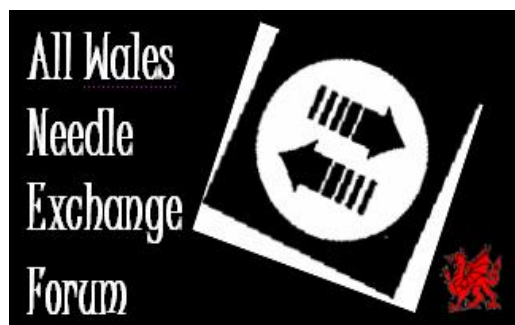




National Public Health
Service for Wales

Gwasanaeth Iechyd Cyhoeddus
Cenedlaethol Cymru



Report on pilot needle exchange data collection project

Author: Josie Smith, Research Scientist and Chair, All Wales Needle Exchange Forum

Date: November 2008

Version: 1c

Status: Approved

Purpose and Summary: To provide a summary report on the findings and issues relating to a pilot data collection system project Jan / Feb 2008

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Introduction

The All Wales Needle Exchange Forum (AWNEF) was established by the National Public Health Service (NPHS) in 2007 as a response to the needs identified within existing needle exchange services in Wales from research undertaken by NPHS in 2004 – 2007.¹ One of the key aims of the Forum was to develop a standardised data collection system for use by all needle exchange outlets in Wales (including Pharmacy and drug service based services). The reasons behind this aim were four fold:

1. To establish the degree to which each needle exchange outlet provides a quality service, not only through the physical exchange of injecting equipment but also the provision of harm reduction information and signposting to appropriate substance misuse services in the area
2. To evidence the type and nature of needle exchange service users in a given area and by doing so describe the injecting populations not accessing or utilising specific needle exchanges
3. To assess the coverage of services across Wales, identify areas of need and ensure that population needs were being met over time
4. To support existing data collection systems (e.g. WNDSM) in ongoing prevalence estimation of the problematic and injecting drug using population in Wales and disseminate this information to a wider audience in support of national and international estimates

Rationale for pilot

- To establish whether a data collection system could be developed and used to provide information on the number and profile of needle exchange service users in a range of needle exchange outlets in Wales
- To evaluate the costs and benefits of such a system
- To clarify the issues relating to collecting data from a range of independently run organisations including information governance issues
- To consider the steps required for this data collection system to be used by outlets and associated organisations for the purposes of stock control and payment for delivery of services

Method

Following discussion by Forum members and investigation of previous and existing data collection systems (see minutes of All Wales Needle Exchange Forum available at www.wnef.org.uk), an optical scanning form was developed (see Appendix A) as an optimal means of data collection in a range of needle exchange services across Wales (given that internet based systems are not a practical option at this time). It was agreed that as the Forum planning group contained a number of needle exchange operators and co-ordinators, a pilot study could be undertaken utilising these services over a limited test period.

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The forum planning group worked in collaboration with DCC document capture company Ltd (DCC), a London based company who have established ethical and information governance agreements with the Health Protection Agency (HPA) in the UK and who have undertaken similar work for the NPHS surveillance team (CDSC) in Wales. DCC operate an optical scanning and data capture service whereby uniquely bar-coded forms are printed and sent out to relevant services, and once completed are posted back and processed through specialist computers. Specification regarding the sensitivity and accuracy of the computers is available from the author. The captured data is then returned to the source for analysis, in this case NPHS.

It was agreed by the Forum Planning Group that the following sites would take part in the pilot and relevant authority to proceed was obtained:

- Swansea voluntary sector needle exchange service
- Bridgend voluntary sector needle exchange service
- Cardiff statutory sector needle exchange service
- Gwent pharmacy based needle exchange service
- Gwent statutory sector needle exchange service
- North Wales pharmacy based needle exchange service

Unfortunately, due to illness, it was not possible to run the pilot within the Cardiff statutory service so a busy Cardiff voluntary sector needle exchange service was selected and agreed to run the pilot. Therefore, there was an overrepresentation of voluntary sector needle exchanges however this was not felt to undermine the value of the pilot and resultant findings.

Along with the optical scanning form, an information sheet (see Appendix B) was developed to ensure that all participating needle exchange services were clear on procedure during the project.

Procedure

During the week of 21st Jan – 25th Jan 2008, DCC sent out sets of forms to each of the participating needle exchanges, each set of forms marked with a unique barcode assigned to each outlet, along with 4 prepaid plastic postage envelopes for the return of completed forms at the end of each week of the pilot. Each needle exchange pilot site also received a copy of the information sheet and had been asked to inform and, where required, train all staff who would be operating the needle exchange service over the 4 week pilot period.

