of the research team and consultation with other agencies who added to the list. It covered the health, social, police and voluntary sectors. In total, 38 centres were given questionnaires to distribute. Questionnaires were completed by IDUs. Built into this distribution was a secondary distribution, a form of snowball sampling in which users of these services were given questionnaires to distribute to others. To further maximize participation, posters were displayed in participating services that had the researcher’s telephone number so that IDUs could phone and complete the questionnaire over the phone if they preferred (e.g. if they did not want to be seen taking a questionnaire away).

Data management and analysis
Questionnaires were entered by the researcher into the Statistical Package for Social Science version 10 for storage and analysis. Simple descriptive statistics such as frequencies were used initially. Chi-squared tests were used to explore the significance of demographic differences where relevant.

Results
Response and demographics
A total of 2180 questionnaires were sent to agencies/services throughout Grampian of which 1111 were distributed to IDUs. The total numbers of questionnaires completed and returned was 370 (33%), of which 250 were male (67.6%) and 120 (32.4%) were female (Table 1). There were no telephone responses. Of the 345 IDUs in the study that reported the type of needle exchange they attend, 166 (45%) attended non-pharmacy services, 57 (15.4%) used pharmacy needle exchange services and 95 (26%) used both (10 missing values). Twenty-five respondents noted on the form that they were ex-injectors. They were excluded from the main analysis as not enough was known about them and the inclusion criteria were for current IDUs.

Participants were asked how often they used a needle exchange service and how frequently they injected. Responses are displayed in Table 1. By excluding those claiming to be ex-injectors ($n = 25$), we can identify those who are injectors but do not use needle exchange services. This leaves 20 participants who claimed never to use a needle exchange.

Identifying and prioritizing service developments
The list of potential service developments and prioritized service developments identified through content setting interviews were:
- Advice from staff on safer injecting
- Antibiotic prescribing
- Dressings for wounds/sores
- Evening opening hours
- Family planning, e.g. condoms, coils, depot injections
- Friendly approachable staff
- Leaflets on safer injecting
- Paraphernalia (citric acid, water and filters)
- Weekend opening hours

These were listed in the questionnaire, and the respondents asked to mark all those that they believed would encourage use of needle exchange services and then to note which two were the most important. Responses are displayed in Table 2. The provision of paraphernalia was ranked first in response to both questions. The vast majority of respondents manage to prioritize as instructed.

### Effect of demographics on prioritization

To further explore how different groups or characteristics might influence people’s prioritization, further cross-tabulations were done and chi-squared performed if it seemed appropriate. Prioritized service developments were cross-tabulated against: age, gender, how often a needle exchange was used and what type of needle exchange was used. There were just a few notable differences and only one was statistically significant. The type of needle exchange used seems to influence the proportion of people noting paraphernalia as there was a higher percentage of users from non-pharmacy needle exchanges noting this, compared with pharmacy needle exchanges ($P = 0.196$). Age may slightly influence the response to antibiotic prescribing with a higher proportion in the 25–30 age group noting this ($P = 0.113$). Frequency of injecting may have a slight influence on antibiotic prescribing as those who inject more frequently were slightly more likely to note this but not significant ($P = 0.860$). This was still not significant when recoded into daily injectors (24.4% noted antibiotics) and less than daily injectors (19.7%) noted antibiotics ($P = 0.196$). The only significant finding was that the proportion of people noting paraphernalia was higher in those who injected one to two times a day ($P = 0.009$).

### Service users versus non-services users

Table 3 displays comparison of the prioritized preferences of non-service using participants. The patterns of responses are similar to service users. Numbers are too small for meaningful statistical comparison.

### Discussion

#### Limitations of this study

Initial face-to-face interviews targeted only service users when they were using the service, so they could give an informed opinion. A disadvantage of this approach is that it may have omitted people who do not use the service, and who may be most dissatisfied because the service is inappropriate to their needs. However, every effort was made on this study to include non-service users at the latter stage.

The challenge of gaining the views of IDUs using standard survey methods is that the population size is not known, thus the exact response rate cannot be calculated. This study used a pragmatic approach to gain the views of as many IDUs as possible by distributing questionnaires as widely as possible to all services and agencies thought to come into contact with IDUs. Thus, in terms of research purity, this is a weakness but at least by noting how many questionnaires were distributed by each agency and explaining the importance of this to agencies, a form of response rate could be calculated.