Staff were advised to complete one form per service user visit regardless of the amount of equipment requested.

The pilot testing period began on Monday 28th January 2008 and ran for 4 complete weeks ending on Saturday 24th February 2008. At the end of each week, all completed forms were placed in the pre-paid plastic envelope and posted back to

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DCC. After 4 weeks, the final batch of completed forms was sent and the pilot period was completed.

Upon receipt of the completed forms, DCC document capture company Ltd processed completed forms and produced an excel spreadsheet of all transactions by pilot site which was then sent to the author, NPHS for analysis. Analysis was undertaken and a report compiled for each of the pilot needle exchange services, and all participating services received their report within one week of the end of the pilot.

All costs incurred during the pilot needle exchange data collection project, including those payments made to DCC document capture company Ltd were covered by NPHS.

Feedback from pilot sites

Positive feedback was received from all but one pilot site, the North Wales pharmacy based needle exchange service. Following discussion this was felt to be because no routine data collection is undertaken within this service and no training, background or encouragement was given to the staff who operate the needle exchange service on a daily basis. On a more positive note, two pilot sites requested to continue use of the optical scanning form as a means of data collection within their services.

Discussion

The findings outlined in this document provide a summary of the data gathered from the 6 pilot sites. Information not previously available, such as a profile of primary, secondary and tertiary drug use by gender provide valuable information for substance misuse service providers, CSPs, SMARTs and policy makers in tailoring services to service user requirements in a given area and also to address short-falls in service provision. In addition, the summary provides a snap shot of activity that, once developed on a national level, would enable analysis of drug use trends over a year (e.g. steroid use) and also on a longer term basis.

Much work is still required to advance development of a national data collection system with the involvement of Welsh Assembly Government, Community Pharmacy Wales, injecting equipment providers, substance misuse / needle exchange providers and commissioners.

Next steps

Following completion of this pilot, further exploratory work is currently being undertaken including discussion of needle exchange data collection systems proposed in Scotland and England. A business case is being drawn up in which the system described here will be evaluated in relation to alternative systems.

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Summary Findings of Pilot Needle Exchange Data**Activity Summary for the four week period: 28th January – 24th February 2008**

	Total	Bridgend Voluntary	Cardiff Voluntary	Gwent Pharmacy	Gwent Statutory	North Wales Pharmacy	Swansea Voluntary
Total Number of Transactions	1772	223	477	74	423	74	501
Total number of unique service users	1067	96	285	38	277	52	319

Total Number of Transactions per Week

Number of transactions per week	Week 1	Week 2	Week 3	Week 4	Total
Transactions	409	446	443	474	1772

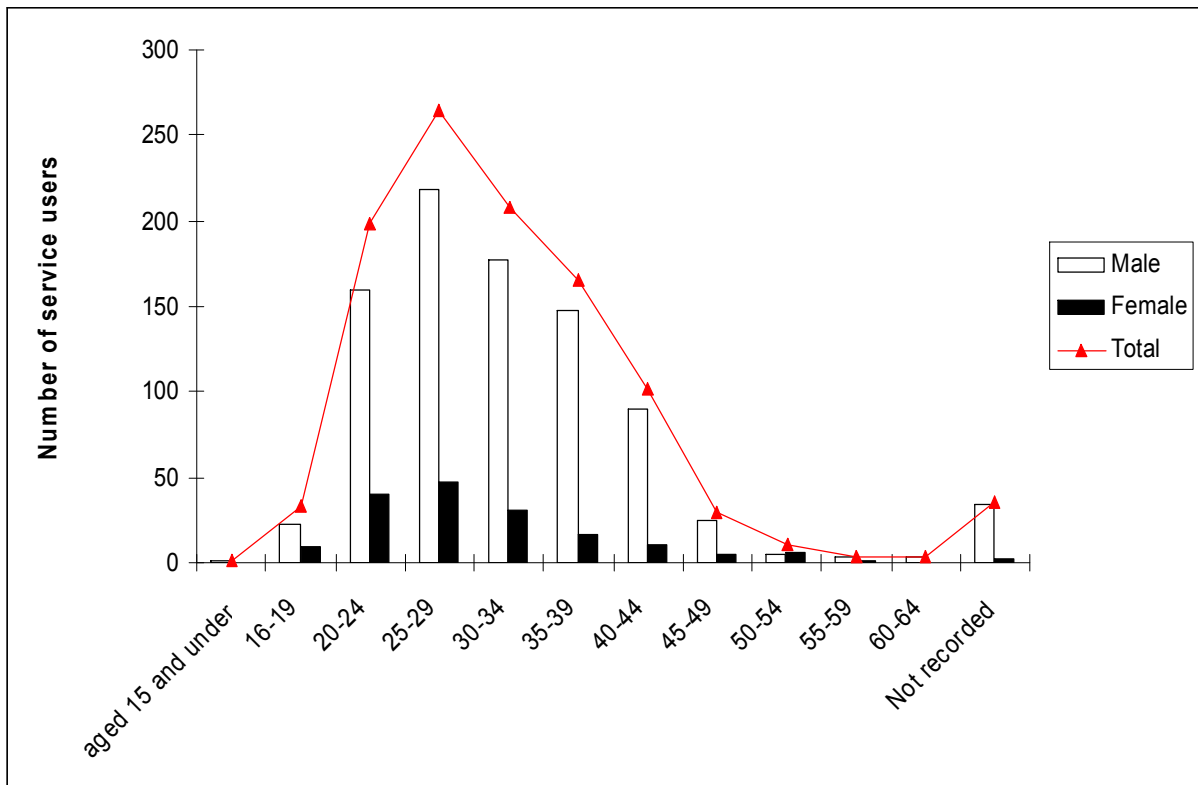
Total Number of Unique Individuals by gender

	Male	Female	Unspecified	Total
Number of unique individuals	864	170	33	1067
Percentage of total	81%	16%	3%	

Age profile of overall dataset

Age of individuals	Male	Female	Total
11-15	1	0	1
16-19	23	10	33
20-24	159	40	199
25-29	218	47	265
30-34	177	31	208
35-39	148	17	165
40-44	90	11	101
45-49	25	5	30
50-54	5	6	11
55-59	3	1	4
60-64	4	0	4
Not recorded	34	2	36

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Figure 1: Age profile of needle exchange service users in pilot study

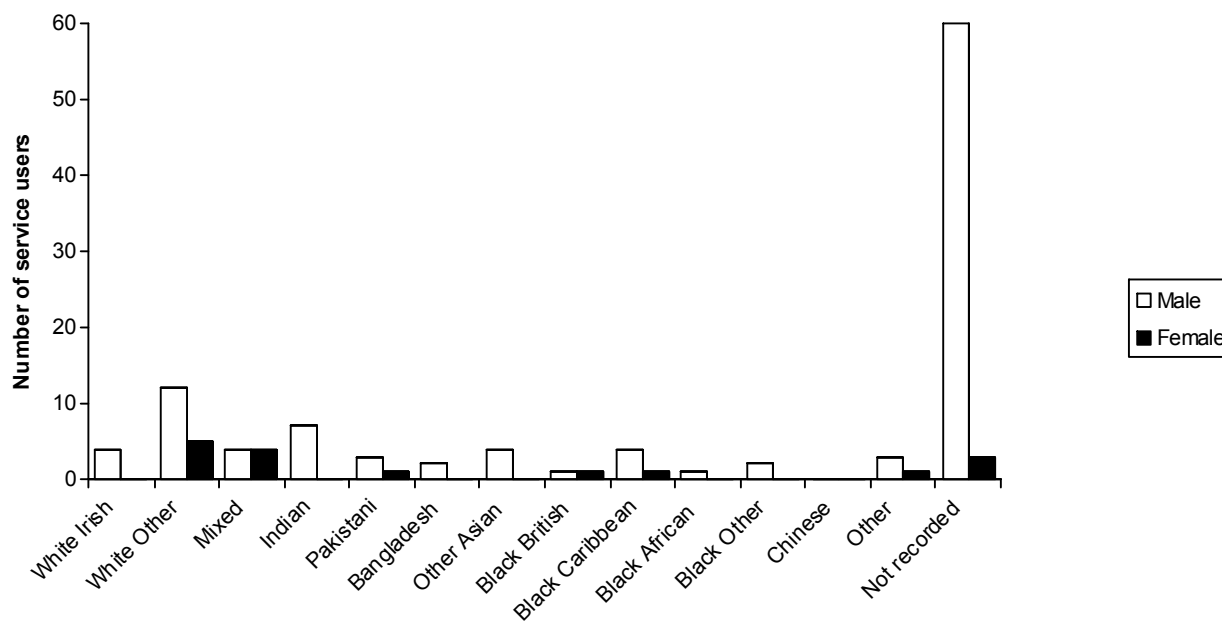
Ethnic profile of overall dataset

Ethnicity	Male	Female	Unspecified	Total
White Welsh	677	132	5	814
White British	114	19	0	133
White Irish	4	0	0	4
White Other	12	5	0	17