### Table 2

<table>
<thead>
<tr>
<th>Prioritizing for needle exchange service developments ($n = 345$)</th>
<th>Which would encourage use?</th>
<th>Which are two most important?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paraphernalia (citric acid, water and filters)</td>
<td>263 (76%) (1st)</td>
<td>185 (54%) (1st)</td>
</tr>
<tr>
<td>Advice from staff on safer injecting</td>
<td>230 (67%) (2nd)</td>
<td>11 (3%)</td>
</tr>
<tr>
<td>Weekend opening hours</td>
<td>228 (66%) (3rd)</td>
<td>83 (24%) (2nd)</td>
</tr>
<tr>
<td>Evening opening hours</td>
<td>220 (64%)</td>
<td>3 (0.8%)</td>
</tr>
<tr>
<td>Friendly approachable staff</td>
<td>217 (63%)</td>
<td>55 (16%)</td>
</tr>
<tr>
<td>Antibiotic prescribing</td>
<td>216 (63%)</td>
<td>78 (23%) (3rd)</td>
</tr>
<tr>
<td>Dressings for wounds/sores</td>
<td>214 (63%)</td>
<td>31 (9%)</td>
</tr>
<tr>
<td>Leaflets on safer injecting</td>
<td>194 (56%)</td>
<td>23 (7%)</td>
</tr>
<tr>
<td>Family Planning, e.g. condoms, coil and depot injection</td>
<td>175 (51%)</td>
<td>36 (10.4%)</td>
</tr>
</tbody>
</table>
Follow-up with phone calls and letters were sent to all services to encourage questionnaire distribution. Despite this the response rate was poor from some centres giving the potential for a biased response, i.e. non-pharmacy needle exchange services (NHS and voluntary sector) distributing more than pharmacies. The proportion of respondents that rarely or never used a needle exchange was small. This means either there are in fact fewer injecting drug users who do not ever use a needle exchange than previously perceived or that the snowball sampling part of the questionnaire distribution had limited success. To explore this further we would need to consider our estimates of the size of the injecting population \( n = 2842 \) relative to use of needle exchange services. Unfortunately, due to the nature of the data available from pharmacy exchanges, this was not possible.

**Main findings of this study**

**Prioritization of potential service developments**

The importance of asking for two prioritized preferences became clear when responses to the question about what might encourage use and then the question asking for two priorities were compared. Many people ticked most of the options when asked what might encourage use, without differentiating between them so this question alone would not have given meaningful results.

Paraphernalia (citric acid, water and filters) was identified as the highest priority by users to be included in service provision. Citric acid increases the solubility of heroin. It is widely used, and many needle exchanges across the world routinely provide this. There is no evidence that the citric acid reduces harm for IDUs; however, some believe providing it would improve the use of services. Only one study of interest was found, conducted in an area of Scotland where citric acid sachets were supplied to IDUs using pharmacy exchanges.\(^1\) Participants found citric acid preferable to their previous acidifier, but there was still some evidence of citric burns indicating the amount of citric acid used needs to be minimized. Unfortunately, this study was not methodologically robust and limited in scope allowing little conclusive evidence for the use of citric acid.\(^1\) However, two studies on risk factors for sero-conversion to HCV virus found increased risk with sharing paraphernalia (self made) and needles and syringes. The greatest risk was for the sharing of ‘cookers’ and cotton filters.\(^1\),\(^2\),\(^3\)

Interestingly, weekend opening hours were rated more highly than evening opening hours. This gives clear direction to service planners when considering extending services. Friendly, approachable staff was the third most prioritized service characteristic believed to encourage service use. IDUs interviewed in previous research a decade ago felt they were not treated the same as other customers when attending pharmacy services.\(^4\) It is disappointing that interpersonal communication skills may still be affecting service use and further training and education of health professional may be necessary.

Dressings for wounds and sores and antibiotic prescribing were also considered to be of importance by participants. This facility could help deal with the reportedly high number of infected wounds seen in needle exchange services daily, especially given the reluctance expressed by IDUs in the interviews\(^5\) for attending their GPs for such problems. However, the reluctance to visit GPs needs further exploration to understand the underlying issues. Whilst advice from staff on safer injecting and leaflets on safer injecting appeared to be important from interviews and the questionnaire, they did not rate highly at the prioritization stage. There was interestingly little variation in preferred service developments according to the demographic variables.
**What is already known about this topic?**

What is already known on this topic is that the introduction of needle exchanges has played an important role in reducing the spread of HIV. There is also some evidence that hepatitis C is prevalent in the IDU population, so current needle exchange provision does not seem to be sufficient at reducing the spread of this particular virus.

**What this study adds**

This study adds a clear guidance from users on what they believe might encourage use of services as well as presenting a new method of involving IDUs. Service development should include: greater provision of paraphernalia, weekend opening hours and antibiotic prescribing. Improved communication skills of some staff may still be needed so that staff appear friendly and approachable.

**Involving injecting drug users in research and development**

This study targeted users themselves to find out what they think might encourage greater use of services. Users need to be valued as equals and experts in their own experience. In this study, IDUs were keen to help and gave clear, practical suggestions to improve attendance at needle exchange services. Participants gave their views without using incentives, i.e. money or vouchers (at least in interviews). It is possible that some form of incentive may have increased the response rate to the questionnaire but this would have been difficult to administer. In the true spirit of patient and public involvement, service planners might want to continue users’ involvement at the next stage of implementation.

**Acknowledgements**

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