Mixed	4	4	0	8
Indian	7	0	0	7
Pakistani	3	1	0	4
Bangladesh	2	0	0	2
Other Asian	4	0	0	4
Black British	1	1	0	2
Black Caribbean	4	1	0	5
Black African	1	0	0	1
Black Other	2	0	0	2
Chinese	0	0	0	0
Other	3	1	0	4
Not recorded	60	3	0	63

Breakdown of Ethnicity 'Not Recorded'

Bridgend Voluntary	Cardiff Voluntary	Gwent Pharmacy	Gwent Statutory	North Wales Pharmacy	Swansea Voluntary
7	0	1	17	28	10

Ethnic profile of service users other than white welsh by gender

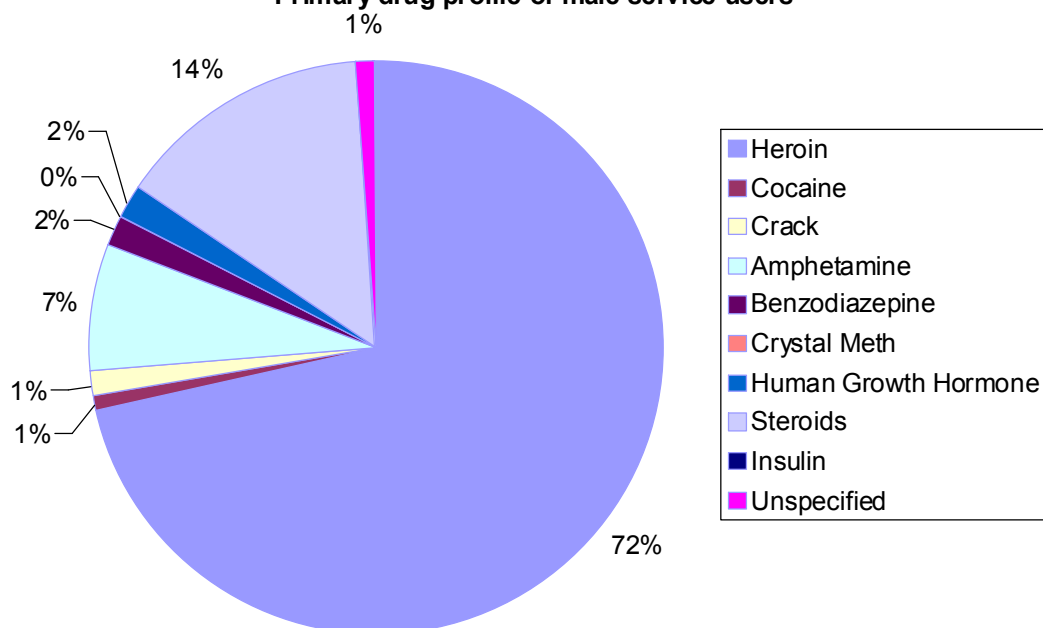


Overall number of services users recorded as out of area or of no fixed address (homeless)

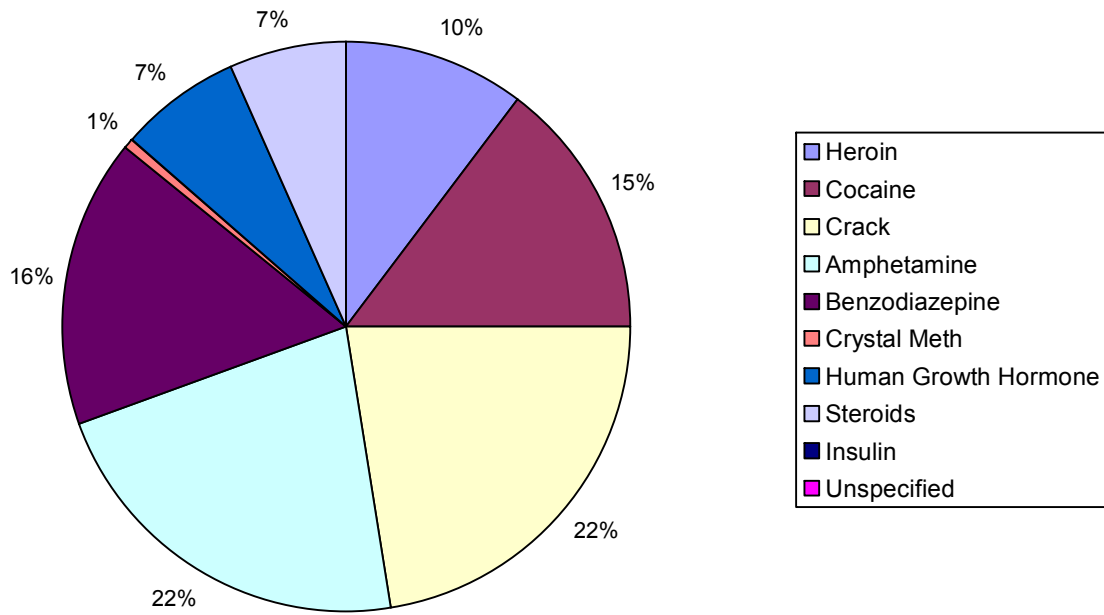
Residence	Male	Female	Unspecified	Total
Out of Area	53	7	1	61
NFA	45	6	0	51

Profile of Substances Injected from overall dataset

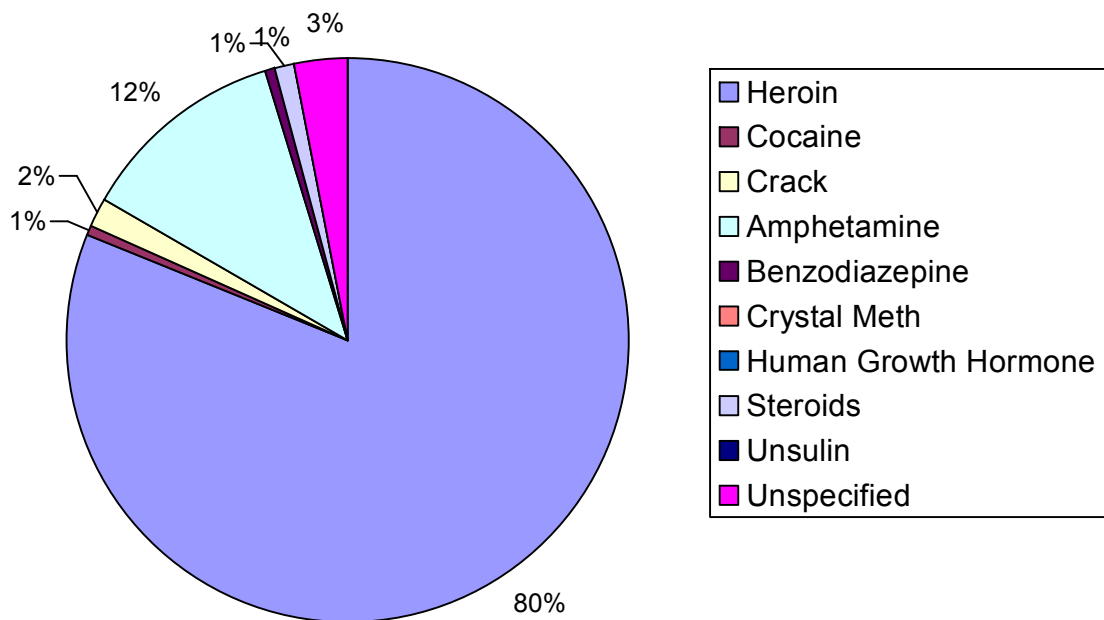
Substance Injected	Male	Female	Male	Female	Male	Female
	Primary		Secondary		Tertiary	
Heroin	633	137	19	4	3	0
Cocaine	7	1	27	4	12	3
Crack	12	3	41	8	14	7
Amphetamine	65	20	40	6	18	3
Benzodiazepine	14	1	30	5	11	3
Crystal Meth	0	0	1	0	8	1
Human Growth Hormone	18	0	13	1	5	1
Steroids	128	2	12	0	6	1
Insulin	1	0	0	0	6	1
Unspecified	9	5	0	0	0	0

Primary drug profile of male service users

Secondary drug profile of male service users



Primary drug profile for female service users



Breakdown of overall number and type of equipment distributed by site

Pick and Mix	Total	Bridgend Voluntary	Cardiff Voluntary	Gwent Pharmacy	Gwent Statutory	North Wales Pharmacy	Swansea Voluntary
1 1/2" Green	3422	341	536	10	1275	123	1137
1 1/4" Blue	3397	706	305	0	1532	132	722
1" Orange	3087	50	1059	0	1648	6	324
5/8" Orange	2586	164	1028	21	930	47	396
1/2" Brown	368	0	0	0	0	0	368
1/2" Grey	242	0	167	10	65	0	0
1/2" White	0	0	0	0	0	0	0
Insulin Injector	14373	3081	5839	0	231	193	5029
1ml Syringe	2113	0	1680	10	225	66	132
2ml Syringe	3357	895	434	0	253	126	1649
5ml Syringe	482	0	35	0	255	7	185
Spoon/Cooker	7129	2018	2588	0	0	0	2523
Citric	7880	895	4243	0	0	190	2552
Ampoule snapper	59	0	0	0	0	8	51
Water	3921	100	0	0	0	42	3779
Swabs	13858	4898	3610	0	0	208	5142
Foil	327	0	0	0	0	0	327
Filters	506	0	362	0	1	41	102
Condoms	737	142	300	0	51	2	242
Lube	6	0	0	0	0	0	6
Vit C	9152	3592	2420	0	0	22	3118

Packs	Total	Bridgend Voluntary	Cardiff Voluntary	Gwent Pharmacy	Gwent Statutory	North Wales Pharmacy	Swansea Voluntary
Red 1ml 10pk	231	0	0	102	129	0	0
Red 1ml 15pk	0	0	0	0	0	0	0
Red 1ml 20pk	1	0	0	0	1	0	0

Blue 2ml 10pk	98	0	0	60	38	0	0
Blue 2ml 15pk	90	0	0	0	0	0	90
Blue 2ml 20pk	0	0	0	0	0	0	0

Yellow 2ml 10pk	174	0	0	0	174	0	0
Yellow 2ml 15pk	0	0	0	0	0	0	0
Yellow 2ml 20pk	0	0	0	0	0	0	0

Insulin 10pk	586	0	0	0	536	49	1
Insulin 15pk	15	0	0	0	0	0	15
Insulin 20pk	1	0	0	0	0	1	0

Orange (5/8") 10pk	107	0	0	72	0	0	35
Orange (5/8") 15pk	0	0	0	0	0	0	0
Orange (5/8") 20pk	26	0	0	0	0	0	26

White (1/2") 10pk	10	0	0	10	0	0	0
White (1/2") 15pk	0	0	0	0	0	0	0
White (1/2") 20pk	0	0	0	0	0	0	0

Long Blue (1 1/4") 10pk	23	0	0	23	0	0	0
Long Blue (1 1/4") 15pk	0	0	0	0	0	0	0

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Long Blue (1 1/4") 20pk	0	0	0	0	0	0	0
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Long Orange (12/16") 10pk	13	0	0	13	0	0	0
Long Orange (12/16") 15pk	0	0	0	0	0	0	0
Long Orange (12/16") 20pk	0	0	0	0	0	0	0

Steroid 10pk	21	0	0	0	0	21	0
Steroid 15pk	0	0	0	0	0	0	0
Steroid 20pk	0	0	0	0	0	0	0

Emergency Packs	Total	Bridgend Voluntary	Cardiff Voluntary	Gwent Pharmacy	Gwent Statutory	North Wales Pharmacy	Swansea Voluntary
Red 1ml Emergency 2pk	1	0	0	0	0	1	0
Red 1ml Emergency 3pk	0	0	0	0	0	0	0
Red 1ml Emergency 5pk	0	0	0	0	0	0	0

Blue 2ml Emergency 2pk	0	0	0	0	0	0	0
Blue 2ml Emergency 3pk	1	0	0	0	0	1	0
Blue 2ml Emergency 5pk	0	0	0	0	0	0	0

Insulin 2pk	1	0	0	0	0	1	0
Insulin 3pk	0	0	0	0	0	0	0
Insulin 5pk	0	0	0	0	0	0	0

Orange 2ml Emergency 2pk	0	0	0	0	0	0	0
Orange 2ml Emergency 3pk	0	0	0	0	0	0	0
Orange 2ml Emergency 5pk	1	0	0	0	0	1	0

Containers	
0.3 Litre	Total
Issued	82
Returned	107
Outstanding Containers	

2 Litre	Total
Issued	3
Returned	3
Outstanding Containers	0

0.45 Litre	Total
Issued	938
Returned	748
Outstanding Containers	

4 Litre	Total
Issued	11
Returned	17
Outstanding Containers	0

1 Litre	Total
Issued	19
Returned	38
Outstanding Containers	0

30 Litre	Total
Issued	8
Returned	5
Outstanding Containers	0

Caveat – as containers / sharps bin distribution is an ongoing process, these figures represent a snapshot of distribution and return and should not be used as evidence of actual monthly figures.

Breakdown of information given and signposting to other services, from overall dataset

Information Given	Total
Hepatitis	112
Overdose	97
Safer Injecting	336
Steroids	70
Safer Sex	46
Groin Injecting	39

Signposting	Total
Drug Treatment Service	62
GP	12
A&E	3

Conclusions

Following the success of the pilot project, conclusions are discussed in relation to the original aims and rationale of the project:

1. To establish whether a data collection system could be developed to provide information on the number and profile of needle exchange service users in a range of needle exchange outlets in Wales

A standardised data collection system can be developed to provide information of direct value to service providers as well as to commissioners, service planners, policy makers and researchers. The pilot project shows that information on the number and profile of service users can be collected and collated with a minimum of effort and resource requirement.

2. To evaluate the costs and benefits of such a system

Costs of pilot project: The costs related to the development and running of this pilot project amounted to £4,000 and related directly to the postage of forms to and from needle exchange pilot sites, and the development, scanning and processing of the forms by Document Capture Company Ltd. Analysis of the data and production of the written reports to pilot needle exchanges was undertaken by the author.

Costs of national system: Further development of this system to a national scale would require the purchase of scanning equipment and report writing software. In addition, needle exchange co-ordinators in each area would need to have responsibility for data collation to address local information governance issues and facilitate routine data collection from all outlets in their area to ensure a robust system. Further investigation into full costs is ongoing and will be outlined in the forthcoming business case.

Benefits of the system: This system provides a user-friendly and consistent means of routine data collection. The type of information collected provides a means of establishing the number of individuals utilising needle exchange services, their needs in terms of information and signposting, and a means of ensuring the correct equipment is being distributed. In addition, the system provides a record of equipment being issued for audit, restocking and payment purposes. The basis of this system, the data collection form, is flexible in that both paper-based and electronic versions of data collection could occur dependent on the nature and resources available at each outlet. It is envisaged that in the next few years, the majority of pharmacy based and other outlets will have secure internet access and an electronic version of the form could be completed for each transaction. A paper based system could continue to run alongside for as long as would be required.

3. To clarify the issues relating to collecting data from a range of independently run organisations including information governance issues

The pilot system ran alongside existing systems in those organisations routinely collecting data for their own service requirements. Any national system would need to take this into account and an audit of existing local data collection systems would

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be useful to establish what information exists and is currently available to CSPs, and SMARTs (some preliminary work was done in this area prior to the pilot but no consistent information was available). In addition, the necessity for an ongoing record of sharp bin distribution to service users was not available through the pilot system and this issue would need to be addressed in further roll out of a national system. For the pilot project, issues of information governance were addressed through MREC and HPA. In the development of a national system, issues of information governance would be addressed by the development of local systems of secure data collation and further clarification of these issues will be addressed in the forthcoming business case.

4. To consider the steps required for this data collection system to be used by outlets and associated organisations for the purposes of stock control and payment for delivery of services

Data from the pilot study indicated that a stock control and payments system could be run as intrinsic elements / benefits alongside data collection. A great deal of additional negotiation and organisation would be required to achieve this but it is the intention of the forum to move towards an incorporated system to streamline the processes involved and thus benefiting needle exchange operators.

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Needle and Syringe Programme - Record Sheet

Please fill in boxes with either a Capital letter or a number depending on the question - e.g. or
 Please cross the circles to make a selection - e.g.

Initials: e.g. J P
Date of Birth: / / D D / M M / Y Y
Today's Date: / / D D / M M / Y Y

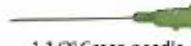

















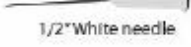


Gender: Please select one Male Female

Town/City of Residence:

Out of Area: **NFA:**

Substance injected	Most often	Sometimes	Least often
Heroin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cocaine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Crack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Amphetamine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Benzodiazepine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Crystal Meth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human Growth Hormone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Steroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insulin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Pick and Mix Please enter a number for all that apply

	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>		<input type="text"/> <input type="text"/>

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Packs:	10	15	20	Emergency Packs:	2	3	5
Red 1ml	<input type="text"/>	<input type="text"/>	<input type="text"/>	Red 1ml Emergency	<input type="text"/>	<input type="text"/>	<input type="text"/>
Blue 2ml	<input type="text"/>	<input type="text"/>	<input type="text"/>	Blue 2ml Emergency	<input type="text"/>	<input type="text"/>	<input type="text"/>
Yellow 2ml	<input type="text"/>	<input type="text"/>	<input type="text"/>	Insulin	<input type="text"/>	<input type="text"/>	<input type="text"/>
Insulin	<input type="text"/>	<input type="text"/>	<input type="text"/>	Orange 2ml Emergency	<input type="text"/>	<input type="text"/>	<input type="text"/>
Orange (5/8")	<input type="text"/>	<input type="text"/>	<input type="text"/>				
White (1/2")	<input type="text"/>	<input type="text"/>	<input type="text"/>				
Long Blue (1 1/4")	<input type="text"/>	<input type="text"/>	<input type="text"/>				
Long Orange (15/16")	<input type="text"/>	<input type="text"/>	<input type="text"/>				
Steroid (N Wales)	<input type="text"/>	<input type="text"/>	<input type="text"/>				

Containers - issued (Yellow or Black) Please enter a number for all that apply



<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
0.3 Litre	0.45 Litre	1 Litre	2 Litre	4 Litre	30 Litre

Containers - returned

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
0.3 Litre	0.45 Litre	1 Litre	2 Litre	4 Litre	30 Litre

Ethnicity Please select one only

<input type="radio"/> White Welsh	<input type="radio"/> Indian	<input type="radio"/> Black Caribbean
<input type="radio"/> White British	<input type="radio"/> Pakistani	<input type="radio"/> Black African
<input type="radio"/> White Irish	<input type="radio"/> Bangladeshi	<input type="radio"/> Black Other
<input type="radio"/> White Other	<input type="radio"/> Other Asian	<input type="radio"/> Chinese
<input type="radio"/> Mixed	<input type="radio"/> Black British	<input type="radio"/> Other

Information / advice given: Please select all that apply

<input type="radio"/> Hepatitis	<input type="radio"/> Safer injecting	<input type="radio"/> Safer Sex
<input type="radio"/> Overdose	<input type="radio"/> Steroids	<input type="radio"/> Groin injecting

Signposting to other services: Please select one only

<input type="radio"/> Drug Treatment Service	<input type="radio"/> GP	<input type="radio"/> A & E
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Appendix B

Instructions for needle syringe programme – Record Sheet

- You will shortly receive one batch of 1000 data collection forms (based on a maximum of 250 transactions per week), each bar-coded to your outlet, and five free post bags (one extra bag for emergency)
- Please begin data collection at start of business on Monday 28th January and finish on Saturday 23rd February 2008 (4 weeks in total)
- **At the end of each week**, place all completed data collection forms in one of the free post bags and put it in the post no later than the Sunday of that week. i.e.:

Week one – post completed forms by Sunday 3rd February

Week two – post completed forms by Sunday 10th February

Week three – post completed forms by Sunday 17th February

Week four – post completed forms by Sunday 22nd February

- The form has been designed to be completed by the dispenser of needle/syringe equipment regardless of type of outlet or by the client. **It is important that the information items are contained within the spaces provided as this is an optical scanning form. Please use capitals and blue or black ballpoint ink. If you make a mistake, please scribble out what you have written and write underneath or reselect box next to original as appropriate**
- The form holds a wide range of equipment so each outlet will only dispense some of the equipment - **it is important to stress to clients when collecting this information that part of the data collection process is to establish what paraphernalia is available in different outlets and where more resources are required to ensure adequate provision of all required paraphernalia**
- **When completing the form, please ask clients to provide initials and date of birth. This information is already requested in many outlets in Wales however for those where it is not, please stress that whilst the client does not have to give their own initials and date of birth, it is important that they provide the same information (initials and date of birth) each time they attend the needle/syringe service subsequently**
- If a client refuses to provide initials and date of birth or any other information, please deliver the service as normal. This data collection system is not meant to be punitive in any way

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- **It may be worth explaining that this system has been designed to further progress the delivery of needle/syringe and paraphernalia to all that require it and to ensure that the most appropriate equipment is being dispensed for the type of injecting drug use the client has described**
- **It is acknowledged that the delivery of needle/syringe exchange is highly sensitive and requires the development of a relationship between client and dispenser over time. The success of this data collection system depends on a pragmatic approach and discussion with the client as to the purposes of the system e.g. It may be appropriate that with new clients on first exchange that details are not taken with the understanding that on subsequent visits, this information will begin to be routinely collected**

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